Australian Government

Productivity Commission

Disability Care and Support

Productivity Commission Inquiry Report
Volume 1

No. 54, 31 July 2011

31 July 2011

The Hon Bill Shorten
Assistant Treasurer
Parliament House
CANBERRA ACT 2600

Dear Assistant Treasurer

In accordance with Section 11 of the *Productivity Commission Act 1998*, we have pleasure in submitting to you the Commission's final report into Disability Care and Support.

Yours sincerely

Patricia Scott

Presiding Commissioner

John Walsh AM

Associate Commissioner

Terms of reference

I, Nick Sherry, pursuant to Parts 2 and 3 of the Productivity Commission Act 1998, hereby refer a national disability long-term care and support scheme in Australia to the Productivity Commission for inquiry and report by 31 July 2011. The Commission will begin the inquiry in April 2010.

Background

The Australian Government is committed to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers.

The Commonwealth, along with the States and Territories, has a major investment in disability specific support. However, there remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers. Demographic change and the anticipated decline in the availability of informal care are expected to place further pressure on the existing system over the coming decades.

While Australia's social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services.

The Government is committed to finding the best solutions to improve care and support services for people with disability. An exploration of alternative approaches to funding and delivering disability services with a focus on early intervention and long-term care will be an important contribution to the National Disability Strategy.

Scope of the review

The Productivity Commission is requested to undertake an inquiry into a National Disability Long-term Care and Support Scheme. The inquiry should assess the costs, cost effectiveness, benefits, and feasibility of an approach which:

- provides long-term essential care and support for eligible people with a severe or profound disability, on an entitlement basis and taking account the desired outcomes for each person over a lifetime
- is intended to cover people with disability not acquired as part of the natural process of ageing
- calculates and manages the costs of long-term care and support for people with severe and profound disability
- replaces the existing system funding for the eligible population

- ensures a range of support options is available, including individualised approaches
- includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available for a person's lifetime
- assists the person with disability to make decisions about their support
- provides support for people to participate in employment where possible.

In undertaking the inquiry, the Commission is to:

1. Examine a range of options and approaches, including international examples, for the provision of long-term care and support for people with severe or profound disability.

The Commission is to include an examination of a social insurance model on a no-fault basis, reflecting the shared risk of disability across the population. The Commission should also examine other options that provide incentives to focus investment on early intervention, as an adjunct to, or substitute for, an insurance model.

2. The Commission is to consider the following specific design issues of any proposed scheme:

- eligibility criteria for the scheme, including appropriate age limits, assessment and review processes
- coverage and entitlements (benefits)
- the choice of care providers including from the public, private and not-for-profit sectors
- contribution of, and impact on, informal care
- the implications for the health and aged care systems
- the interaction with, or inclusion of, employment services and income support
- where appropriate, the interaction with:
- national and state-based traumatic injury schemes, with particular consideration of the implications for existing compensation arrangements
- medical indemnity insurance schemes.

3. Consider governance and administrative arrangements for any proposed scheme including:

- the governance model for overseeing a scheme and prudential arrangements

- administrative arrangements, including consideration of national, state and/or regional administrative models
- implications for Commonwealth and State and Territory responsibilities
- the legislative basis for a scheme including consideration of head of power
- appeal and review processes for scheme claimants and participants.

4. Consider costs and financing of any proposed scheme, including:

- the costs in the transition phase and when fully operational, considering the likely demand for, and utilisation under different demographic and economic assumptions
- the likely offsets and/or cost pressures on government expenditure in other systems as a result of a scheme including income support, health, aged care, disability support system, judicial and crisis accommodation systems
- models for financing including: general revenue; hypothecated levy on personal taxation, a future fund approach with investment guidelines to generate income
- contributions of Commonwealth and State and Territory governments
- options for private contributions including copayments, fees or contributions to enhance services.

5. Consider implementation issues of any proposed scheme, including:

- changes that would be required to existing service systems
- workforce capacity
- lead times, implementation phasing and transition arrangements to introduce a scheme with consideration to service and workforce issues, fiscal outlook, and state and territory transitions.

The Government will establish an Independent Panel of persons with relevant expertise to act in an advisory capacity to the Productivity Commission and the Government, and report to Government throughout the inquiry.

The Commission is to seek public submissions and to consult as necessary with the Independent Panel, State and Territory governments, government agencies, the disability sector and other relevant experts and stakeholders.

Nick Sherry

Assistant Treasurer
[Received 17 February 2010]

Contents

The Commission's report is in two volumes. **This volume 1 contains the Overview, the Recommendations and chapters 1 to 10**. Volume 2 contains chapters 11 to 20, Appendix A and the References. Appendices B to N will only be available on the Commission's web site (http://www.pc.gov.au). Below is the table of contents for both volumes.

Volume 2

Appendices

Acknowledgements

Abbreviations

ACC	Accident Compensation Corporation (New Zealand)
AIHW	Australian Institute of Health and Welfare
BoD	burden of disease
COAG	Council of Australian Governments
CSTDA	Commonwealth/State Territory Disability Agreement
CTP	compulsory third party insurance
DALY	disability adjusted life year
DIG	Disability Investment Group
DSP	Disability Support Pension
EFT	equivalent full time
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
HACC	Home and Community Care Program
IAC	Industries Assistance Commission
IC	Industry Commission
LTCSA	Lifetime Care and Support Authority (New South Wales)
LTCS	Lifetime Care and Support Scheme (New South Wales)
MAIB	Motor Accident Insurance Board (Tasmania)
MS	multiple sclerosis
NDA	National Disability Agreement
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NES	National Employment Standards
NHMRC	National Health and Medical Research Council
NHS	National Health Service (United Kingdom)

NIIS	National Injury Insurance Scheme
PC	Productivity Commission
QALY	quality of life year
SACS	Social and Community Services
SCS	Survey of the Community Sector
SDAC	Survey of Disability, Ageing and Carers
TAC	Transport Accident Commission (Victoria)
VET	Vocational Education and Training

OVERVIEW

Key points

- Most families and individuals cannot adequately prepare for the risk and financial impact of significant disability. The costs of lifetime care can be so substantial that the risks and costs need to be pooled.

- The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments.

- There should be a new national scheme — the National Disability Insurance Scheme (NDIS) — that provides insurance cover for all Australians in the event of significant disability. Funding of the scheme should be a core function of government (just like Medicare).

- The main function (and source of cost) of the NDIS would be to fund long-term high quality care and support (but not income replacement) for people with significant disabilities. Everyone would be insured and around 410 000 people would receive scheme funding support.

- The NDIS would have other roles. It would aim to better link the community and people with disabilities, including by using not-for-profit organisations. It would also provide information to people, help break down stereotypes, and ensure quality assurance and diffusion of best practice among providers.

- The benefits of the scheme would significantly outweigh the costs. People would know that, if they or a member of their family acquired a significant disability, there would be a properly financed, comprehensive, cohesive system to support them. The NDIS would only have to produce an annual gain of $3800 per participant to meet a cost-benefit test. Given the scope of the benefits, that test would be passed easily.

- The scheme should involve a common set of eligibility criteria, entitlements to individually tailored supports based on the same assessment process, certainty of funding based on need, genuine choice over how their needs were met (including choice of provider) and portability of entitlements across borders. There would be local area coordinators and disability support organisations to provide grass roots support. The insurance scheme would take a long-term view and have a strong incentive to fund cost effective early interventions, and collect data to monitor outcomes and ensure efficiency.

- The above features would be best met by a having a single agency overseeing the NDIS — the National Disability Insurance Agency. It would be created by, and report to, all Australian governments. It would have strong governance arrangements, with an independent commercial board, an advisory council of key stakeholders, clear guidelines to ensure a sustainable and efficient scheme, and legislation that protected the scheme from political influences.

- It would be the assessor and funder, but not the provider of care and support. Services would be provided by non-government organisations, disability service organisations, state and territory disability service providers, individuals and mainstream businesses. Increased funding, choice and certainty are the key features of the recommended scheme. Advocacy would be funded outside the scheme.

- An alternative but inferior option would be a 'federated' NDIS. This would give state and territory governments control over their own systems, but with some common core features. Such an arrangement could easily revert to the current flawed and unfair system, with 'agreements' breaking down into disputes about who is to pay, how much and for what.

Key points (continued)

- People would have much more choice in the proposed NDIS. Their support packages would be tailored to their individual needs. People could choose their own provider(s), ask an intermediary to assemble the best package on their behalf, cash out their funding allocation and direct the funding to areas of need (with appropriate probity controls and support), or choose a combination of these options.

- The NDIS would cover the same types of supports currently provided by specialist providers (but with sufficient funding), give people more opportunity to choose mainstream services, and encourage innovative approaches to support.

- The Australian Government currently provides funding to the disability sector of around $2.3 billion, while state and territory governments provide funding of around $4.7 billion — a total of over $7 billion.

- Current funding for disability is subject to the vagaries of governments' budget cycles. People with disabilities have no certainty that they will get reasonable care and support over the long run. Resourcing might be good one year, but insufficient the next, with many people missing out. The Commission estimates that the amount needed to provide people with the necessary supports would be about double current spending (an *additional* $6.5 billion per annum).

- The Commission proposes several options for providing certainty of future funding. Its preferred option is that the Australian Government should finance the entire costs of the NDIS by directing payments from consolidated revenue into a 'National Disability Insurance Premium Fund', using an agreed formula entrenched in legislation. The amount needed could be funded through a combination of cuts in existing lower-priority expenditure, fiscal drag, and if necessary, tax increases.

- A less preferred option is that all governments could pool funding, subject to a long-run arrangement based on the above formula, and with pre-specified funding shares. This would need to be closely monitored by transparent accounting and penalties for failure to meet commitments.

- The scheme would gradually be rolled out from mid-2014. It would start in a few regions. That would allow fine-tuning of the scheme, while providing high quality services to many thousands of people. In 2015-16, the scheme should cover all regions of Australia for the highest priority groups, and should progressively expand until the scheme covered all people by the end of 2018-19.

- A separate scheme is needed for people requiring lifetime care and support for catastrophic injuries — such as major brain or spinal cord injuries. Currently, many Australians get poor care and support when they acquire such injuries because they cannot find an at-fault party to sue.

- A no-fault National Injury Insurance Scheme, comprising a federation of individual state and territory schemes, would provide fully-funded care and support for all cases of catastrophic injury. It would draw on the best schemes currently operating around Australia. State and territory governments would be the major driver, developing a comprehensive scheme by 2015.

Overview

Current disability support arrangements are inequitable, underfunded, fragmented, and inefficient and give people with a disability little choice. They provide no certainty that people will be able to access appropriate supports when needed. While some governments have performed much better than others, and there are pockets of success, overall, no disability support arrangements in any jurisdiction are working well in all of the areas where change is required. The current arrangements cannot be called a genuine 'system' in which different elements work together to achieve desired outcomes.

The central message of this report is that a coherent and certain system for people with a disability is required — with much more and better-directed resourcing, a national approach, and a shift in decision-making to people with a disability and their carers. This overview explains what is wrong with the current arrangements and how to improve them. It shows how a new system would work for people with a disability and their families, and how it would provide benefits for the community as a whole.

Why is change needed?

The existing disability support 'system' is unsustainable on multiple grounds.

It is becoming increasingly unstable. The high costs of addressing people with crisis needs impede funding for other support services. This is because when faced with budget constraints, systems have little choice but to give priority to families in crisis. This displaces funds for early intervention and respite programs, increasing further the number of families falling into crisis, and leading to an ongoing causal relationship between shortages and crises.

Another contributor to the pressure on existing arrangements is that people with disabilities are living longer, and at some point can no longer be supported by their ageing parents or partners. Eventually this cycle must either absorb more and more funds, or leave people in increasingly abhorrent conditions.

Moreover, there is general agreement by people with a disability, their families, service providers and governments that existing support services for those with significant disabilities are not functioning well in many other areas, even for those who do receive funding.

- There is not sufficient resourcing, with many gaps in services in all jurisdictions and most locations. Rationing is likely to get worse unless there is reform.

- Rationing places an unreasonable burden on people with a disability and their families. It means lower levels of wellbeing and large forgone life chances. There are particularly big gaps in the availability of support at key transition points in people's lives. People wait years for specialist wheelchairs, need to stay with their parents instead of moving into independent supported accommodation, and do not get timely or sufficient access to support. Carers have among the lowest levels of wellbeing of any group of Australians.

- People with similar levels of functionality get access to quite different levels of support, depending on their location, timing or the origin of their disability — what some call the 'lottery' of access to services. For instance, some jurisdictions have fault-based motor vehicle compensation arrangements (Queensland, ACT, Western Australia, and South Australia). In these jurisdictions, someone acquiring a catastrophic injury in a motor vehicle accident would have to successfully sue an at-fault party to get adequate lifetime care and support. Other jurisdictions provide comprehensive coverage on a no-fault basis for such accidents.

- People with disabilities and their carers do not get the certainty of lifelong support needed for proper life planning and cannot avoid the extreme anxiety about the adequacy of future funded support when informal care is no longer reasonable or feasible. Current funding for disability comes from two levels of government, which are subject to annual budget cycles — making it hard to give people with disabilities any certainty that they will get reasonable care and support over the long run.

- Inadequate services can hit certain communities particularly hard — such as people in regional and remote areas, people from a non-English speaking background and Indigenous people.

- Under-servicing in one area — such as not enough access to respite and home modifications — results in costly additional servicing in another less appropriate area or at a later time (such as someone staying in hospital because their home has not been modified).

- People with a disability have too little control over what happens to them and limited choice of service providers. The usual justification for such paternalism — the complexity of services — has little application in a sector where one of

the most important services is relatively straightforward personal support in which the empathy and responsiveness of the carer is the most important feature.

- The 'system' is hard to navigate (a 'confusopoly' in the words of one participant — box 1) and is not well integrated nationally. Even within a jurisdiction, people deal with a multitude of programs and agencies, few of which coordinate or share information. If people move across state boundaries, their entitlements can stop at the border.

- People are told they must fit the programs — rather than have programs meet their needs — with wasteful effort going into manoeuvring around the rules. Some people fall inevitably through the cracks, notwithstanding administrators accepting that their reasonable needs are not being met.

- Apart from its inadequacy, funding for service providers uses outdated models and comes with unnecessary compliance burdens, stifling innovation and flexibility.

- Approaches to delivery of supports and administrative processes are only weakly evidence-based, despite the billions of dollars given to such services each year.

People often experience these deficiencies over their whole lives. Disability exacerbates disadvantage. People with a disability and their carers often also experience low levels of income, educational attainment, employment, superannuation, health and wellbeing.

The costs of doing nothing

The cost of doing nothing would be the persistence and increasing intensity of the above deficiencies. Moreover, governments could not feasibly do absolutely nothing. They would need to patch up their systems to arrest the vicious cycle produced by systems in crisis. In effect, all governments face future liabilities with their current unstable systems. The implication of this is that the upfront *fiscal* costs, while significant, are partly offset by eliminating the hidden future liabilities of the current system. Moreover, from an *economic* perspective, the benefits of the NDIS will exceed the costs.

A new approach is needed

The flaws of the current system have driven strong demand for an entirely new approach. The key test of a new scheme will be the extent to which it can address existing deficiencies in an equitable, efficient, cost-effective and accountable way (while avoiding new pitfalls).

Box 1 Some comments from participants in this inquiry

The regularity with which I meet parents with murder suicide ideation as they have been unable to find adequate help for their child is both alarming, but also a marker of the failure of coordination of any service … I also note that murder suicide in these families is becoming a more recognised event, as recently occurred in Victoria. (personal submission, senior psychiatrist)

Those still having to fight for reasonable care and respect, have little hope of departing this world in peace their adult family member will receive consistent quality of life care. (LISA, sub. 1023)

We have from our personal point of view been spending over a year to just try and get a high-low bed because my son is 113 centimetres tall at four, he weighs 25 kilos and he does not walk. He also has hypotonia, so has low tone, so he is very floppy. (Timothy Smith — Fortitude Parents Group, Sydney Hearings, Transcript, p. 716)

We saw our adult children reach their late twenties and thirties with no hope of achieving the independence that moving out of home brings. We saw ourselves caring until we die, with no hope of humanely and gradually transitioning our people into a new residential setting. (Ryde Area Supported Accommodation for Intellectually Disabled, sub. 204, p. 1)

I am a mum of a young child … with multiple impairments – physical, sensory, intellectual – she is expected to be non-verbal for life … There is a myriad of paperwork to be completed, you must re-prove your child's disability to every agency that you encounter … there are wait lists for services, lack of physiotherapists, lack of funding. (name withheld, sub. 9, p. 1)

Unnecessary paperwork and revision [is] required when care requirements are ongoing. (Debra Australia, sub. 554, p. 3)

… it took over 2 years from when it became pretty clear I needed a motorized wheelchair to when I finally got one, and then yet longer to get transport training. This held me back unnecessarily from gaining independence and impacted on my self-confidence. I missed out on many opportunities to take part in the community, including doing some valuable volunteering. (Samantha Peterson, sub. 581, p. 1)

When I was vertical I had a lot more respect. As soon as I parked my backside into a wheelchair, the way society treated me and the way that I was shunned and excluded just blew my mind. I had no idea what people in chairs had been facing all their lives … We only get four hours of help a week, and with those four hours there are very strict, rigid guidelines that we can use them for, so therefore they will say, "No, we can't do that to help you," "No, if it's classed as respite, we can only do this, this and this" … I got extremely depressed, and that was the only time that I thought to myself, "I'm living in Australia and yet I'm reduced to this." (Ms Shaunagh Stevens, Melbourne Hearings, Transcript, p. 180)

… not only do you have to deal with disability, but the uncertainties of disjointed, complex and inadequate array of disability supports. (Ben Lawson, sub. 103, p. 2)

I find myself dealing with anxiety and loneliness and the possibility of when my parents grow older, that I will have no support and services available. (Garry Burge, sub. 2, p. 1)

We currently have over 100 women with disabilities throughout WA as members. There is widespread agreement from our membership that the current disability support system has many flaws and often fails to provide women with disabilities in particular with the supports they need to live a safe, happy and productive life. (Women with Disabilities WA, sub. 1009, p. 1)

Box 1   Participants' comments (continued)

Following our paediatricians pronouncement that she was indeed permanently intellectually disabled, we were very much left to navigate the maze of disability life by ourselves, unsupported, save for some family members and close friends, and the kindness and understanding of some of our daughter's initial therapists … The confusopoly added anxiety and pressure to an already extremely stressful situation. (Name withheld, sub. 482, pp. 1–2)

The scheme needs to be national so that people with disability can take their funding with them when they move across state and territory boundaries. The money needs to be attached to the person (direct funding) and not to an organisation or program. Families at present are bound to stay in the same place as the funding they have received. If that place is the ACT then you can't move anywhere. (Sally Richards, sub. 26, p. 5)

Then "sliding doors and groundhog day" revisited with government changes to policy and funding arrangements which stopped funding to individuals on the basis of individual need and went back to block funding of organizations — leading again to disempowerment, no choice, a take or leave it attitude of service providers and retribution for leaving, or complaining, about a service that is unacceptable, inadequate or unsatisfactory. … All the power is vested in the service provider. (Felicity Maddison sub. 380, p. 1)

This group [acquired brain injury] rarely receives adequate funding to fully support their needs because of the high cost of those needs and as a result experience pain and discomfort, isolation, loneliness and despair. This limited funding also impacts on their capacity to receive appropriate allied health supports and the ability to access their local and broader community. (Inability Possability, sub. 514, p. 4)

I have seen grandparents weeping in despair at a public meeting about disability support, as they describe how badly they need help, and appropriate supported accommodation for their violently autistic grandson. (Name withheld, sub. 253, p. 3)

No one likes to see innocent kids suffer in any way and the pain we feel as parents having to watch this every day and to be helpless to change things, all we can do is scream out for assistance, and now is the time for some screaming (Name withheld, sub. 13, p. 4)

The way funding is allocated is a joke. Submissions are sent in and if you are about to die or divorce or have a breakdown, you might get considered. (Leonie Walker, sub. 12, p. 1)

Looking overall as a money matter, what strikes me is that money is being wasted here. By not spending the money on aids, you're probably creating disability for the future and also by not meeting properly the costs of disability, you're putting more stress on those carers and you're probably causing more suicide, divorce, separation, abandonment. As economists, this is an area crying out for an economic improvement. (Richard Cumpston, Canberra Hearings, Transcript, p. 370)

For many people with acquired brain injuries and their families in Western Australia it has to be said that the system is not just broken, it barely exists at all. (Helen Lynes, Headwest Brain Injury Association of Western Australia, Perth Hearings, Transcript, p. 941)

There are many possible models for a national disability scheme, varying in scope (relevant users, types and levels of support, generosity and duration), funding sources, decision-making arrangements and governance.

One option would be to substantially increase disability funding, but otherwise largely preserve the current arrangements. That would have beneficial effects, but it would fail to provide the certainty of support, early intervention and power over their lives that people are seeking. It would also not overcome the fragmentation and other inefficiencies identified above.

As such, the inquiry has focused on designing a coherent national system for disability support that is centred on removing the deficiencies of the current arrangements (table 1).

First, the Commission is proposing a National Disability Insurance Scheme (NDIS) overseen by a new organisation, the National Disability Insurance Agency. This would provide assessments, and funding to individuals and to organisations.

Second, the Commission is proposing a National Injury Insurance Scheme (NIIS) to address catastrophic injuries from accidents, such as quadriplegia, acquired brain injuries, severe burns and multiple amputations. The scheme would comprise a coherent set of state-based, no-fault arrangements for providing lifetime care and support, building on existing schemes. It would have the same basic goals as the NDIS, but would be funded differently. Its role and links with the National Disability Insurance Agency and NDIS are discussed later.

Who is the National Disability Insurance Scheme for?

The NDIS aims to achieve better outcomes for three different groups of people.

Tier 1: Everyone

In one sense, the NDIS is for all Australians, since it would provide insurance against the costs of support in the event that they, or a family member, acquire a significant disability. Insurance is valuable even if someone makes no claim. (Many people, for example, insure their houses against loss. Most never make a claim, nor do they expect to, but they willingly pay premiums each year to cover the risk.) The likelihood of someone acquiring a significant disability in any given year is low, but much higher than in many other areas where people want insurance.

Table 1 Overcoming the problems of the present system

Current problem	How the proposed arrangements would address the current problems
Poor national insurance (people without a disability have no clear coverage if they acquire a disability)	Full coverage of all Australians for the costs of long-term disability care and support, so people without a disability could feel confident that they or their families would be supported in the event of a significant disability. Insurance has value for people even if they make no claims
Inequitable (eg what you receive in assistance depends on where you live)	A national scheme with national standards and entitlements that would cover people with significant disabilities arising from non-accidents State-based arrangements for no-fault insurance coverage of all catastrophic accidents — with minimum national standards
Underfunded with long waiting lists	Funding would be doubled and tied to the Australian Government's revenue-raising capacity (characterised by more efficient and sustainable taxes)
Failures to intervene early (eg people stuck in hospital because of insufficient funds for minor home modifications)	The schemes, like all insurers, would aim to minimise long-term costs, so they would have a strong incentive to undertake early intervention where it is cost effective. The scheme would spend dollars to save more dollars and people would not have to wait for basic supports like wheelchairs and personal care
Fragmented	Universal schemes; locally responsive within nationally coherent framework; funds and assessments portable across borders and support providers
Lack of clear responsibilities	Assessments under the NDIS would identify and facilitate referrals to the right supports outside the NDIS
People with disabilities and their families are disempowered and have little choice	People would be able to choose their provider or providers. They could choose to have a disability support organisation manage their packages or to act in other ways on their behalf They would be able to manage their own funds if they wish (within rules)
Little future planning	The NDIS would encourage and support people into work and/or being more involved in the community. People's short and long-term plans would be reflected in their individual support packages
Family and carers are devalued	The support provided by families would be considered in assessments, and where appropriate, carers also assessed and given additional supports
Insufficient engagement with the community	The NDIS would leverage a bigger role for community groups and not-for-profit organisations to connect people with disabilities with the community
Economically unsustainable	Appropriate funding would stabilise the withdrawal of informal care under the present crisis-based system (which is leading to the costly withdrawal of informal supports by non-coping carers)
Inefficient with weak governance	The new scheme would be run to insurance principles by a commercial board with strong and constant monitoring by Treasury. Advice from a council of stakeholders (people with disabilities, carers and providers). People with disabilities and their families would have more control over the services they receive. They would have a strong incentive to maximise outcomes, and a direct stake in cutting waste and unnecessary services. Many safeguards to ensure costs did not get out of control. Benchmarking against schemes overseas and between the NIIS and NDIS
People have no confidence about the future: what services will and will not be available	The scheme would focus on long-term care and support needs. People would have clear entitlements to their assessed needs. There would be arrangements to guide people through the system, with strong complaints and appeals mechanisms Strong reserves to buffer the insurance fund. The scheme funds would not be tied to the annual budget cycle, but would have mandated funding hypothecated to a separate fund
Poor information, poor data collection for disability services to ensure efficient management	Information provision through web and other means by a single national agency, disability support organisations to act on behalf of people, availability of objective information about supplier performance; coherent collection of data by the scheme to manage costs and to assess outcomes
Poor evidence base	Research function and evidence-based practice

For instance, Down syndrome (trisomy 21) affects around one in every thousand live children born each year, and more than one in 50 for mothers aged in their early forties. This is just one of many conditions leading to lifelong support needs for the person with a disability. To give an overall indication of the risks, on average every 30 minutes someone is diagnosed with a significant disability requiring the kind of support that the NDIS would provide.

Some people are uncomfortable with the word 'insurance', but the Commission's use of the word simply reflects the need to ensure that the community pools resources to provide reasonable long-term supports for people acquiring a significant disability.

An important role of the NDIS would also be to minimise the impacts of disability. This includes:

- promoting opportunities for people with a disability

- creating awareness by the general community of the issues that affect people with a disability, and the advantages of inclusion

- drawing on its data and research capabilities to engage with other agencies to improve public health and safety.

In the awareness area, for example, the NDIS could recognise and encourage employment of people with a disability and try more generally to combat stereotypes that reduce opportunity. The potential benefits of a more inclusive society also extend to the wider community, including to employers. The costs associated with undertaking the three functions above would be very small and in some cases would come from existing resources. The agency heading the NDIS, the National Disability Insurance Agency, would collaborate with not-for-profit organisations and other stakeholders in undertaking these functions.

Tier 2: People with, or affected by, a disability

Anyone with, or affected by, a disability could approach the scheme for information and referral services (as distinct from funded support). The scheme would also provide general information about the most effective care and support options. This would include providing linkages and referrals to relevant services for which the NDIS was not directly responsible, such as mainstream services and community support groups and services. However, it would be critical to provide any referral and information services cost-effectively, with strict cost limits. As in tier 1, the population of potential 'customers' would be very high, but the overall costs would be small.

An important role for the NDIS in both tiers 1 and 2 would be to strengthen voluntary links between the community and people with disabilities — to stimulate 'social capital'. The goal would be to increase, rather than crowd out existing formal and informal arrangements. For example, local area coordinators (the scheme's case managers) could help link people with disabilities to local community groups (for example, a sailing club) and the NDIS would sometimes provide small grants to help such groups involve people with disabilities. Not-for-profit organisations would take the lead in community capacity building, marshalling the voluntarily provided resources that they previously used to prop up under-funded direct services. Local government may also be providers of such activities when they wish to take on that role or already do.

Consistent with these aims, all governments would continue to support a range of community and carer support services, including some existing or modified Home and Community Care services, for people with lower level or shorter-term disabilities. These would be similar to those proposed within a reformed aged care system, and would be directly accessible by people with disabilities and their carers. They would be largely block-funded, with some limited user charges.

Tier 3: Access to funded individualised supports

Tier 3 would be targeted at the much smaller group of people with significant care and support needs. A focus on pooled funding to meet such needs is consistent with the fact that risk-pooling through insurance tends to focus on higher-cost, less frequent events, like early death, serious injury and property loss. Many families and individuals have an ability to bear and finance some risks themselves, and this is often a more efficient and flexible way of addressing smaller and more common risks than formal risk pooling through insurance. The focus on those most in need of funded supports would also recognise that it is important not to displace the role of the family and the community in engaging and supporting people with disabilities where people's needs are smaller or best met in ways other than taxpayer funding. As one participant said: 'you cannot buy a friend'.

The NDIS would also not cover people whose requirements for support would most appropriately be met by other systems. Accordingly, the NDIS would not cover people:

- acquiring new catastrophic injuries, which would be covered by the NIIS as it developed (though people with injuries acquired before the establishment of the NIIS would be covered by the NDIS)

- with certain health conditions for which the publicly-funded healthcare system was best suited. For example, the care needs of people with terminal cancer would be best addressed in a palliative care setting. People with less severe musculoskeletal and psychological conditions would also typically receive assistance from the health system

- people acquiring a disability after the age pension age

- people *defined* as having disabilities, but for whom the NDIS is not needed. For example, a person whose periodic back pain sometimes prevents them from picking up an object from the floor without assistance, and a person with asthma who could not communicate while having an attack are both defined as having a disability using current disability classification systems. (The latter would be defined as having a severe disability.) These people would not typically need (or want) funded support.

A person getting funded support from the NDIS would have a disability that is, or is likely to be, permanent. 'Permanent' refers to the irreversible nature of the disability, even though it may be of a chronic episodic nature. For example, this would include people with significant and enduring psychiatric disabilities, who periodically rely exclusively on support from the clinical services of the mental health system, but at other times are able to live in the community provided they have appropriate supports.

In addition to the above requirements, people would have to meet at least one of the following conditions. They would:

- have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support. For example, this would include people who need support in toileting, who require significant support for mobility and/or communication or who require supports in self-management and planning to live successfully in the community (such as those with intellectual disabilities or those with significant and enduring psychiatric disabilities). This group comprises around 330 000 people (3a in figure 1), and/or

- be in an early intervention group (3b) (around 80 000 people). This would encompass people for whom there was good evidence that the intervention would be safe, significantly improve outcomes and would be cost-effective. It would include those for whom interventions would improve functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments) or delay or lessen a decline in functioning. This might include people with newly diagnosed degenerative diseases, such as multiple sclerosis and Parkinson's disease, for whom early intervention would enhance their lives. For instance,

assisting in retaining bladder control can benefit people with worsening multiple sclerosis.

There would also be scope to include people who have large identifiable benefits from support that would otherwise not be realised (3c). This category takes account of the difficulties of slotting everyone into the specific groups above. The National Disability Insurance Agency would apply this third criterion judiciously rather than routinely. It would be constrained by guidelines, and monitored rigorously for its effects on scheme costs. If the Agency were to use this criterion loosely, it could pose a risk to the overall financial sustainability of the scheme. Finally, some funding would be available for carers who were under great strain and needed some support (3d).

Figure 1   **The three tiers of the National Disability Insurance Scheme**
2009 population estimates

Tier 1

Social participation, minimising the impact of disability, insurance (target = Australian population) **22.5 million**

Tier 2

Information, referral, web services, and community engagement. Target = all people with disabilities (**4 million**) and their primary carers (**800 000**)

Tier 3

People receiving funding support from the NDIS Target = people aged 0 to the pension age with sufficient needs for disability support and early intervention

(3a) People with intellectual, physical, sensory, or psychiatric disabilities who have significantly reduced functioning (330 000)

(3b) Early intervention group (80 000)

(3c) Others optimally supported (unknown, but modest)

(3d) Funded support for some carers

Total = around 410 000

3a
3b
3c
3d

The population estimates are indicative rather than precise because the survey and epidemiological data available are not designed for providing information on eligibility for supports, but for more general purposes. The ultimate numbers that would actually use funded NDIS services would depend on who approached the scheme and the results of their assessments. The Commission has not produced a long list of conditions covered by the NDIS because eligibility would be determined by functional limitations, not conditions.

The population of people accessing funded supports would be a fraction of those people who access (or are the targets of) tiers 1 and 2. But the overwhelming costs

of the NDIS will relate to tier 3, and it is here where good governance will be critical to ensure both high quality supports and scheme sustainability.

The NDIS would fund all people who met the criteria for tier 3 funding, and not just people who acquired a disability after the introduction of the scheme (as was the case with the NSW Lifetime Care and Support Scheme). Limiting the scheme to new cases of disability would create severe inequities, with the persistence of sub-standard support for hundreds of thousands of people for decades.

Many people currently eligible for specialist disability services may be concerned about whether they would still be able to get funded services under the NDIS. The NDIS would have broader criteria for providing funded services than existing state and territory arrangements and be based on guaranteed access to supports identified in an objective assessment process. Most people currently getting disability services would receive more support under the NDIS.

Aged care is a particularly important parallel support system

While there are many similarities between the conventional disability system and aged care, there are also many differences, such as in philosophy, employment goals, and the appropriateness of co-contributions, which mean that two systems are required.

However, many people who acquired their disability earlier in life are concerned that, as they age, they may 'fall between the cracks' of the two systems. They want to preserve the continuity of their support arrangements and ensure the adequacy of funding. For example, many people want the capacity to stay in their own homes (say a group home), to stay with the support workers they like and to use the service providers that best meet their needs, regardless of the system that accredits these providers.

The Australian Government has agreed to fund the disability support needs of such people under the National Health and Hospital Network Agreement with state and territory governments. It has agreed to fund specialist disability services provided under the National Disability Agreement for people aged 65 years and over (50 years and over for Indigenous Australians). This agreement is already factored into the Australian Government's budget commitments, and therefore does not need to be incorporated into the estimated costs of the NDIS. (The only variation to the Agreement we are recommending would be that the NIIS would fund people over the age pension age who acquire catastrophic injuries, such as from a motor vehicle crash.)

That nevertheless leaves the practical issue of achieving the continuity of support as people with disabilities get older. The Commission proposes that, upon reaching the pension age[1] (and at any time thereafter), a person with a disability could elect either to stay with the NDIS or move to the aged care system.

- If a person elected to move to the aged care system, they would be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches).

- If a person elected to stay with the NDIS care arrangements, their previous support arrangements would continue, including any arrangements with disability support organisations, their group accommodation, their local area coordinator, or their use of self-directed funding. The NDIS assessment tool would be used to determine their entitlements.

- If a person over the pension age required long-term residential aged care then they would move into the aged care system to receive that support, regardless of the age at which they acquired their disability.

The advantage of these flexible arrangements is that the NDIS would — from the perspective of any person — become a lifetime scheme if that was preferred.

Regardless of which system organised the supports, *after* the age pension age people with a disability would be required to make a capped co-contribution to their care on the same basis as the general population, if they had the financial means. This is consistent with the co-contribution arrangements recommended in the Commission's parallel inquiry into aged care. The co-contribution reflects that the likelihood of disability in old age is high, can be anticipated, and that people can save to meet those costs. This proposal would not affect most people who acquired a disability earlier in life because they would not have earned enough income or acquired enough assets to trigger any requirement for co-contributions after the age pension age. However, some people who acquired a disability prior to the pension age may have built up sizeable assets and entitlements to retirement income. These would mostly be people who acquired a disability just a few years before the pension age, but it could include others. Like any other aged person, people in these circumstances would be expected to contribute to their care. Moreover, it would prevent people with assets or high incomes from attempting to enter the NDIS prior to the age pension age to escape the co-contribution arrangements in the aged care system. To provide an additional impetus for workforce participation, it may be appropriate for a lower co-contribution for people acquiring a disability early in their life. The Commission considers that the Australian Government should

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[1] A younger age threshold would apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

determine the appropriate aged co-contribution level as part of the implementation arrangements for the NDIS.

For people with disabilities who are eligible under the NDIS and who are below the age pension age but need to access aged care services, those costs would be met by the NDIS, without any co-contribution being required.

The assessment, funding and planning process

The NDIS would provide a number of supports and services, depending on a person's circumstances. The assessment and planning process would be a layered approach (figure 2). It would:

- determine the tier/s of the NDIS that would be appropriate to each person who contacts the system

- determine what supports outside the NDIS that people should be referred to, such as a not-for-profit organisation, Job Services Australia or a mental health service. This would be mainly targeted at people in tier 2, but would also be relevant for people in tier 3 who need supports both in and outside the NDIS

- for tier 3 contacts,

    - involve working with the person with a disability to develop a personal plan about what the person wants to achieve, including their employment and social participation goals

    - assess the nature, frequency and intensity of an individual's support needs, regardless of how these might be met. The assessment process would be person-centred and forward looking. It would consider the supports that would allow a person to fulfil a range of functions, rather than only respond to what an individual cannot do. However, the assessment would not be simply based on what people want, and it would be undertaken independently rather than through self-assessment alone

    - consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports'). For example, it would not be reasonable to expect an 85 year old carer to provide the bulk of the support to her son with a disability. However, it would usually be appropriate to expect parents of a young child to provide low-intervention support overnight and for a reasonable period during the week, as this is what parents usually do for their children. Where informal carers meet a large share of a person's support needs, they would receive their own assessment to establish the sustainability of that care and ways in which they could be supported

–   translate the assessment process's identified reasonable needs into a person's individualised support package to be funded by the NDIS, after taking account of natural supports. Most people would get an entitlement to particular supports (hours of person-centred active support, aids and appliances, and so on). They could decide what service providers they wanted, or whether they wanted a disability support organisation to arrange their supports. Importantly, people could elect to get an individualised budget under self-directed funding if they wanted to manage their budget directly and were able to do so (see later). They might want to have a mix of options, such as choosing their own attendant carers, but having a disability support organisation manage all the administration.

The NDIS would periodically reassess people's need for funded support as their circumstances changed, especially at key transition points, like leaving school, getting a job, moving out of home, or losing a natural support.

Assessments and information would be portable across the system — subject to protection of privacy — so that people would not have to repeat information for different providers or government agencies (such as repeated proofs that a child has a congenital intellectual disability). Support packages would also follow people across state and territory borders.

The assessment tools

Assessment tools are needed to determine the level of needs and funding for a person covered by the scheme. Good tools should be valid (testing what they purport to test), reliable (giving similar answers if people are re-tested, tested by another assessor, or if people with similar characteristics are assessed), rigorous and cost-effective. The Commission proposes a coherent package of tools (a 'toolbox'), to be used across Australia, with different tools suited to particular needs for support (for example, aids and appliances compared with needs for job readiness training). The assessment tools would be developed within the framework of the widely accepted International Classification of Functioning, Disability and Health (ICF).

There is currently no ideal tool to use in the NDIS, but governments should not delay implementation of the scheme in the absence of 'perfect' tools. Accordingly, the NDIS would use the best available tools in its initial implementation phase, with the ongoing development of best practice approaches. Over the longer-term, the NDIS should oversee the development of its tools (and ideally hold copyright) since such tools effectively determine resource allocation and because the NDIS would

have the best evidence for their ongoing development. The tools should also be made available at no cost to researchers wanting to develop them further.

Figure 2 **The assessment, funding and planning process**
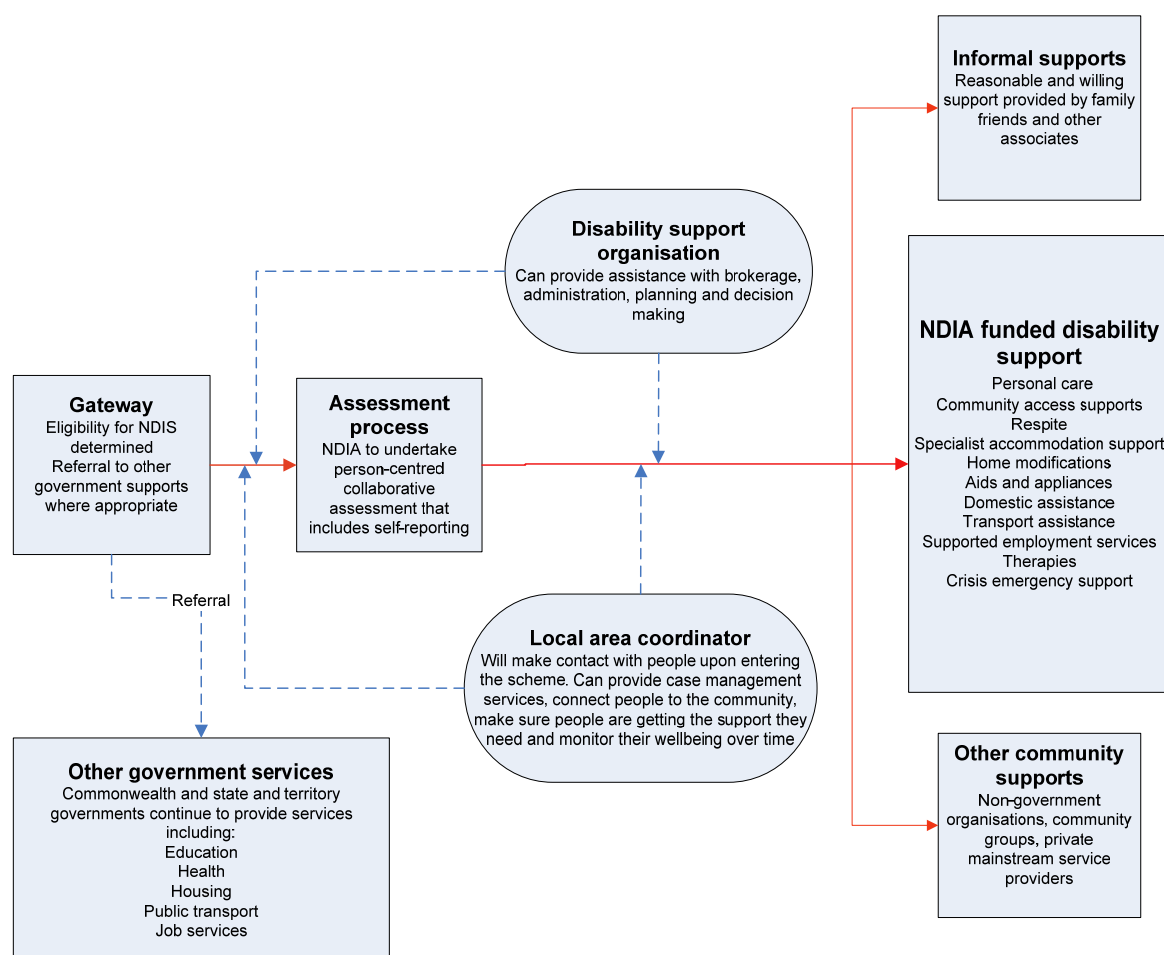
Careful use of assessment tools is critical

Wide or vague assessment criteria for funded support, exaggerated claims for supports, or the increasingly generous use of assessment tools by assessors would risk diluting resourcing, be unfair, undermine community acceptance of adequate public funding and threaten scheme sustainability. There are several safeguards to prevent this.

- Assessments would be designed to be as objective as possible. The people making assessments would need to be independent from the client (unlike treating general practitioners), be properly trained in the use of the tools and be approved or appointed by the National Disability Insurance Agency for the purpose of conducting NDIS assessments. The agency would monitor assessors

for their appropriate use of the assessment tools. 'Hard' assessments would be unfair on the client. Assessment 'softness' could jeopardise the scheme.

- Assessments would concentrate on the reasonable and necessary supports people require. People would be asked what they had received under the old system, what their goals are and what they need. Information about a person's relevant medical conditions and specialist assessments would be made available to the assessor. Consideration would also be given to the informal care or natural supports available to the person, and any supports needed to assist carers in their role. The discussion would focus people on reasonable expectations about the packages they would receive (and in most cases, people would get greater, or more appropriate, support than at present). That information would also be useful in modelling the impacts of the new system. While there would always need to be stringent safeguards against soft assessments, an additional safeguard would be the reluctance by many people to receive more than the necessary personal care by non-family members.

- The assessments would not be 'rubber stamped'. Prior to making budgetary decisions, the National Disability Insurance Agency would confirm that the particular assessment followed the appropriate protocol, and was consistent with the 'benchmark' range of assessed needs for other people with similar characteristics. Deviations outside the norm would need to be reviewed. That means that the agency would detect and adjust excessively hard or soft assessments before people got their individual packages. The NDIS would initially be rolled out in several regions in Australia — and this would help create sensible benchmarks and test assessment arrangements to ensure timely responses.

- The National Disability Insurance Agency would collect data to assess the reliability and validity of the assessment tools, and the tools would be developed over time. The assessment process would also be an important source of data for program planning, high level reporting, monitoring and judging the efficacy of interventions. It would also assist in forecasting the likely long-run liabilities for the scheme — a major focus for the management and sustainability of the NDIS.

Those safeguards aside, the goal of the NDIS would be to properly fund the reasonable assessed needs of people with a disability. This is an essential element of avoiding the uncertainty, chronic underfunding and unmet demand that has beset past allocation systems. Currently, the level of support is determined by annual government budgets that bear no consistent relationship to people's actual needs.

What supports could people get and on what terms?

What's in?

The scheme would cover the current full range of disability supports (box 2). The development of more innovative supports would also be encouraged.

Supports would need to be reasonable and necessary. For instance, funded therapies would have to be in keeping with current clinical practice, evidence-based practice and/or clinical guidelines.

Should the NDIS cover all the costs of its supports?

Insurance products often require some form of co-funding from beneficiaries, and do so for a variety of reasons, such as reducing insurance costs, discouraging 'over-consumption' of services, reducing risk-taking behaviour, and targeting of taxpayer-funded measures at those without financial means. However, the grounds for such co-funding arrangements are weak, given the distinctive characteristics of the NDIS.

There should be no means testing. The Commission proposes that there should be no income or asset tests for getting funded NDIS services. This is because the social gains from insurance also apply to higher income groups, and asset and means tests would discourage work and savings incentives for a group of people already facing weak incentives in these areas. (This is quite different from aged care for the reasons given earlier, and where a co-contribution based on a means test is justified.)

Co-payments would not apply for clinically proven therapies funded by the NDIS. Co-payments are charges made each time a person uses a service. They can discourage people from using low-value therapies, which is both fair and efficient. However, co-payments can also have unintended effects because sometimes people might be discouraged from using essential therapies — and end up using more publicly-funded services elsewhere (for example, through hospitalisation or greater long-term use of personal care). Given this, the Commission proposes that the NDIS would fully fund the number of episodes of therapy appropriate to the person and that were supported by clinical evidence, with people meeting their full costs of further episodes if they want them.

Box 2　　**What supports would the NDIS provide?**

Aids & appliances and home & vehicle modifications, including prosthetics and communications aids.

Personal care that supports an individual to take care of themselves in their home and community. This includes help with showering, bathing, dressing, grooming, personal hygiene including bowel and bladder care/toileting, assistance with eating and/or drinking, mobility and transfers; health maintenance, such as oral hygiene, medication use or regular and routine exercises and stretches. This would also include nursing care when this was an inextricable element of the care of the individual (for example, when meeting the care and support needs of a ventilated quadriplegic).

Community access supports to provide opportunities for people to enjoy their full potential for social independence. The intention is to allow people a lot of choice and innovation in this area. Supports would focus on learning and life skills development, including continuing education to develop skills and independence in a variety of life areas (for example, self-help, social skills and literacy and numeracy) and enjoyment, leisure and social interaction. The supports would:

- include facility and home-based activities, or those offered to the whole community
- include supervision and physical care
- range from long-term day support to time-limited supports.

Respite to provide a short-term and time-limited break for people with disabilities, families and other voluntary carers of people with a disability. Respite is designed to support and maintain the primary care giving relationship, while providing a positive experience for the person with a disability and includes:

- respite provided in the individual's own home
- respite provided in a community setting similar to a 'group home' structure
- host family respite that provides a network of 'host families' matched to the age, interests and background of the individual and their carer
- 'recreation/holiday programs' where the primary purpose is respite.

Specialist accommodation support, such as group homes and alternative family placement (but not places that provide primarily clinical supports)**.**

Domestic assistance to enable individuals to live in the community and live on their own, such as meal preparation and other domestic tasks; banking and shopping; assistance with selecting and planning activities and attending appointments.

Transport assistance to provide or coordinate individual or group transport services, including taxi subsidies.

Supported employment services and specialist transition to work programs that prepare people for jobs.

Therapies such as occupational and physiotherapy, counselling, and specialist behavioural interventions.

Local area coordination and development, which are broad services, including individual or family-focused case management and brokerage (disability support organisations), as well as coordination and development activity within a specified geographical area. They aim to maximise people's independence and participation in the community.

Crisis/emergency support, following, say, the death of a family member or carer, or in other crisis situations, including emergency support, accommodation and respite services.

Guide dogs and assistance dogs, including the reasonable costs of being assessed for a dog, a dog, user training and veterinary costs.

Excesses ('front-end deductibles') are not appropriate. An excess is a fixed amount that a person must pay when making an insurance claim, with the remaining portion paid by the insurer. It is common in motor vehicle and health insurance. Excesses can reduce insurance costs where small claims make up a significant share of costs, or there is a risk that people make unjustified or trivial claims. However, the high needs basis for initial assessment, the rigorous nature of the assessment process itself and the fact that high needs will dominate NDIS costs means that there would be little need for an excess, or real scope for such an excess to materially reduce costs. Without specifying a dollar amount, the criteria for entry to the scheme would already have established a threshold level of need to warrant public insurance. However, there would be grounds for introducing some upfront charge if the regional rollout of the NDIS revealed that many small and unnecessary claims were clogging up the assessment process. These charges could take several forms, such as a small minimum threshold for funding by the NDIS, or the imposition of a small excess (say $500) that would be progressively waived as people's total support costs rose (so that, for example, it would be zero for people needing more than $3000 a year). Decisions about any excesses should be deferred until after the initial rollout of the NDIS.

Defining the boundaries of the scheme

Some services meet the needs of broader groups of people with a disability and Australians generally. These would continue to be provided outside the scheme (though the NDIS would provide referrals to them and, where appropriate, support the activity of people in them). Ultimately, there must be boundaries to the NDIS — it cannot take over responsibility for all services and supports that people with a disability use, or it would be too unwieldy and governments would be unlikely to implement it. The main complementary services are education, employment, health, housing, income support and public transport.

The Department of Education, Employment and Workplace Relations provides open employment services through Job Services Australia. This covers disability employment services (which are uncapped and include specific supports for people with disabilities) and generic employment services (which offer standard employment assistance to job searchers regardless of disability). The number of people with disabilities covered by Job Services Australia would be much greater than those eligible for NDIS-funded supports. Given that, and the significant benefits from having a single coherent system for open employment services, these services should lie outside the NDIS. However, the NDIS would fund specialised 'job readiness' programs (such as the 'Transition to Work' program in NSW) and Australian Disability Enterprises (currently funded by FaHCSIA), with a clear focus

on lifting employment outcomes. At the same time, the Australian Government should initiate further measures to achieve improved employment outcomes for people with disabilities, many of whom languish on the Disability Support Pension.

State and territory departments of education (supported by Australian Government funding) are responsible for disability support in schools. That might involve structural modifications for buildings to ensure better accessibility, aids and appliances to increase educational opportunity, teacher aides, development of new curriculum materials, and teacher training (for example, in sign language). Many of these expenditures are hard to attribute to a specific individual, since they often meet the needs of many students with disability. As such, they should not form part of the scheme. (Similar arguments apply for post-school educational services.) However, the scheme would cover goods and services used in employment or in education if these were also necessary for everyday living (such as personal care, a hearing aid or a wheelchair).

The NDIS would cover provision of specialised accommodation services (such as group houses) — net of the standard contribution from a person's income for rent. When reasonable, it would also fund home modifications for privately-owned housing and the old stock of disability-unfriendly public housing, noting that such housing is often the key form of accommodation for people with a disability. In general, the NDIS would encourage the development of an accommodation model that gives people the capacity to unbundle the provision of the 'bricks and mortar' of specialised accommodation and the provision of services in those homes. That would allow people to choose to live in a dwelling owned by one provider and to purchase other services from another.

More broadly, shortages of public housing are often a major problem for people with a disability and can undermine the objective of independence. However, shortages are common to many prospective clients of public housing. Given that, there are strong grounds for the resourcing and locational decisions for public housing to remain a mainstream policy concern. Moreover, were the NDIS to fund any gaps in housing for people with a disability, state and territory governments might withdraw funding for public housing for people with a disability ('cost shifting' to the NDIS). The Commission has raised the possibility of an entirely new model for housing for people with long-term disability, based on 'cashing out' the costs of public housing and specialised accommodation. People could then decide where they might live and what type of dwelling they might like. They (and their families) would be able to add their own finances to any housing decision. This model would require cooperation with state and territory governments.

Primary care and hospital (in-patient and outpatient) based services, medical services, and pharmaceutical products should remain a mainstream concern. As is the case with the community more generally, people will continue to access the existing health care system as the need arises. However, the scheme would have a role in reducing disability specific barriers, such as where a person has difficulty communicating their symptoms to a doctor (and has no guardian to perform that function) or where they need care that a familiar personal support worker is best placed to provide.

Advocacy

Advocacy plays an important role in the disability system. Systemic advocacy pushes for broad policy and social change, while individual advocacy promotes the interests of particular individuals by acting on their behalf to resolve specific issues. These functions should lie outside the NDIS, reflecting the potential conflict of interest that would arise were the NDIS to fund advocacy bodies whose role was to challenge the disability system overseen by the NDIS. Current funding arrangements through FaHCSIA and various state and territory governments should continue.

Significant and enduring psychiatric disability should be included in the NDIS

The Commission took wide soundings on the best way to support people whose primary disability reflects a mental health condition. In particular, the Commission requested feedback on which system was best placed to meet the non-clinical, support needs of individuals with a significant and enduring psychiatric disability.

The dominant view of participants in this inquiry, consistent with the advice of experts independently consulted by the Commission, was that the NDIS should meet the disability support needs of individuals with significant and enduring psychiatric disability. This reflected the similarities in support needs and the broad principles underpinning the community mental health system and disability supports generally:

- Many people with significant and enduring psychiatric disabilities have the same day-to-day or weekly support needs as people with an intellectual disability or acquired brain injury. These can include assistance with planning, decision making, scheduling, personal hygiene and some communication tasks. Regular support and, in some cases, supported accommodation, allows such people to live successfully in the community.

- The NDIS is the more appropriate vehicle for managing community supports. The NDIS would be underpinned by support and planning that helps people achieve their goals and maximises their participation in the community. Only a small part of the existing mental health system — the community mental health system — shares similar approaches and philosophies to the NDIS. However, this part is placed in a broader mental health system that, given its clinical orientation, has been slow to recognise these approaches, and has given priority to managing and funding the clinical, rather than the community needs, of people. The poor fit of the emerging community mental health system and the traditional clinically-oriented mental health system, means that the NDIS would be a more appropriate umbrella for the provision of community support. Community mental health services would be strengthened by the extra resources provided through the NDIS.

In the light of the evidence, the Commission determined that the NDIS should meet the community support needs of people under the pension age who have significant and enduring psychiatric disabilities and who have scope to be supported in the general community.

Supports would include expert support in people's homes and provision of group-based accommodation, but not of clinical facilities. As with other instances, where clinical supports are also important for good outcomes — such as degenerative diseases or stroke — a memorandum of understanding and coordination would be needed with the clinical services of the mental health system. In particular, there would need to be:

- clear lines of responsibility and strong communication between the NDIS and the mental heath system, given the ongoing need for clinical support. New arrangements announced in the Australian Government's 2011-12 budget are an attempt to address this need and will require some adjustment as the NDIS is established

- agreement from state and territory governments that they would provide complementary supports, such as public housing and clinical care, which are essential in achieving better outcomes for these groups

- the recruitment of a trained workforce to give high quality daily supports to this group (the workforce will typically require more complex skills than those providing many forms of attendant care).

Overall, the Commission estimates that there would be 57 000 people with enduring and significant psychiatric disabilities who would meet the eligibility criteria described earlier (and, as such, would comprise around 15 per cent of the group, 3(a) in figure 1). The gross cost of their inclusion would be around $1.85 billion per

annum, but there would be offsets of around $600 million from existing government expenditure, so that the net cost would be $1.2 billion.

Income support measures — in or out?

The Mobility Allowance is a fixed amount paid to certain people with disabilities who need transport for (primarily) employment and training purposes, but who cannot readily use public transport without substantial assistance. However, a flat rate of Mobility Allowance is inconsistent with the individualised approach of the NDIS. Where people were entitled to a funded package in the NDIS, they would not be eligible for the Mobility Allowance, but instead would have their reasonable assessed mobility needs met by the NDIS (but they would retain the health care card were they to meet the Mobility Allowance eligibility criteria). This change would provide more funding for necessary transport requirements. Others outside the NDIS would still get the Mobility Allowance if they were eligible for it.

The Disability Support Pension (DSP) should be outside the NDIS. It is an income support payment, like unemployment benefits, and covers a broad group of people with disabilities. There were 793 000 recipients in June 2010 of which around 250 000 would be eligible for the NDIS. DSP recipients include people whose incapacity for work is due to illness or injury and people without a lifelong disability, who do not need the individualised supports that the NDIS would provide.

There are strong grounds for (further) reform of the DSP, given that its design can significantly undermine the NDIS's goals of better economic, employment and independence outcomes for people with a disability. Some people have disabilities so severe that they could not realistically ever work — and the DSP would continue to be the major source of long-term income support for them. However, some people receiving the DSP have the potential for employment — with the associated gains of higher income, social connectedness, health benefits and the contribution they could make to the Australian community (and the evidence for such benefits is strong).

Reforms would aim to encourage the view that the norm for many people should not be the long-term use of the DSP (unlike the current 'until death or the aged pension us do part'). Those changes would be mainly oriented to people with typically non-permanent conditions and at people who could have much higher hopes for longer-run employment participation with appropriate supports. The Commission has proposed several options for the Australian Government to explore, including:

- creating tiers within the disability income support system that recognise the varying prospects for economic and community participation by people with disabilities

  – a 'transitional disability benefit' could be paid for people who currently go onto the DSP, but who have some current work capacity or where their work capacity is hard to assess. These people should be assisted in getting a foothold in the job market. The changed name of the payment recognises that the 'pension' terminology is not appropriate for this group, as a pension implies a permanent need for income support when that is counterproductive for the genuine economic engagement of people with disabilities

  – the pension would continue for those with very low employment prospects, but even in these cases, the system should encourage and facilitate employment. The Commission has seen examples of innovative arrangements that have led to employment for people with severe disabilities

- reducing the financial barriers to work posed by the high effective tax rates on wages for those on DSP who work. The Commission suggests that:

  – while a 15 hour work test for entry to the disability benefit is probably appropriate, it may be desirable to relax or remove altogether the work test for people already on the pension (without this being a temporary exemption as is currently proposed). It would then effectively become an in-work benefit

  – there are grounds to reduce the rates of withdrawal of the disability benefit as people work. This would act like a working credit and encourage people to work while remaining eligible for at least a part pension

- more targeted wage subsidies and support for employers to overcome obstacles to jobs for people with disabilities

- innovative arrangements for engaging people on the DSP with work, such as social bonds, in which a business or not-for-profit organisation forms a contract with the public sector to pay for and generate improved social outcomes that result in public sector savings.

Reduction in DSP numbers would also provide a financial offset for the NDIS, noting that the present value of 30 years of one person's entitlement to the DSP is around $500 000 and that the budgetary costs of the DSP were around $12 billion in 2009-10. But the prime motivation would be to improve people's genuine participation in society, their wellbeing and to raise their lifetime income — consistent with the goals of the NDIS.

Other payments — Carer Payment, Carer Supplement, Carer Allowance and the Child Disability Assistance Payment — encourage the provision of informal care. These payments apply to a broader population than that covered by the NDIS (particularly care for the aged). In theory, these payments could be transferred to the NDIS and directed more flexibly to people's support needs, while reducing the poverty traps that sometimes apply to carers from such payments. However, the issue is complex. The gains may be small relative to the disruption created by the change, especially if carers viewed the change as undermining or diminishing recognition of their critical role. In these circumstances, it could inadvertently impose higher costs on the NDIS. There may be better options for addressing the work disincentives posed by the Carer Payment (such as by changing the work and education tests in the payment). The Australian Government should investigate these options. Either way, the NDIS should share information about carer payments with Centrelink and take into account the receipt of such payments when assessing people's needs.

How would people be given greater control and choice?

There is a strong rationale for people with a disability to have much more control over what and how support services are delivered. As one participant said: 'This scheme is for people with disability, not for service providers. Not for governments, not for empires or private agendas. This scheme is for people who are as individual as their fingerprints.'

The Commission agrees that a new scheme should reflect this goal. The Commission proposes an 'individual choice' model, in which people with a disability (or their guardians) could choose how much control they wanted to exercise. There would *not* be one model that forced people to take full control or none. So people could:

(a) after consultation and assessment, receive a package of supports (not a budget amount) from the NDIS. People would be able to choose their service providers, and, if they wished, have the support of disability support organisations acting as brokers. People could switch disability support organisations and service providers if they did not meet their needs well. They might choose one service provider for one support need and another service provider for another need, or choose one provider to meet all their needs. They might ask a disability support organisation to bring together the package of supports and the best service providers on their behalf. A disability support organisation or service provider would only act for a person with a disability where that person had chosen to assign them that responsibility

(b) have the choice (subject to some conditions — see below) to cash out their support package and manage it at *the detailed level*, allocating it to specific supports they assemble themselves (so-called 'self-directed funding'). Under self-directed funding, people could employ the support workers they want (and when), and choose to trade off some services against another. For example, the Commission knows of one case where a person with an intellectual disability used some of her funding to go to a movie weekly as her form of community access (replacing much more expensive and less enjoyable specialist day services). Self-directed funding is already partly implemented in some Australian states, and common in the United Kingdom and the United States. There is widespread and compelling evidence that it leads to good outcomes (in life satisfaction, confidence in their care, feelings of control, health, employment, a variety of other wellbeing dimensions, and potentially all at lower cost). There would be no obligation for people to use self-directed funding, and many would find it too bothersome or complicated, or would be happy to choose the disability support organisations and service providers and let them bundle supports for them. Moreover, the experience in the United Kingdom suggests that take-up may be initially slow. In England, just over 10 per cent of people aged less than 65 years completely manage their own funding. The share has been growing rapidly and some local councils have much higher rates than this. Under the NDIS, the pace of adoption of self-directed funding can be expected to grow as people gain confidence in the new system, as the market evolves, and as the system provides more support for exercising choice (for example, through disability support organisations).

The difference between the two ways of achieving choice is that the first is like consumers finding a restaurant. They do not cook the food, but they do get to choose the restaurant that suits their preferences. They will not go back if the food or service is poor. The second is like a person cooking the meal. He or she would have the freedom to choose the exact recipe, cooking methods, utensils, and when to cook, but it would involve a lot of work and they could make mistakes.

Of course, there is also the third option of taking personal charge of some aspects of support (say, hiring of attendant carers), but choosing a broker or service provider to handle other matters (akin to eating at home and at other times in a restaurant). The point is that the person with a disability would ultimately be in charge.

Model (a) is relatively easy to implement and probably the most common way in which people would exercise power (at least initially). Self-directed funding (model b) involves some complexities. To use self-directed funding:

- People would be told their individual budget — an outcome of the National Disability Insurance Agency assessment process — and would be told what parts

of that budget could be 'cashed out' to use flexibly. (For example, they could not cash out essential therapies.)

- People would create a personal plan and develop a concrete funding proposal, which if accepted by the National Disability Insurance Agency, would be the basis for spending the money. They would have a lot of choice. As shown to be effective overseas, people could hire the workers they want, including neighbours and friends, rather than going through specialist disability agencies. The agency would run a trial to assess the risks and benefits from paying family members for some of their care and support. This has been a successful innovation overseas, particularly in the United States, but would need to be tested carefully, given its evident risks and some concerns about its effects in one recent Australian study.

- The National Disability Insurance Agency would help by providing videos, written material and other guidance, as occurs in Victoria already.

- Disability support organisations (or indeed service providers) would help people (if they wanted) to handle the administrative and accountability requirements of self-directed funding (keeping receipt records, and dealing with workers' compensation, any required insurance, tax withholding, superannuation obligations and police checks) for a fee. Such agencies might also develop short training sessions in people skills and confidence to self-direct, especially as so many people with a disability have been used to a system in which they only had a passive role.

- There would need to be strong accountability measures. The National Disability Insurance Agency would not allow some people to self-direct if it gauged that the risks were too high, for example, past fraud or if there were concerns about coercion. People could spend within the bounds of their plans, but would have to spend on and attend agreed therapies. They would not be able to shift money earmarked to essential long-term assets (like a wheelchair or home modification) to current consumption, and there would be some blanket prohibitions, such as gambling with the funds.

- The National Disability Insurance Agency and its local area coordinators would monitor the use of self-directed funding. (The Victorian Government requires that the funds be placed in a separate bank account that can be monitored by the relevant department.) Self-directed funding would be formally evaluated three years after the commencement of the NDIS.

How should the NDIS be financed?

Whatever its exact form, the financing mechanism must give people with a disability certainty about getting reasonable supports over their lifetime. Moreover, a stable revenue stream is needed to underpin a proper governance arrangement for the NDIS (see below). Accordingly, funding for disability must move away from the uncertainty underlying the annual determination of government budgets for disability support.

While private voluntary insurance policies can provide useful cover for income loss for people experiencing disability (and would not be affected by the NDIS), they are not suited to universal coverage of the population against the potential costs of long-term care and support associated with disability. The private insurance market does not operate well in this area, the costs would be prohibitive and many people would not get full coverage.

This suggests some sort of compulsory insurance contribution — effectively a claim on general revenue or tax. There are several options, but some are not appropriate. Savings-type models — like compulsory additions to superannuation levies or mandatory savings accounts — are ill-suited to disability support because disability can occur at any age (as compared with the need for aged care or retirement income), and fail to pool risks appropriately. The general design of so-called 'social insurance' schemes, in which employees and employers make compulsory contributions, is usually centred around income replacement related to people's previous wages, rather than focused on financing long-term care and support.

These concerns suggest that either an agreed amount of revenue or a new specific tax should be dedicated exclusively to long-term disability support ('hypothecation').

The exact form of taxpayer-funded arrangement is dependent on the roles of the Australian Government compared with state and territory governments.

One funder would be the preferred approach

The Commission recommends that the Australian Government would take responsibility for meeting the entire funding needs of the NDIS. This would provide certainty, clear lines of funding responsibility, avoid the inefficiencies of the Commonwealth-State 'blame game' that afflicts some shared funding arrangements, and reflect the Australian Government's unique capacity to raise efficient and sustainable taxes of the magnitude required. The Australian Government would

direct payments from consolidated revenue into a National Disability Insurance Premium Fund using a *legislated* formula to achieve transparency and certainty.

This approach means that the Australian Government could use several financing options, including:

- the scope to partly finance the NDIS by cutting some other spending, noting that the ongoing commitments to the NDIS required by funding of the full cost of the NDIS would represent around 4 per cent of total Australian Government spending. The potential for shifting from other spending areas to the NDIS recognises that were government to be starting with a blank slate in determining its funding priorities, provision of disability services would be one of its highest spending priorities.

- whatever was the most efficient tax financing arrangement at the time (recognising that there may be further tax reform).

A hypothecated tax imposed on personal income to meet the needs of the premium fund would be an alternative source of revenue, but would lack the flexibility and efficiency of a legislated contribution from consolidated revenue. Were the Australian Government to introduce a new disability insurance levy, it should implement it by adding an increment to existing marginal tax rates, rather than using different income thresholds or new complex tax schedules.

The extra amount of revenue required for funding the NDIS would be around $6.5 billion (given present funding of about $2.3 billion by the Australian Government and $4.7 billion by state and territory governments). Were the Australian Government to be responsible for the *entire* (gross) costs of the scheme (of just over $13.5 billion), and were state and territory governments to deflect their existing disability spending to other areas, then Australians would face tax rates that were higher than necessary.

In that context, the Commission proposes that the quid pro quo for the exclusive funding role of the Australian Government would be some relief for Australians generally from inefficient state and territory taxes. The Commonwealth would reach agreements with state and territory governments to reduce their inefficient stamp duties by the amount of own-state revenue they used to provide to disability services (a 'tax swap'). Some state and territory governments have rejected this idea. However, it still has merit. All jurisdictions would be able to point to a much better system for disability care and support (in which they would play a major role — see later).

The funding of the scheme is feasible and manageable

The Commission considers that the funding of the scheme along the above lines would be feasible and manageable, taking into account that:

- Australia is a wealthy country (with $7700 billion of net national wealth) with a large economy ($1300 billion GDP) and the prospects of strong projected growth

- Australian taxpayers only need to finance the additional amount of resources needed to fund a proper disability system

- the full fiscal implications of the scheme would only be felt by 2018-19, reflecting the need for a careful transition

- there would be some savings over the longer-run from the fruits of early intervention, the fiscal gains from reduced income support as people with disabilities and carers increase their economic participation, and from the likelihood of increased productivity in the current, disjointed, disability system.

Payments into the premium fund would meet immediate costs and would build up reserves to spread the costs of the scheme over time and for prudential reasons. The revenue formula may need to be periodically adjusted if the reserve position deteriorated, but only if the cost increases did not reflect poor cost management. The quid pro quo of revenue certainty would have to be strong cost management in the NDIS (see later) and tightly defined and appropriate assessment arrangements.

This approach would need to be strictly monitored by transparent accounting and clear indications to state and territory governments that if they reneged on their commitments, they would face reduced future transfers or other financial penalties. An intergovernmental agreement would spell out the obligations of all jurisdictions.

Regardless of the choice of financing model, it would be critical that the revenue requirements of the National Disability Insurance Premium Fund were fully met.

A pooled funding approach is a weaker alternative

An alternative but weaker (and therefore less preferred) funding option would rely on ongoing contributions from both state and territory governments and the Australian Government. This would still involve the creation of a National Disability Insurance Premium Fund with a legislated formula for determining contributions to the fund. The only difference would be that each year, state and territory governments would need to contribute a clearly formulated and agreed amount to the premium fund. The Australian Government would fund the remaining

share. This formula-based approach would provide clarity about the long-run obligations of both levels of government (unlike some other agreements between governments).

How should the NDIS be structured and governed?

A single system or a federated model?

Any governance arrangement for running an effective *national* system would need to be structured so that it had several core features, including:

- the same national eligibility criteria, assessment toolbox, arrangements for assessors, and access to the full range of necessary supports. That would mean that regardless of location, people with equal disability status and traits/natural supports would receive the same entitlements based on need

- certainty of future resourcing

- the model and management of an insurance scheme, including the sophisticated collection and analysis of data to measure the outcomes and performance of the system, and a national research capacity. That would maximise efficiency and underpin a framework for decision-making that considers the whole-of-life costs of support for a person, with the capacity to make early investments that save future costs

- a shift from block funding and a service centred model to one in which people with disabilities and their carers would wield the greatest control, whether that be to cash out their package, or to have it met in flexible ways by providers. Under any arrangement, people could choose their providers, which would have to conform to common quality standards, compete on a competitively neutral basis and be remunerated using efficient prices. Informed choice would be supported by providing nationally consistent and publicly available measures of the performance of service providers

- a focus on individual needs and outcomes, allowing people with disabilities to reach their potential through funded supports and/or active interaction with the community. In many cases, this will include supporting individuals in understanding how to take advantage of choice and options

- the inclusion of local area coordinators, disability support organisations and a wider community role for current not-for-profit specialised providers

- a national service provider strategy (capacity building and attitude change) and workforce development strategy.

The Commission's strong view is that these core features would be best organised using a single agency — the National Disability Insurance Agency — that would oversee a coherent system for all Australians, regardless of their jurisdiction. The national model and its overseeing agency would learn from the best arrangements in place around Australia (such as local area coordinators in Western Australia and the accident schemes in Victoria, NSW and Tasmania).

A less preferred, but clearly workable, model would be to roll out the NDIS to those states and territories that saw the advantages of a better-funded and coherent system, with other jurisdictions joining later if they wished to gain the advantages of that system. The advantages of such an arrangement would be that the reforms would not be delayed for all of those in need, and the logistical exercise would be made easier. The clear downsides would be the continuation of fragmented and inadequate arrangements in some states.

The third and most inferior option would be a 'federated' NDIS. In this model, the Australian Government would provide additional disability funding to state and territory governments and stipulate some common national features, but would otherwise leave state and territory governments in control of their own systems. This approach would recognise that federalism can generate useful experiments, and that state and territory governments would still have control over complementary services (such as housing, health and education). This would be better than current arrangements. However, the system would remain fragmented, and the support received would retain features of the postcode 'lottery'. Moreover, such an arrangement could easily revert to the current dysfunctional and unfair system, with 'agreements' breaking down into disputes about relative contributions, special variations and carve-outs. In particular, a loose arrangement would expose Australians to the significant risk of:

- divergence rather than convergence in the essential aspects of a coherent system (such as jurisdictions adopting their own unique assessment tools and eligibility criteria over time)

- undermining the core requirement that funding be sufficient to meet people's entitlements for their assessed needs This would occur, for example, if governments' funding contributions started to again reflect the vagaries of their budget cycles or were based on arbitrary criteria (such as maintaining real per capita spending levels, despite growing needs).

A federated scheme would not offer people the *assurance* of high-quality long-term care and support.

A single agency model avoids many of the disadvantages of a federated model, has many other unique advantages, and structured properly, can emulate the apparent advantages of a federated model. The national model proposed by the Commission would:

- better facilitate the achievement of the core features above, recognising that it can be hard (and slow) to get agreement about national approaches in even minor areas (such as disabled parking permits which took three years) from eight jurisdictions

- explicitly encourage innovation and test its benefits. The historical reality is that innovation in the current nationally fragmented disability system has not been rapid or uniform across jurisdictions, and not all have embraced the importance of people with disabilities as the centre of a disability system. Genuine cultural change across all Australian jurisdictions will only be achieved by disrupting existing institutional arrangements

- be responsive to local needs. The Commission envisages that the National Disability Insurance Agency would have a strong regional presence. There would be local area coordinators, based in, and with close connections to, the local community, with knowledge of local providers and not-for-profit organisations, and with some scope to respond flexibly to people's needs. (Kununurra is going to have a different set of local issues compared with North Sydney and local managers will need to have some common sense discretion.) The Agency would get input from all jurisdictions

- coordinate well with other critical supports outside the NDIS (disability employment services, income support, education, public transport, housing and health). Indeed, one of the advantages of a NDIS is that expectations about, and measurement of, the performance of these complementary services would be nationally consistent and equitable

- reduce the number of bureaucracies across the eight jurisdictions

- involve independence in decision-making from any governments (such as avoiding political advocacy for special arrangements for given clients or for the investment decisions of the scheme fund).

The Commission's recommendation for a single agency model does not stem from any inherent hostility to federalism (hence our recommendation for a federated injury scheme — see later). Rather, it stems from an analysis of the benefits that would derive from a unitary scheme. Moreover, the Commission sees considerable risks that a federated NDIS would revert to the current flawed and fragmented system.

Structuring the National Disability Insurance Agency

What happens 'behind the scenes' will be critical to the success of the National Disability Insurance Agency. Assessment and funding would be undertaken by the agency but services would be provided by not-for-profit organisations, state and territory service providers and businesses. The Commission opposes setting up a big new Commonwealth bureaucracy whose costs would eat up resources that should be allocated to people with disabilities. So instead, the NDIS would use a corporate model of governance, as in other insurance arrangements in the private and public sectors. Government accident insurance schemes, like the Victorian Transport Accident Commission, and the NSW Lifetime Care and Support Authority, also use a corporate insurance model.

The agency would have responsibility for supervising key aspects of the scheme. It would provide information to people generally ('tier 1' users); undertake research to identify best practice interventions; oversee assessment and the ongoing development of assessment tools, and would authorise individuals' assessment results (and funding proposals for those managing their own funds). It would provide support to people through local area coordinators and to providers through capacity building, workforce development and sharing of best practice innovations. It would determine efficient prices.

A critical part of its function would be strict management of the NDIS, supported by systematic national data collection for actuarial analysis. As discussed earlier, effective ongoing commercial management is essential to avoid a blowout in assessment outcomes (and the funding associated with them) and to ensure appropriate service utilisation and costs. Poor management is the largest risk to the scheme's sustainability, and thereby the largest risk to long-run reasonable support of people with a disability and their families.

The National Disability Insurance Agency would be free to subcontract functions to third parties — for example, research.

Some of the most critical aspects of the NDIS would lie outside the National Disability Insurance Agency. In particular, people funded by the NDIS would be at the centre of the new scheme (figure 3). They, rather than just a few governments or suppliers, would largely control their individual support packages. Indeed, from day to day, a person with a disability and their family would mostly have direct contact with the service providers they have chosen, just like most consumers. Much of the complex business of managing the NDIS would (and should) be invisible to them. In the main, people's contact with the National Disability Insurance Agency would be through their local area coordinator.

In addition, some key features of the NDIS would be structurally separated from the National Disability Insurance Agency (figure 4). Funds management would be integrated with existing Australian Government arrangements for investing in long-term assets (the Future Fund). The agency would still have a role, setting broad guidelines for acceptable levels of risk and return on the scheme's investment funds.

Figure 3   **From a consumer's perspective, the NDIS will give them the means to choose supports that best meet their needs**
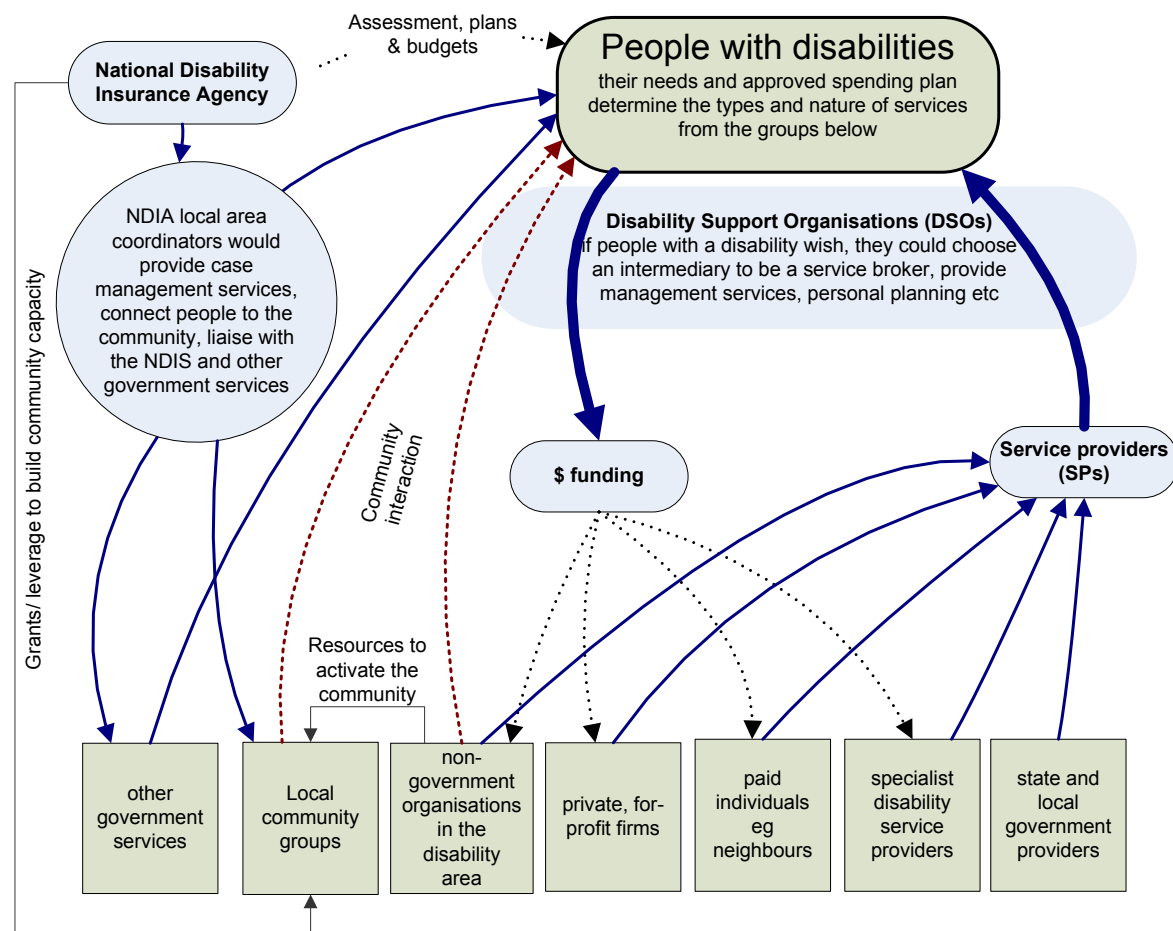
The agency would not deliver mainstream services or provide specialised services, since it would be unlikely to be proficient at this and it would be inconsistent with a consumer choice model.

A new form of organisation, 'disability support organisations', would offer people brokering services, the skills and confidence to practically exercise choice, management services (such as dealing with the administrative aspects of self-directed funding, were a person to go down that route), personal planning, and orientation supports for people who are suddenly faced with the unfamiliar world of severe disability.

Figure 4   Who does what in the NDIS?

Functions controlled by the NDIA

Governing board

- Appoints CEO
- Sets corporate plan
- Oversees the performance of the NDIA
- Ensures financial sustainability and good governance
- Seeks advice from Independent Advisory Council as to how well the NDIA meets the needs of its stakeholders
- Reports to Minister and the community

National Disability Insurance Agency

- Assesses needs and determines individual plans and budgets
- Authorises funding of services and supports
- NDIA local area coordinators oversee system at local level
- Web and information services for people with disability, carers and Australians generally
- Assists people in contacting other government service providers
- Helps build capacity among participants and providers to work within the scheme
- Helps build local community capacity for inclusiveness, including encouraging not-for-profits to take on this role, and through small grants to local community groups
- Determines efficient prices for supports provided
- Central purchasing of some goods & services
- Manages costs and future liabilities
- Collects and analyses data about services used, outcomes, efficacy of interventions and provider performance
- Research function
- Provides advice to and monitors fund holder
- Innovation fund
- Interacts with and reports to the board
- Creates a stakeholder group that advises the NDIA on ways of controlling compliance burdens on services providers and people with disabilities, and to ensure plain English forms

Internal but independent review process overseen by Inspector-General to:

- Manages complaints about suppliers
- Reviews NDIA decisions where a person appeals
- Provides mediation services
- Oversees quality assurance of service providers

Functions controlled outside the NDIA

Functions focused on people with disabilities

Government disability & mainstream services outside the NDIS
- Provides other government-funded services to people with disability
- Provides income support
- Agreements with NDIA about respective responsibilities
- Referral of clients to the NDIA
- Provides data to NDIA

DSOs (intermediaries)
- Provides personal planning services & individual guidance
- Links people to the community
- Assembles 'packages' of supports from specialist and mainstream providers
- Undertakes administrative tasks for people using self-directed funding
- Provides data to NDIA
- Innovation in coordinating services

Disability service providers
- Supplies & promotes services to people
- Coordination of a specific provider's services
- Internal complaint mechanisms
- Provides data to NDIA
- Innovation in service delivery

Private mainstream providers
- Supplies services to people

The wider community (not-for-profit organisations, local councils, businesses)
- Community awareness of disability issues
- Economic and social inclusion of people with disability
- A compact with the NDIA to improve outcomes

NDIA-focused functions

Governments
- Form policies
- Appoint Board
- Monitor sustainability
- Guarantees collection of funds (Australian Government)

Courts
- Hears appeals on matters of law

Treasury
- Assesses scheme performance
- Reports to governments about problems with performance

Fund manager
- Manages funds on behalf of the NDIA
- Provides advice to NDIA
- Responds within constraints to advice from the NDIA

Auditing
- Provides professionally independent audits and accounting reports on the NDIA to the government and public

They would also develop linkages with mainstream local community groups (such as Scouts or Rotary) so that these were receptive to the inclusion of people with

disabilities generally — in effect, a community capacity building role. Disability support organisations and local area coordinators would then be able to match specific people to such community groups, depending on the preferences and personal plans of the person.

People with disabilities and service providers would need to be able to complain to, and contest the decisions of, the National Disability Insurance Agency. The Commission proposes that there would be an Office of the NDIS Inspector–General to hear complaints by people with disabilities and providers about the conduct of the Agency, and reassess contested decisions on a merit basis. While located within the NDIA, the legislation for the National Disability Insurance Agency would ensure the independence of the Office. The Inspector–General would be separately appointed by the Australian Government, and the legislation would specify that the Inspector–General be independent (an 'independent statutory officer'), would act fairly and impartially, would base decisions on the available evidence, and could not be directed in his or her decision-making. The Inspector–General would be required to follow complaints made, and would have the power to undertake investigations and to direct the National Disability Insurance Agency to alter contested decisions. The legislation would require that regard be given to the legal entitlements of the individual and the sustainability of the scheme. The Inspector–General would report publicly to Parliament and to the board. People could appeal decisions to the courts on matters of law in the usual way.

The NDIS would not represent an Australian Government takeover of disability services. Rather, the goal would be to create a new federal social and economic institution that would be independent from all governments in operational matters. In consultation with state and territory governments, the Australian Government would draft legislation setting up the National Disability Insurance Agency and defining its functions. (At the practical level, the Australian Government would have carriage of the legislation through the Australian Parliament and Senate.) As founders of the scheme, all Australian governments would oversee the appointment of a skills-based board.

The scheme would particularly benefit from having some board members who also have direct experience with disability, and also with the management of long-term care or insurance schemes, since this is how the NDIS should be structured. Governments could sack the board if it failed to perform. All jurisdictions would also be involved in appointments to a disability advisory council to advise the board on the performance of the NDIS and its scope and activities from the perspectives of people with disabilities, carers, suppliers of equipment and services, and state and territory service providers. The agency would provide reports about its financial and other performance to all governments.

What about accident insurance arrangements?

The Commission is proposing a separate 'federation' of accident insurance schemes for catastrophic injury (the National Injury Insurance Scheme or NIIS), drawing on the best arrangements already in place around Australia, and extending their scope. Catastrophic injuries mainly comprise major acquired brain injuries, spinal cord injuries, burns and multiple amputations. In most instances, people need lifelong supports and, particularly in the initial post-injury phase, have intensive clinical needs and require post treatment supports, early interventions and rehabilitation services. A key focus of the NIIS would be coordinating these services and supports.

Currently, there is a range of state and territory arrangements for insuring people for disability arising from accidents, including workers' compensation schemes throughout Australia, hybrid no-fault third-party motor vehicle insurance arrangements in some states and territories (Northern Territory, Victoria, Tasmania and New South Wales), limited provision for people suffering disability as a result of crime (a major and rising source of catastrophic injury) and fault-based medical indemnity and public liability insurance.

There is little rationale for the striking differences in state and territory arrangements for dealing with catastrophic injury. Only no-fault accident compensation schemes meet people's lifetime care and support costs efficiently. The major flaw in the remaining fault-based arrangements is that people who cannot establish the legal liability of another party in a catastrophic accident get inadequate supports. Even when an at-fault party *can* be identified, the processes for securing compensation for support through litigation are drawn out and costly in fault-based regimes. Nor is there evidence that the common law right to sue for compensation for care costs increases incentives for prudent behaviour by drivers, doctors and other parties. The Commission recommends no-fault insurance arrangements — operating at the state and territory level — for the long-term care and support of people experiencing catastrophic injuries from all types of accidents. Acting collaboratively, the state and territory no-fault schemes would ensure national coverage. People would retain the right to sue for care costs for less severe injuries, and for economic loss and pain and suffering for all injuries.

The creation of a national injury scheme would avoid many of the deficiencies of common law compensation systems and improve outcomes for people with catastrophic injuries. It would comprise a system of premium-funded, nationally-consistent minimum care and support arrangements for people suffering catastrophic injuries. It would reduce the legal and frictional costs associated with

the current fault based adversarial arrangements. It would promote rehabilitation and adjustment and, where possible, employment.

Ultimately, the NIIS would cover (nearly) all causes of catastrophic injuries, including those related to motor vehicle accidents, medical treatment, criminal injury and general accidents occurring within the community or at home. One exception to this would be cerebral palsy associated with pregnancy or birth. In this area, there are compelling grounds for funding future care and support from the NDIS rather than the NIIS. This reflects several factors:

- the scientific evidence suggests that most cases of cerebral palsy are not accidents in the typical sense of the word. Most do not involve cases where clinical practices could avoid the disability, but are more akin to other birth defects, which would be covered by the NDIS

- it is particularly hard to reliably determine medical treatment or care by the physician as the cause in any individual case. Individually risk-rated insurance is not an efficient way of moderating risks compared with other approaches, such as training programs, clinical protocols and other measures aimed at the relevant group of physicians.

As in other areas of catastrophic injury, common law rights for suing for the future care and support needs for cerebral palsy would be removed. This would give people immediate support, whereas currently the particularly complex issues arising from determining fault in this area and the associated protracted litigation processes mean people can face significant delays in receiving adequate services. People would still be able to sue for economic loss and pain and suffering. However, people may decide not to pursue such litigation given the difficulty in establishing fault and the fact that their most important need — adequate long-term care and support — would have been met by the NDIS.

While existing workcover schemes would stay in place, there are strong grounds for state and territory governments to transfer the care and support of catastrophic workplace claims to the NIIS through a contractual arrangement with their respective workers' compensation schemes. This reflects the fact that the incidence of catastrophic injuries under workcover schemes is low and that their systems are not well geared to provide coordinated lifetime care for such cases. Notably, Victoria has already transferred such cases to its motor vehicle scheme. (Existing no-fault workcover arrangements would continue to cover the management of non-catastrophic workplace injuries.)

The appropriate funding for full no-fault coverage of lifetime care depends on the source of the injury, and should include:

- maintaining existing revenue sources for funding catastrophic injuries (mainly premium income from mandatory insurance policies)

- compulsory third party premiums for motor vehicle accidents in those jurisdictions without no-fault motor vehicle schemes

- a small surcharge on passenger tickets of all rail transport regulated under the new rail safety national laws

- a modest levy on domestically registered passenger carrying vessels regulated under the Australian Maritime Safety Authority (as the proposed new safety regulator for all commercial shipping in Australian waters by 2013) and a small levy on existing state-based registration for privately owned 'pleasure' vessels

- contributions from the insurance (including self-insurance) arrangements of hospitals and the medical indemnity premiums of physicians for medical treatment accidents

  – If the removal of the insurance costs associated with the lifetime care and support of cerebral palsy cases does not sufficiently outweigh the additional costs associated with the inclusion of no-fault catastrophic injuries, then any premium increases should be modest and could gradually be phased in. State and territory governments should fund any gap between premium income and catastrophic medical injury claims.

  – Regardless, the Australian Government subsidy schemes would continue to safeguard the affordability of medical indemnity cover.

- state and territory governments' funding of catastrophic injuries arising from criminal injury or general accidents in the community and in people's homes. One efficient avenue for doing this would be through a small impost on municipal rates. While local governments are opposed to such a funding approach, such taxes are economically efficient and recognise that local governments can adopt practices to reduce injuries (for example, through planning rules and by-laws). If the states do not support a small increase in rates as the means to fund this reform, they should fund such catastrophic accident costs by other means. Regardless, the capacity to reduce the risk of such accidents is greatest at the state, territory and local government level, which is why they would be the most appropriate funders of the NIIS in this area.

In all cases, one source of revenue would be savings in legal costs (which account for a significant component of premiums in fault-based systems).

Overall, a ballpark estimate is that the net annual costs of a comprehensive no-fault scheme covering all catastrophic injuries would be around $35 per Australian.

It would take some time to introduce no-fault arrangements for all catastrophic injuries, but fast progress could be made in some areas.

- State and territory governments would set up no-fault catastrophic injury schemes for motor vehicle accidents by the end of 2013 (table 2). All catastrophic injuries would be covered by 2015, but funding for the scheme should commence in 2014 to establish a funding pool prior to any claims.

- The NIIS would be structured as a federation of separate, state-based injury insurance schemes. The purpose of federation membership should be to ensure consistency in assessments and to provide certainty around a benchmark minimum standard of care. Benchmarking would need to be transparent and agreed. Jurisdictions would learn from existing no-fault schemes — making progress quicker. New schemes would include well-developed and coherent models for rehabilitation and care, funds management, cost control — emphasising management of long-run expected liabilities — and information collection and analysis (just as in the NDIS). There should be a national arrangement for reinsurance coverage of high risks among the separate schemes.

- Jurisdictions with a small client base or without sufficient expertise could choose to sub-contract scheme management to another state (or to a private sector insurer operating across jurisdictions or to the NDIS) to reduce the fixed costs of establishing their own schemes.

- Over the medium to long term, and after the NIIS is well established, governments could consider whether the NIIS should eventually provide coverage for care and support for all significant severities of accidental injury, except where the only care needed could be provided by the health sector.

- Similarly, over time, there may be logic in extending coverage of the NIIS to provide no-fault cover for economic loss and general damages. However, this would be a radical shift, and its practicability, costs and efficiency would have to be carefully tested. The Commission proposes a review of the NIIS in 2020, of which a part would examine these issues.

The National Disability Insurance Agency itself would play an important role in the NIIS (figure 5). It could act as a host for cooperation, assist in and publish benchmarking information for both schemes, and encourage diffusion of best practice.

Other than in its role in the National Disability Insurance Agency, the Australian Government would be a less important party in the NIIS than state and territory governments. The Australian Government may also need to contribute to premiums in the Northern Territory, where the injury risks are higher. (This reflects the same equalisation principles underpinning the Commonwealth Grants Commission's

distribution of the GST.) Moreover, the Australian Government would push the establishment of the NIIS as a quid pro quo of its very large additional revenue contributions to the NDIS.

Table 2   Implementing the NIIS

Date	Milestone
Second half of 2011, or early 2012	COAG would: • agree to the establishment of the NIIS, whereby states would implement no-fault accident insurance schemes for long-term care of new cases of catastrophic injury • agree to have these arrangements in place in all jurisdictions for motor vehicle accidents by the end of 2013 • establish a full-time high level taskforce to help implement this The taskforce would report back regularly to Heads of Treasuries meetings and COAG on milestones reached
end 2013	NIIS to cover catastrophic injuries from motor vehicle accidents in all jurisdictions on a no-fault basis
2015	People suffering catastrophic injuries from other causes should be covered by at least 2015
2020	Independent review of the NIIS

Why two schemes?

The Commission has deliberately recommended two schemes, rather than a single disability scheme. This reflects the distinctive characteristics of catastrophic injury schemes. The NIIS would:

- have as one of its goals, the reduction of local risks that can contribute to accidents. For example, state and local governments can affect public safety through local initiatives, and accident schemes can use premiums to deter high-risk behaviour. One of the reasons for using sources of funding (premiums and state and territory funding) different from the National Disability Insurance Agency is that these send price signals that encourage greater incentives for safety

- cover a variety of health costs associated with catastrophic accidents, such as trauma retrieval, acute care and rehabilitation services. A major rationale for this is that when setting premiums or determining optimum injury prevention approaches, it is important to take into account the full 'external costs' of catastrophic injuries, and not only those associated with lifetime care and support (an issue that does not apply to the NDIS). The knowledge gained by the NIIS in its coordination with, and development of, specialist health services

would help frame the NDIS's memorandum of understanding with the health sector.

- draw on its revenue sources to cover the expected lifetime liabilities of new cases (it would primarily be a 'fully funded' scheme)

- be focused on a relatively small group of people subject to very particular and individualised intensive management. When the NIIS is fully operational, the caseload would be around 30 000 people, or about 8 per cent of the caseload of the NDIS.

Figure 5   **Links between the NIIS and the NDIS**
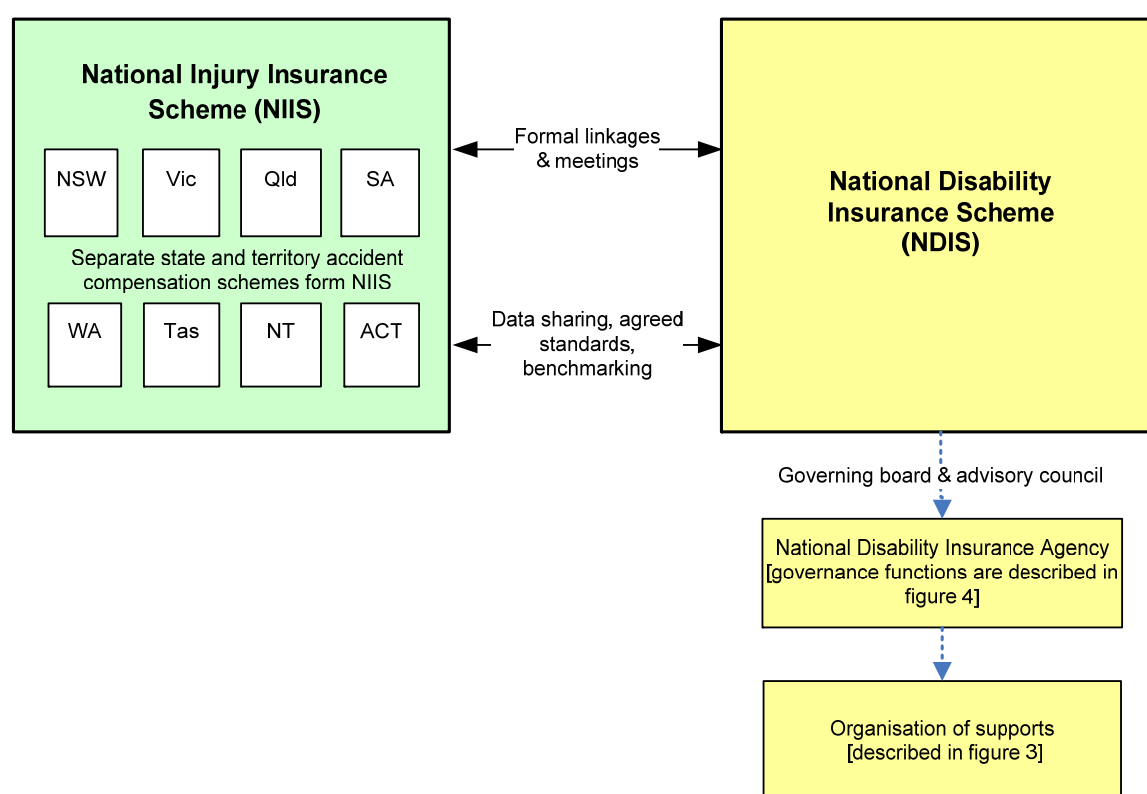
Moreover, it is a practical reality that there is already a nucleus of existing, well-functioning schemes, like those run by the Tasmanian Motor Accident Insurance Board, the Transport Accident Commission and the NSW Lifetime Care and Support Authority. There would be significant legislative change required to wrap up such accident schemes into a giant NDIS, and the resulting 'neatness' may not be worth the gains. That said, this issue should be revisited at the time of the proposed review of the NIIS in 2020.

Workforce issues

The expansion in the disability system will increase the demand for disability support staff. Workforce pressures will also rise as the aged care system expands (and as labour force growth subsides with population ageing). The capacity to provide expanded services will depend on attracting new employees and enabling workers in the system to work longer or more flexible hours if they want to.

The long-run response to shortages will be wage increases following competition between suppliers for labour (the current low wage levels are a major deterrent to staff working in the industry). The scope for wage increases associated with excess demand also affects how fast governments can implement the NDIS. Were governments to increase funding for disability services suddenly, the immediate effect would be significant wage increases, without the necessary expansion of supply. The phased implementation of the scheme proposed below would allow for both wage increases and a sustained increase in the workforce.

Apart from wage increases, other options for alleviating workforce shortages are:

- initiatives by service providers to adapt the work environment to increase workforce retention (such as shorter shifts, longer breaks between shifts, and greater certainty about shift arrangements)

- productivity increases from new technologies that cut the need for personal care

- supporting the current informal workforce, including using self-directed funding to allow the payment of friends, neighbours and, if justified by the trial results, relatives for some personal care and support

- a workforce strategy to retain and attract people with specialised skills where shortages are apparent or impending (such as orthotists)

- an advertising campaign for new staff (a successful initiative in New South Wales)

- identifying disability support as a career option for people seeking careers advice at school and other educational institutions

- using immigration of appropriate workers, but only if acute and persistent shortages are present. Ideally, wage increases would elicit a sufficient supply response within Australia.

Requirements for training and credentials should follow the 'horses for courses' principle, taking into account the needs of the person with disabilities and matching them to the skills required. Some support services will require extensive training, others not. To achieve good quality outcomes and reduce risks, regulations and

training — sometimes of a highly developed and specialised kind — are required for certain functions, such as manual handling, administering medication, and restrictive practices, therapeutic services, and fitting and creating prosthetics. Moreover, formal and on-the-job training would be likely to expand under the NDIS, because there would be more funding available for training and because it would be one of the competitive strategies used by service providers to attract customers (who will have more choice) and to retain or recruit workers.

While training is a critical element of a workforce strategy for the NDIS, governments should not require that *all* disability workers have minimum training. In some instances, the essential skills that workers need are intangible — empathy and a capacity for listening and social skills — and are not necessarily amenable to training. Moreover, the most important 'training' of attendant carers/support workers is often by the person with a disability and their families (but should sometimes be supplemented by orientation courses from service providers). It should also be emphasised that the overwhelming current source of care is unpaid and usually untrained family carers, who are usually preferred by people with a disability.

The NDIS should also undertake research to examine how training affects outcomes for people and ensures safety for workers. Where training was unlikely to respond quickly to market signals, the Australian Government should examine the obstacles to training and, if required, provide scholarships and subsidies in areas where impending shortages would undermine quality outcomes for people. This strategy may be particularly relevant for attracting staff into locations with acute shortages. Training would also have to emphasise the need to respect the rights and wishes of people with disabilities.

Overall, the creation of the NDIS (and the NIIS) would have significant positive impacts on the disability workforce. The new system will translate to greater pay, more jobs, better working conditions, the capacity for innovative practice, enough resources to do the job properly, recognition of the critical role of workers, more choice of employers, and greater satisfaction from working in a system that achieves better outcomes for the people they support. These outcomes will be critical to attracting the workforce needed to underpin the expansion of the NDIS.

What are the implications for delivery of support services?

The NDIS would have significant implications for service delivery. Under a consumer choice model in the NDIS, it would mean that:

- service providers and (the newly created) disability support organisations would need to adapt to a new way of thinking and supporting people with a disability

- block funding to service providers supplying individual supports would generally phase out. Providers would compete for custom, as people with a disability, or their agents, could 'shop' around for the service providers that best met their support needs, subject to the resources specified in people's support packages. Providers would need to deal with competitive risks in the way most businesses do. The National Disability Insurance Agency would reimburse service providers or disability support organisations for those parts of a person's support package that they supplied. The Agency would set prices for such reimbursement to ensure the long-run viability of efficient providers, which would include adequate returns for capital investments. (Only people using self-directed funding would pay providers directly.) Ultimately, the pricing role of the Agency would diminish as the market developed, and this could allow disability services to even more closely resemble the economy-wide service sector. However, block funding may continue in certain circumstances, such as in building community capacity, pilots of innovative services, in some rural areas where markets might not support the provision of any service, and where there is a need to build longer term capacity, such as Indigenous-specific services

- people with a disability would more often use mainstream services, placing additional pressures for high quality performance by specialist agencies.

There would be significant IT infrastructure needs associated with an integrated disability system, in particular for obtaining access to clients' assessments or other information relevant to their support needs, for financial management, and for collecting data and passing it to the NDIS. (Notably, the Australian Government employment department had to oversee the creation and deployment of a sophisticated IT system with the creation of the Job Network. The lessons learned from that exercise will be important for the National Disability Insurance Agency.) Moreover, the Australian Government is currently considering the adoption of standard business reporting for the not-for-profit sector to reduce regulatory burdens for that sector. This should make reporting of any required financial information to the National Disability Insurance Agency easier and less costly.

There are significant opportunities for service providers under the NDIS.

- Many not-for-profit organisations partly fund their current provision of services through volunteers and philanthropy, and with full funding of NDIS supports, could divert those resources to wider disability concerns. This would include enhancing employment opportunities, increasing community engagement with people with disabilities, research, or resourcing of complementary areas outside

the NDIS (such as supports for people who have been in the justice system or who are homeless).

- The amount of funding to disability would be much greater, and there would be strong incentives for innovative practice (with providers as well as people with a disability 'unshackled' from block funding).

- The Commission proposes that the National Disability Insurance Agency include an innovation fund that providers would use for developing and/or trialling novel approaches to disability services.

- There would be arrangements that encourage the diffusion of best practice throughout the disability sector.

A focus on quality

A quality framework for service providers would also include the development of complete, nationally consistent standards that would apply to all funded specialist service providers and disability support organisations. These would provide greater national consistency in service quality and equivalent treatment of service providers across jurisdictions. These standards should be complete, rather than augmented on a state-by-state basis — replacing state and territory equivalents for the purposes of the NDIS. A period of mutual recognition of state and national accreditation would be required to minimise the transitional impact on service providers.

Wherever possible, standards should be set in terms of directly observed outcomes, easily understood by people with disabilities, independently verifiable, and targeted at those most vulnerable or at risk of harm. The approach should focus on effective safeguarding and raising the quality of supports, rather than 'paperwork' initiatives, which would do little to ensure quality assurance but would impose compliance burdens on service providers.

Quality and outcomes would be tested through periodic audits (potentially triggered by complaints), consumer surveys and surveillance by local area coordinators (*not* by service providers themselves). Independent state-based statutory organisations (such as the Office of the Public Advocate) should continue to function as an avenue of complaint, investigation and recommendation, with an advisory role to the National Disability Insurance Agency. Official Community Visitors should play an important role in promoting the rights of, and overseeing the welfare of, the most vulnerable people in the disability system (and be introduced in jurisdictions where they do not already exist). Evidence of non-compliance with standards and breaches of contractual or other legal obligations would lead to enforcement by the National

Disability Insurance Agency using the typical enforcement 'pyramid' — advice, penalties and ultimately forfeiture of certification.

Empowerment of people with a disability — a driver of quality service provision — could be improved by giving people information about providers' performance, such as auditors' reports, the number of substantiated complaints, and the results of consumer satisfaction surveys. That information, along with the assistance of local area coordinators and the services of disability support organisations (such as planning and brokering), would help people make informed choices.

There has been a trend over the last 30 years towards provision of services by not-for-profit organisations, but government-run services still play a role, as do some for-profit agencies and local governments. As a funding and purchasing agency, the National Disability Insurance Agency would give no preferences to suppliers based on their ownership. Under a consumer choice model (supported by disability support organisations), the degree to which these different suppliers flourish or decline in importance would depend on their performance.

That said, in some cases, not-for-profit organisations and private operators may be unwilling or unable to operate (though presumably they would often do so if prices were set sufficiently high). In any such instance, state and territory government agencies may be the only tenable service provider ('providers of last resort'). This may occur for clients with highly complex needs or challenging behaviours, as well as in remote settings. The National Disability Insurance Agency would need to fund such services on a fee-for-services basis, taking into account capital costs.

An Indigenous strategy

Indigenous disability rates are around double those of non-Indigenous Australians. Disability often coincides with other major problems with housing, health, substance abuse, poverty and community breakdown. Indigenous Australians also face significant barriers to accessing disability support services. This occurs due to remoteness (with typically only limited HACC and visiting services in very remote areas), social marginalisation, cultural attitudes towards disability and culturally inappropriate services.

These barriers to service delivery suggest that the service delivery model underpinning the proposed NDIS may not, on its own, deliver adequate care and support to Indigenous people with a disability. While Indigenous Australians would have access to individual support packages on the same basis as non-Indigenous Australians, it may also be necessary to block fund some services in order to overcome the additional barriers that Indigenous Australians face. In addition,

Indigenous people with disabilities often do not make claims for support. These distinctive aspects suggest that disability support for some Indigenous communities will probably need to take a different form.

Several other strategies may be useful in helping to overcome the barriers to service delivery, including:

- providing funding for early intervention and, in particular, working with local organisations to better resource preventative programs aimed at reducing the rate of disability in Indigenous communities

- fostering and building capacity in community-based operations, in consultation with local communities, and through the engagement of local staff. Larger experienced service providers would provide support. This strategy would apply across all parts of Australia — urban, regional and remote communities. But the strategy would need to recognise the particular challenges of adequate support in remote locations where even mainstream services are often absent

- employing Indigenous staff and providing appropriate training

- developing the cultural competency of non-Indigenous staff.

But ultimately, Indigenous disadvantage and the disability that is one component of it, reflect a complex set of linked factors that require a whole of government approach and community involvement.

What are the long-term benefits of the proposed schemes?

As a major reform, the proposed NDIS will generate profound economic benefits. These benefits arise from many sources:

- wellbeing gains to people with disabilities and informal carers, noting the very poor outcomes under the current system described earlier. While it is hard to assign market values for these intangible benefits, they nevertheless are still economic benefits, and likely to eclipse the benefits of many things that are counted as valuable in official statistics

- efficiency gains in the disability sector. Much of the existing system has been centred on the contractual relationships between service providers and governments, not supports chosen by people to suit their lives. As one participant noted, a support provided at the wrong time is like 'sending a bald man to a barber'. A new coherent system would achieve much better value for

money. Every one per cent increase in productivity would lower scheme costs by $130 million

- savings to other government services, such as reduced 'bedblock' in hospitals and savings in the justice system through better community support of people with significant and enduring psychiatric disability

- increased economic participation for people with disabilities (against a background of Australia's low performance in this area compared with most other developed economies) and their informal carers

- fiscal gains, for example those associated with reduced use of income support by people who enter employment.

Moreover, in weighing up the above benefits against the costs, it should be emphasised that the net *economic* cost of the NDIS is not the budgetary cost of around $6.5 billion (which is a transfer), but rather, the distortionary impacts of raising the revenue. That represents a cost of around $1.6 billion. Given this, the NDIS would only have to produce a gain of $3800 per participant to meet a cost-benefit test. Given the scope of the benefits, that test would be passed easily.

Some quantitative measures

The most important of the economic benefits are the welfare impacts for people with a disability and their carers. One, partial way of assessing these gains is the value of the implicit income transferred by the NDIS to people with disabilities. Commission estimates suggests net benefits of such transfers of around $7.8 billion annually. This is likely to significantly understate the benefits.

It is harder to measure some of the other economic *benefits* of the NDIS, but it is possible to assess some of its economic *effects*. Were Australia to achieve employment ratios for people with disabilities equivalent to the average OECD benchmark — a highly achievable target given the proposed reforms — employment of people with mild to profound disabilities would rise by 100 000 by 2050. In fact, the package of measures, including through DSP reforms, would be likely to raise employment by considerably more than 100 000. Under a reasonable scenario, the Commission estimates that there could be *additional* employment growth of 220 000 by 2050 (including those without core activity limitations).

By 2050, the collective impact of these two employment gains would be around a one per cent increase in GDP above its counterfactual level, translating to around $32 billion in additional GDP (in constant price terms) in that year alone. However,

it is important to note that there would be some offsetting reductions in unmeasured informal employment and output.

There would also be fiscal gains from reductions in DSP beneficiaries and an increase in part-rate DSP payments. These gains materialise slowly, but the value rises steeply. Taking account of the benefits over the longer run, the reforms would produce the equivalent of a $2.7 billion (constant price) annuity with the gains less than that initially, but growing well above it in later years.

The bottom line is that the NDIS would have substantial economic impacts, and its benefits would significantly exceed the additional costs of the scheme.

How to implement the NDIS effectively

People want more supports urgently. But too much haste in structuring and commencing the NDIS could mean less speed and effectiveness. Governments cannot put a full-scale 'well-oiled' system in place in a year or two, but will need to plan carefully, develop systems, accumulate resources and build infrastructure. Implementation of the NDIS will have to confront the difficulties of reform in a system involving multiple jurisdictions and overlapping responsibilities. This means that present arrangements for state, territory and local government disability services will have to remain for a while and, after the introduction of the NDIS, coexist for a few years as people move over to the NDIS. In the interim, the Australian Government should supplement funding under the National Disability Agreement to reduce some of the worst rationing.

In the period up to the full operation of the NDIS, there would need to be:

- discussions between state and territory governments and the Australian Government about the legislation that would establish the National Disability Insurance Agency, set the boundaries for the NDIS, and the formula to finance the scheme. In consultations with all participating state and territory governments, the Australian Government would draft legislation

- finalisation of an intergovernmental agreement setting out the various obligations of governments

- development of linkages so that the NDIS would coordinate well with the supports that would lie outside it (education, housing, health, public transport, open employment services and income support)

- establishment of a National Disability Insurance Agency and appointment of a board (by all Australian governments)

- work undertaken on the detailed features of an effective and efficient organisation (IT, data systems, information dissemination strategies, research functions), and more broadly for an effective scheme (workforce strategies, arrangements to encourage the formation of disability support organisations, and systems for managing self-directed funding and providing development support for service providers).

To oversee this process, the Australian and state and territory governments would form a joint taskforce. It would be headed by a person with insurance and/or disability experience who has driven change successfully in a large organisation, appointed with the agreement of all jurisdictions. The taskforce would report back regularly to Heads of Treasuries meetings and COAG on milestones reached in the planning for the commencement of NDIS by July 2014. An expert project management implementation team would be tasked to plan the fine detail of the scheme and the transition arrangements.

The costs of setting up the NDIS, while significant, would be reduced by learning from the existing no-fault accident insurance schemes around Australia. And, in the past, large structural changes have been achieved in several years, for example, as with the introduction of the Superannuation Guarantee, and Centrelink. The Job Network — a sweeping change in employment services — took two years to implement. Medibank was implemented in one year after the passage of its enabling legislation.

The NDIS would begin at a manageable size. A workable way of proceeding must recognise that there would have to be enough people initially in the scheme for the National Disability Insurance Agency to learn about how the scheme works (and how to adapt it).

The scheme would be launched in mid-2014 in a few suitable regions in different jurisdictions, providing high quality services to many thousands of people. These regional arrangements would incorporate all of the functions and structures of the NDIS, and offer supports to the full range of eligible people with a disability in those regions. This would allow ongoing fine-tuning to test and refine the new scheme structures with a population that is not overwhelming. It would also help build a robust and sophisticated resource allocation process that would serve people's needs appropriately, while reducing the risks of cost blowouts. In successive years, the scheme would be scaled up (table 4).

Table 3   **Implementation of the NDIS**

Date	*Milestone*
Second half of 2011, or early 2012	COAG would: • agree to an MOU that sets out in-principle agreement that the NDIS should commence in stages from July 2014 • create a **high level taskforce** with agreement of participating jurisdictions, to be headed by a person with insurance or disability experience who has driven change successfully in a large organisation (appointed with the agreement of participating jurisdictions) The taskforce would: • develop a draft intergovernmental agreement for final signing in 12 months • establish an expert **project management implementation team** with experience in commercial insurance and disability to work full time on planning the details of the scheme – including targeted consultation and early work on key operational arrangements, including assessment tools, risk management and transition arrangements • report regularly to Heads of Treasuries meetings and COAG on milestones reached in the planning for the commencement of NDIS in July 2014
July 2012 to June 2013	*During 2012-13*, the following need to be well underway: • drafting of legislation • preparing MOUs with government departments • developing data collection protocols • researching appropriate IT arrangements • recruiting and training of staff • testing of assessment tools • preparing manuals • determining pricing arrangements • working with providers to identify likely areas of workforce shortage and strategies to address them, with a particular focus on regional launch sites • drawing up of tenders • developing communications strategies • detailed planning for the regional launch sites, including with new and potential service providers, DSOs, not-for-profit organisations and community groups By Feb 2013: final consideration and agreement by COAG to the intergovernmental agreement, including an agreement on funding arrangements March to June 2013: Commonwealth to introduce legislation to create NDIS and NDIA, with an initial appropriation • state legislation and further Commonwealth legislation to follow Announcement of the NDIA board

(Continued next page)

Table 3   (continued)

Date	Milestone
July 2012 to June 2013 (continued)	The NDIA board to commence formally • the board to appoint a CEO • the board to appoint interim staff from the taskforce executive, the project management implementation team, and/or from elsewhere, as determined by the board • staff recruitment to begin The NDIA should be established by June 2013.

July 2013 to June 2014	*During 2013-14:*
	
	 • NDIA staffing levels would be rising (including regional offices)
	
	 • IT infrastructure would be purchased
	
	 • workforce strategy would be implemented
	
	 • capacity building would commence, including providing information and assistance to service providers in preparation for moving away from block-funding
	
	 Intensive work for rollout of the scheme in selected launch regions, including:
	
	 • appoint and train NDIA regional managers (July – Dec)
	
	 • establish local and regional offices for NDIA for the initial launch regions (July – Dec)
	
	 • regional managers would engage with existing and potential service providers (Aug – Dec)
	
	    – and check on their preparations for expansion in 2014, including recruitment, and testing of IT systems (early 2014)
	
	 • intensive training of allied health professionals as NDIS assessors for the initial launch regions (early 2014)
	
	 • recruitment and training of local area coordinators
	
	 • public information campaigns and outreach in the initial regional launch sites by local area coordinators to local disability organisations, people with disabilities, existing and potential service providers, local community service groups and local media (early 2014)
	
	 • information sessions in these regions for people with disabilities, their families and carers, service providers and the general community (early 2014)
	
	    – what the NDIS will do for people
	
	    – the assessment process
	
	    – people's rights and responsibilities
	
	 • disability support organisations may also undertake group information sessions
	
	 • call for interest and pre-registration of those participating in the initial launch

(Continued next page)

Table 3 (continued)

Date	Milestone
July 2014	In July 2014, the NDIS would commence providing full services in a few regions of around 10 000 clients per region
	• thereby providing high quality services to many thousands of people, while allowing fine-tuning of the scheme in the light of lessons learned
	Throughout 2014-15, all local and regional offices would be established across Australia, with local staff engaged and trained
	• a national information campaign would be undertaken, including information sessions by local area coordinators to local disability organisations; people with disabilities, their families and carers; existing and potential service providers; local community service groups; local media; and the general community
	– in all regions, work would commence with local groups on a compact to increase social participation and employment opportunities for people with disabilities
	The NDIA would work with providers to monitor the developing workforce and to address emerging shortages.
July 2015	In July 2015, the NDIS would extend nationally to cover all of Australia
	• progressively it would be expanded to cover all relevant people with a disability, commencing with all new cases of significant disability and some of the groups most disadvantaged by the current arrangements.
2016-17	Second year of national rollout
2017-18	Third year of national rollout
	NDIA evaluation of effectiveness of self-directed funding
2018-19	Final year of national rollout: all current and new clients to be receiving NDIS services
2020	Independent review of NDIA and NDIS

In 2015-16, the scheme would be extended to all of Australia. However, from a practical perspective, the scheme could not immediately support the entire eligible population across all regions in just its second year of operation. This reflects the large scale of the scheme, and the fact that it will take time to:

- develop a high quality workforce

- develop capabilities in the National Disability Insurance Agency and specialist providers

- make assessments of around 410 000 people's reasonable needs.

Accordingly, the Commission proposes that over the period from 2015-16 to 2018-19, the scheme would progressively expand to cover all relevant people with a disability. In its first stages, the NDIS would cover all new cases of significant disability and some of the groups most disadvantaged by current arrangements, such as:

- children aged under five years who have substantial core activity limitations

- select groups for whom involvement in pilot early intervention programs looks promising

- people who are now cared for by ageing carers

- people who have been inappropriately placed in nursing homes.

The NDIS is a major reform requiring careful planning and a workable transition period, but given the risks of delay, there should be an early commitment to future resourcing and a sense of urgency to deliver in the timescale proposed by the Commission.

Table 4   **Progressive costs of the NDIS, 2011-12 to 2018-19**

Year	Stage of implementation	Likely annual costs
remainder of 2011-12	getting agreement	$10 million
	planning the details of the scheme	
2012-13	setting up legislation	$50 million
2013-14	bedding down administrative arrangements	$550 million
2014-15	scheme begins with regional rollouts	$900 million (net)
2015-16	first full year of national rollout	$2.4 billion (net)
2016-17	second full year of national rollout	$3.9 billion (net)
2017-18	third full year of national rollout	$5.4 billion (net)
2018-19	final year — rollout now complete	$6.5 billion (net)

- *The economic benefits of implementing the NDIS.* The scheme would substantially increase the personal wellbeing of many people with disabilities and their carers. Such benefits are economic gains, even though they cannot be measured with any accuracy and do not show up in conventional measures such as GDP. There would also be beneficial employment effects, increased efficiency and fiscal offsets (which would grow over time). The benefits are sufficiently large to exceed the estimated costs of the scheme.

- *The benefits of greater community engagement with people with disabilities.* There should be concerted efforts to support 'community capacity building' and 'social inclusion' initiatives.

- *Options to reform the Disability Support Pension to align its goals with those of the NDIS.*

- *Special arrangements for cerebral palsy.* The NDIS should fund all cases associated with pregnancy or birth that meet the NDIS eligibility criteria. Most cases of cerebral palsy cannot be avoided through clinical practices, and it is very hard to determine whether clinical care was the cause.

- *Revised criteria for obtaining assistance under tier 3. The* NDIS should provide supports for people under the pension age who have significant and enduring psychiatric disabilities, and who have scope to be supported in the general community.

- *The criteria for eligibility do not separately identify people with intellectual disabilities*. They are grouped with other people with 'significantly reduced functioning in self-management' (this criteria would also capture some people with acquired brain injuries and those with significant and enduring psychiatric disability). There is full coverage of intellectual disability.

- *There is no longer a requirement for a front-end deductible.* However, one should be considered if, after the implementation of the NDIS, small claims clog up the NDIS assessment process.

- *Qualifications for the disability services workforce.* Professional development involves both experience and formal training, but while formal training is important, it should not be compulsory for all employees.

- *Revised estimates of the numbers of people likely to be receiving supports, and of the costs of the scheme.* About 410 000 people would meet the criteria to receive funded individualised supports under tier 3 of the scheme. The increase principally reflects the inclusion of people with significant and enduring psychiatric disability, who would benefit from community supports. When fully operational, the scheme would cost about $6.5 billion more than is currently spent by all governments.

- *Net costs of the NDIS*. Despite the inclusion of people with significant and enduring psychiatric disability, overall net costs have only risen slightly compared with the draft. This mainly reflects greater analysis of the spectrum of people's needs and associated costs.

- *Approaches to funding of the NDIS.* The Commission's first preference remains that the Australian Government should finance the entire costs of the NDIS by directing payments from consolidated revenue into a 'National Disability Insurance Premium Fund', using an agreed formula entrenched in legislation. An alternative but inferior option would be that all governments could pool funding, subject to a long-run arrangement based on the above formula, and with pre-specified funding shares.

- *Governance models.* The Commission still strongly favours a national approach through the NDIA, in which all governments would play a role. The NDIA should still be used as the model if some governments decide not to participate. An alternative but inferior option would be a 'federated' NDIS. This would give state and territory governments control over their own systems, but with some common core features. The risk is that disagreements could see it revert to a broken and inequitable 'system'.

Recommendations

Chapter 3 Who is the NDIS for?

The National Disability Insurance Scheme (NDIS) should have three main functions. It should:

- *cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, create community awareness of the issues that affect people with disabilities and facilitate community capacity building. These measures should be targeted at all Australians*

- *provide information and referral services, which should be targeted at people with, or affected by, a disability*

- *provide individually tailored, taxpayer-funded support, which should be targeted at people with significant disabilities who are assessed as needing such support (but excluding those people with newly-acquired catastrophic injuries covered by the National Injury Insurance Scheme — recommendation 18.1).*

Individuals receiving individually tailored, funded supports through the NDIS:

- *should have a disability that is, or is likely to be, permanent, and*

- *would meet one of the following conditions:*

  - *have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support*

  - *be in an early intervention group, comprising individuals for whom there is good evidence that the intervention is safe, significantly improves outcomes and is cost effective*

In exceptional cases, the scheme should also include people who would receive large identifiable benefits from support that would otherwise not be realised, and that are not covered by the groups above. Guidelines should be developed to inform the scope of this criterion and there should be rigorous monitoring of its effects on scheme costs.

RECOMMENDATION 3.3

The NDIS should cover:
- *all residents of Australia who are also one of the following:*
  - *Australian citizens*
  - *Australian permanent residents*
  - *New Zealand citizens who were Australian residents on 26th February 2001*
- *asylum seekers.*

NDIS entitlements should be available to eligible people only while they are within Australia.

The Australian Government should consider reciprocal arrangements for disability support with other countries, including New Zealand, after the NDIS is rolled out.

RECOMMENDATION 3.4

The NDIS should provide advice to people about those instances where support would be more appropriately provided through non-NDIS services. Support should be provided outside the NDIS for people whose:
- *disability arose from a workplace accident or catastrophic injury covered by the National Injury Insurance Scheme (NIIS)*
- *support needs would be more appropriately met by the health and/or palliative care systems, comprising:*
  - *those who would benefit from largely medically oriented interventions (including less restrictive musculoskeletal and affective disorders, and many chronic conditions)*
  - *many people with terminal illnesses*
- *support needs would be more appropriately met by the aged care system*
- *needs were only in relation to open employment, public housing or educational assistance.*

The NDIS should put in place memoranda of understanding with the health, mental health, aged and palliative care sectors to ensure that individuals do not fall 'between the cracks' of the respective schemes, and to have effective protocols for timely and smooth referrals.

Upon reaching the Age Pension age (and at any time thereafter), a person formerly receiving an individualised package from the NDIS should be the given the choice of:

- *staying with NDIS service arrangements, where their support arrangements would continue as before, including any arrangements with disability support organisations, their group accommodation, their local area coordinator and their use of self-directed funding*

- *moving to the aged care system, where they would be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches).*

If a person over the Age Pension age requires long-term residential aged care then they should move into the aged care system to receive that support.

The Australian Government funding responsibility for the support of aged people using disability services should be along the lines specified in the National Health and Hospitals Network Agreement.

In implementing this recommendation, a younger age threshold than the Age Pension age should apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

Following the transition spelt out in recommendation 19.1, the NDIS should fund all people who meet the criteria for individually tailored supports (as specified in recommendations 3.2 to 3.4), and not just people who acquire a disability after the introduction of the scheme.

The supports to which an individual would be entitled should be determined by an independent, forward-looking assessment process by the NDIA, rather than people's current service use.

Chapter 4 The role of the community

RECOMMENDATION 4.1

The NDIA should improve engagement of the general community and people with disabilities by:

- *forming a 'compact' with not-for-profit disability service providers that would:*
  - *use the voluntary and philanthropic resources freed up by the creation of a properly funded NDIS for activities that promote community engagement and employment for people with disabilities*
  - *clarify their new roles in the system*
- *undertaking local initiatives, including improving access to buildings and public spaces, to address disability issues within the community*
- *offering modest grants that leverage engagement by community clubs and associations with people with disabilities and that would be likely to yield social or economic benefits consistent with the size of the grant. The effectiveness of such financial incentives should be independently evaluated after a reasonable period*
- *specifying roles for local area coordinators and disability support organisations to connect NDIS participants with the local community and to build the capacity of the community for such interaction.*

RECOMMENDATION 4.2

Prior to implementing recommendation 4.1, the NDIA should consult with not-for-profit organisations and relevant government agencies on the best arrangements for 'community capacity building' or 'social inclusion' initiatives to ensure that any overlap or paperwork burden, or displacement of funding, is kept to a minimum.

Chapter 5 What individualised supports will the NDIS fund?

RECOMMENDATION 5.1

The NDIS should cover the current full range of disability supports. The supports would need to be 'reasonable and necessary'. The NDIS should also support the development by the market of innovative support measures (using the approaches set out in recommendation 10.3).

The delivery of prosthetics should be reformed by:

- *establishing proper funding for prostheses and attachments, including timely replacements and reasonable repairs*

- *improving the level of prostheses available to a reasonable and necessary standard, as determined by the NDIA on the advice of a clinical board.*

The NDIS should fund permanent functional prosthetic limbs for those eligible for individualised funded supports. The health system should continue to fund and provide interim prostheses provided in hospitals.

The NIIS should fund functional prosthetic limbs for amputations arising from future catastrophic injury.

The NDIS should allow co-contributions from amputees who wish to upgrade their prostheses, subject to an agreement about the costs of, and responsibilities for, repair.

There should be no income or asset tests for obtaining funded NDIS services and no general requirement for a front-end deductible. A front-end deductible should only be considered if, after the implementation of the NDIS, small claims clog up the NDIS assessment process.

People should pay the full costs of services (primarily therapies) for which clinical evidence of benefits are insufficient or inconclusive if they wish to consume those services.

Services that meet the needs of much wider populations, including people with disabilities not covered by the NDIS, should lie outside the scheme:

- *health, public housing, public transport, education and open employment services should remain outside the NDIS, with the NDIS providing referrals to them*

  - *but Australian Disability Enterprises, disability-specific school to work programs, some taxi subsidies, and specialised accommodation services should be funded and overseen by the NDIS.*

The Australian Government should not pay the Mobility Allowance to people eligible for individually funded packages in the NDIS. The NDIS should assess people's individual mobility needs and fund these on a reasonable and necessary basis. People not eligible for funded support by the NDIS should continue to get the Mobility Allowance if they meet the eligibility requirements for that Allowance.

RECOMMENDATION 5.7

The NDIS should seek memoranda of understanding (MOUs), with relevant mainstream services, including housing, education, transport and employment. The MOUs should detail the separation between specialist disability and mainstream services and the process for making referrals between the two.

Chapter 6 Aligning the goals of the Disability Support Pension with the National Disability Insurance Scheme

RECOMMENDATION 6.1

The Disability Support Pension (DSP) should not be funded or overseen by the NDIS. The Australian Government should reform the DSP to ensure that it does not undermine the NDIS goals of better economic, employment and independence outcomes for people with disabilities.

Reforms to the DSP should aim to:

- *encourage the view that the norm should not be lifelong use of the DSP, among:*
  - *people with non-permanent conditions*
  - *people with permanent conditions who could have much higher hopes for employment participation*
- *redefine the DSP as a transitional disability benefit, not as a pension, for those with some employment prospects, while retaining the pension for those with low employment prospects*
- *reduce the disincentives to work while on the benefit by reducing benefit taper rates, permanently relaxing or removing the work test for people already receiving disability benefits, and trialing 'sign-on' bonuses for those on DSP who gain paid work*

- *provide greater support to employers to encourage employment of people with disabilities, including greater wage subsidies*
- *tap private innovative arrangements for greater economic and social participation of people on the DSP through social bonds*
- *improving data collection and analysis for monitoring outcomes for people on the DSP and the interventions that produce the largest impacts.*

The above reforms should not be limited to new entrants into the DSP.

As a general principle, all people with disabilities should face the same eligibility test for the DSP. However, the longstanding automatic qualification of blind people for the DSP should remain for current recipients of the pension, but should not apply to new applicants.

While the Australian Government should consider the early implementation of some of the above measures, it should also establish a public inquiry into the DSP to:

- *develop the best path to implementation of the above options, where they cannot be put in place quickly*
- *assess how the DSP could be further redesigned to be compatible with the social and economic participation goals of the NDIS.*

Chapter 7 Assessing care and support needs

Working within the framework of the International Classification of Functioning, Disability and Health (ICF), the assessment process undertaken by the NDIA should identify the supports required to address an individual's reasonable and necessary care and support needs across a broad range of life activities, and should take account of an individual's aspirations and the outcomes they want to achieve.

The assessment process should be a valuable intervention in its own right, rather than just an entry point to supports. The process should:

- *draw on multiple sources of information, including:*
  - *information provided by the individual with a disability, including their aspirations and requirements for supports*

- *information provided by an individual's circle of support, including family members, carers and direct support professionals*
- *information on the current support provided both formally and informally*
- *current medical information on the person with a disability*

- *assess the nature, frequency and intensity of an individual's support needs. The process should be person-centred and forward looking and consider the supports that would cost-effectively promote people's social and economic participation, rather than only respond to what an individual cannot do*

- *determine what supports outside the NDIS people should be referred to, including referrals to Job Services Australia providers*

- *consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports')*

- *translate the reasonable needs determined by the assessment process into a person's individualised support package funded by the NDIS, after taking account of natural supports*

- *provide efficiently collected data for program planning, high level reporting, monitoring and judging the efficacy of interventions.*

RECOMMENDATION 7.3

The assessment tools should be valid and reliable, relatively easy to administer and exhibit low susceptibility to gaming. The tools should be employed nationally to ensure equitable access to nationally funded support services (and allow portability of funding across state and territory borders when people move).

RECOMMENDATION 7.4

Assessments should be undertaken by trained assessors engaged by the NDIA. To promote independent outcomes, assessors should not have a longstanding connection to the person. The NDIA should continually monitor and evaluate assessors' performance to ensure comparability of outcomes and to avoid 'bracket creep'.

RECOMMENDATION 7.5

The NDIA should periodically reassess people's need for funded support, with a focus on key transition points in their lives.

Where an informal carer provides a substantial share of the care package, they should receive their own assessment if they wish. This should seek to identify their views on the sustainability of arrangements and the ways in which the NDIS should support their role, including through the initiatives recommended in recommendation 15.3.

The consultation with the family as part of the assessment process should also explore the need for:

- *assistance with long-term planning, particularly for adults with cognitive impairments living at home with elderly parents*
- *family/sibling counselling where there are high levels of carer stress.*

Responses to family needs should be tiered, with referrals to local support groups for those with less significant needs, and access to NDIS-funded specialist assistance where the needs were high.

The NDIS should establish a coherent package of tools (a 'toolbox'), which assessors would employ across a range of disabilities and support needs (including planning and active support, attendant care, aids and equipment, and home modifications).

The assessment tools should be subject to ongoing monitoring, as well as a regular cycle of evaluation against best practices, including the ICF framework, and, if necessary, recalibration. The scheme should have systematic internal mechanisms to ensure that anomalies can be analysed and addressed.

The NDIS should use the best available tools in its initial implementation phase, with the ongoing development of best-practice tools.

Chapter 8 Who has the decision-making power?

RECOMMENDATION 8.1

Governments should give people with disabilities eligible for benefits under the NDIS, and/or people who act on their behalf, various options for exercising choice, including the power to:

- *choose service provider/s to meet their needs specified in their individual packages*

- *choose disability support organisations that would act as intermediaries on their behalf when obtaining the supports specified in their individual packages from service providers*

- *'cash out' all or some of their individual packages if they wish, with the NDIA making direct payments to their bank accounts, and allowing people to purchase directly the detailed package of supports that best meets their preferences ('self-directed funding'), subject to the constraints set out in recommendations 8.2, 8.7 and 8.8.*

  - *the specific arrangements for self-directed funding should be underpinned by the principle that, subject to the assessed individual budget and appropriate accountability requirements, the arrangements should maximise the capacity for a person to choose the supports that meet their needs best and that promote their participation in the community and in employment*

- *choose a combination of the above.*

RECOMMENDATION 8.2

Self-directed funding should include the following key stages.

- *It would be informed by any prior planning and aspirations expressed by the person during the assessment phase (recommendation 7.2).*

- *The individual budget for self-directed funding would be based on the formal individual assessment of the person's needs. The budget should include the cashed out value of all goods and services covered by the NDIS, with the exception of those where cashing out would pose credible risks to the person and/or the sustainability of the scheme.*

- *The person with a disability — and/or their support network or chosen disability support organisation — would create a personal plan and a concrete funding proposal to the NDIA that outlines the person's goals and the type of support that would be necessary and reasonable to achieve within the allocated budget.*

- *The resulting funding proposal would require approval by the NDIA.*

There should be a capacity for a person to:
- *obtain quick approvals for changes to a funding proposal*
- *add their own private funds to a funding proposal*
- *allocate the individual budget to any mix of preferred specialist and mainstream goods and services, subject to the requirements that the person spend the budget in areas related to his or her disability needs and consistent with the agreed funding proposal*
- *jointly manage their cashed out benefits with a disability support organisation ('shared management').*

The NDIA should pay annual allocations of self-directed funding in monthly instalments paid one month in advance, with the capacity for the person to 'bank' up to 10 per cent of the annual allocation to the subsequent year.

There should be a capacity for people to recruit and employ their own support workers, subject to the proviso that these should not be close family members, other than when:
- *care is intermittent and provided by a non-resident family member*
- *exceptional circumstances are present and after approval by the NDIA*
- *the person is in the family employment trial spelt out in recommendation 8.5.*

There should be a trial of the employment of family members under self-directed funding to assess its risks, advantages, disadvantages and optimal design, with its wider adoption if the evaluation proves positive. The trial should use an appropriately rigorous scientific approach, drawing on the evaluations used in the United States 'Cash and Counseling' programs. For the trial:
- *the NDIA should determine that there are low risks from hiring relatives for each family in the trial*
- *the individual budget should be discounted by 20 per cent*
- *support should be initially limited in duration to six months, with continuation of any arrangement for a given family based on a short review*
- *risks should be carefully managed to ensure appropriate use of funds and to safeguard people with disabilities and carers (recommendation 8.8).*

The NDIA should:

- *inform people with disabilities and/or people who act on their behalf of the various options for self-directed funding*

- *encourage the formation of disability support organisations to support people in the practical use of self-directed funding*

- *provide support for people using self-directed funding, including:*

  - *easy-to-understand guidance about the practical use of self-directed funding*

  - *the provision of examples of innovative arrangements*

  - *standard simple-to-follow forms for funding proposals, hiring employees and acquittal of funds*

  - *making people aware of their capacity to contract out the administrative tasks associated with self-directed funding to disability support organisations*

- *provide training to local area coordinators, service providers and NDIA front-line staff about self-directed funding.*

RECOMMENDATION 8.7

Before offering self-directed funding to a person, the NDIA should:

- *meet with the person with a disability (and if appropriate, others involved in their care and support), and take account of their experience and skill sets*

- *use that and any information provided during the assessment phase to determine whether the person and/or their support network are likely to be able to:*

  - *make reasonably informed choices of services*

  - *manage the administrative and financial aspects of funding if they wish to oversee these aspects by themselves.*

RECOMMENDATION 8.8

In offering self-directed funding, the NDIA should ensure that:

- *it reduces the risks of neglect or mistreatment of people with a disability by support workers or other service providers hired by users in the informal sector, by:*

- *ensuring easy and cheap access to police checks*

- *giving users the capacity to complain to the NDIA about inappropriate behaviour of providers, and to have these investigated*

- *monitoring by local area coordinators*

- *it reduces the risks to support workers employed under self-directed funding by requiring that they are covered by workers' compensation arrangements and have an avenue for lodging complaints*

- *it adopts a risk-management approach for receipting and other accountability requirements, which:*

  - *requires less accountability for people with low risks or who have demonstrated a capacity to manage their funds well*

  - *takes into account the compliance costs of excessive accountability measures*

  - *allows a small component of the individual budget to be free of any receipting requirements*

- *there is adequate data disclosure, subject to measures to limit unnecessary 'red tape burden'.*

RECOMMENDATION 8.9

The NDIA should undertake ongoing monitoring of self-directed funding arrangements, with a quarterly report to the board of the NDIA on issues arising from self-directed funding. There should be a full evaluation three years after their commencement to assess any desired changes in their design.

RECOMMENDATION 8.10

The Australian Government should amend the Income Tax Assessment Act 1936 and the Social Security Act 1991 so that the following are not treated as income for assessment of taxes or eligibility for income support or other welfare benefits:

- *self-directed funding paid by the NDIA and, in the interim, by state and territory governments*

- *early compassionate release of eligible superannuation amounts for disability expenditures which meet the criteria set down by the Superannuation Industry (Supervision) Act 1993.*

Chapter 9 Governance of the NDIS

RECOMMENDATION 9.1

The Australian Government should establish a new independent Commonwealth statutory authority, the National Disability Insurance Agency (NDIA), to administer the National Disability Insurance Scheme.

The NDIA should be subject to the requirements of the Commonwealth Authorities and Companies Act 1997 (CAC Act), not the Financial Management and Accountability Act 1997.

RECOMMENDATION 9.2

An independent skill-based board should oversee the NDIA. The board should comprise people chosen for their commercial and strategic skills, and expertise in insurance, finance and management, and should include some people with these skills who also have experience and understanding of disability.

- *As specified in the CAC Act, the board should not be constituted to be representative of particular interest groups, including governments, disability client or service provider groups.*

State and territory governments and the Australian Government should together establish an appointment panel comprising people with skills and experience in these areas, including people with a clear interest in disability policy issues.

- *The panel should nominate multiple candidates for each board vacancy against tightly specified selection criteria set down in the Act governing the NDIA. Appointments should be based on the majority decision of governments.*

With the agreement of the majority of state and territory governments, the Australian Government should have the power to remove the chair or dissolve the board as a whole.

The board would have the sole power to appoint the CEO and to dismiss him or her if necessary, without authorisation from governments.

RECOMMENDATION 9.3

State and territory governments together with the Australian Government, should establish an advisory council. The council should provide the board of the NDIA with ongoing advice on its activities and effectiveness in meeting its objectives, from the perspectives of people with disabilities, carers, suppliers of equipment and services, and state and territory service providers.

- *The council should comprise representatives of each of these groups.*

There should be a red-tape advisory group for the NDIA that includes key stakeholders — people with disabilities, carers, service providers and disability support organisations. It should advise the NDIA on ways of controlling compliance burdens on providers, people with disabilities and carers, and to ensure plain English forms, letters and emails.

The arrangements between the NDIA and governments should be at arm's length, and subject to strict transparency arrangements.

The federal Treasurer should have responsibility for the NDIA.

With the agreement of, and input from, state and territory governments, the Australian Government should provide the NDIA with its own legislation that specifies its objectives and functions, and its governance arrangements.

- *Financial sustainability should be a specific obligation of the board, the management and the minister, and this obligation should be enshrined in legislation. It should specifically guide any external review (recommendation 9.9).*

- *An entitlement to reasonable support should be enshrined in legislation, together with details about people's eligibility for services and the range of services to be offered.*

Future changes to the key features of the scheme should be undertaken only by explicit changes to the Act itself, be subject to the usual processes of community and Parliamentary scrutiny, and require consultation with all state and territory governments.

- *Such proposed legislative changes should be accompanied by an independent assessment of the impact of the changes on the sustainability of the scheme, which should be made publicly available.*

RECOMMENDATION 9.7

An independent actuarial report on the NDIA's management of the NDIS should be prepared quarterly and annually, and provided to the board, the regulator (the Australian Treasury), the federal Treasurer, and to all state and territory governments. It should assess risks, particularly in regards to the capacity of the expected funding stream to meet expected liabilities within its funding framework, the source of the risks and the adequacy of strategies to address those risks.

RECOMMENDATION 9.8

A specialist unit should be established within the federal Treasury to monitor the performance of the NDIA against a range of cost and performance indicators, to report its findings annually to its minister, state and territory governments and the public, and to provide policy advice to the Australian Government on the scheme.

RECOMMENDATION 9.9

The NDIA should be independently reviewed, initially after its first three years of operation, and every five years thereafter, with the outcomes publicly and promptly released.

RECOMMENDATION 9.10

The NDIA should be subject to benchmarking with other comparable corporate entities to assess its relative efficiency in its various functions, with the federal Treasury initiating benchmarking studies.

RECOMMENDATION 9.11

The NDIS and the NDIA should cover all Australian jurisdictions.

In the event that all jurisdictions do not agree to the establishment of a single national scheme then, as a second-best option, it should still be established, but with its funding and scheme design only applying to participating jurisdictions.

In the event that this second-best option is not adopted, a third-best option would be greater Australian Government funding of state and territory disability systems, but matched by the requirement that to receive that funding, any jurisdiction would need to:

- *adopt the same national eligibility criteria, assessment tools and arrangements for assessors*

- *ensure entitlements to the full range of necessary individually tailored supports are based on the national assessment process*
- *provide certainty of funding based on need*
- *give genuine choice over how people's individual packages were met, including choice of provider and portability of entitlements across borders*
- *shift from block funding to individualised funding in the forms spelt out in recommendation 8.1*
- *use the model and management of an insurance scheme, including the sophisticated collection and analysis of data to measure the outcomes and performance of the system, and a national research capacity*
- *require providers to conform to common quality standards, compete on a competitively neutral basis and be remunerated using efficient prices determined by the NDIA and taking account of regional and other variations*
- *adopt nationally consistent and publicly available measures of the performance of service providers*
- *include local area coordinators and disability support organisations in their schemes*
- *adopt service provider and workforce development strategies.*

RECOMMENDATION 9.12

The NDIA should establish two service charters that specify respectively the appropriate conduct of the (i) NDIA and (ii) specialist service providers and disability support organisations.

RECOMMENDATION 9.13

The wording of the NDIA Act should limit the capacity of merits review processes to widen eligibility or entitlement. It should require that any claims by NDIA participants would need to:

- *meet a 'reasonable person' test*
- *balance the benefits to the person with a disability against the costs to the scheme, including any adverse implications for the long run sustainability of the scheme from the review outcome*
- *take into account the obligation of people with disabilities or their families to avoid decisions that unreasonably impose costs on the scheme.*

RECOMMENDATION 9.14

The legislation establishing the NDIA should create an Office of the Inspector–General as an independent body within the NDIA. The Office should be headed by an independent statutory officer (the Inspector–General), to be appointed by the Australian Government.

The Inspector–General should:

- *hear complaints about breaches of the service charters (recommendation 9.11)*
- *review contested NDIA decisions on a merit basis (but with appeals on matters of law being heard by courts in the usual way)*
- *have the power to direct the NDIA to alter contested decisions*
- *oversee quality assurance of service providers*
- *be separate from the other parts of the NDIA dealing with people with disabilities and service providers.*

The legislation should specify that the Inspector–General would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making. The Inspector–General should report to the public and to Parliament on the number, types and outcomes of complaints and appeals (subject to privacy protections), and regularly advise the NDIA board on issues arising from its independent investigations.

RECOMMENDATION 9.15

If the Australian Government does not accept the Commission's proposed appeals process (recommendation 9.14), two other less preferred options would be that:

- *the NDIA should use the Inspector–General as an interim arrangement during the setup and establishment years of the NDIS, and then revisit the appropriateness of external administrative tribunals*
- *the Australian Government should create a specialist arm of the Administrative Appeals Tribunal to hear appeals on merit about the NDIA's decisions subject to the constraints of recommendation 9.13. In this instance, the Australian Government should set aside significant additional resources to fund this specialist arm and should include a larger reserve for the NDIS, calculated to take account of the higher risks of this approach.*

Chapter 10 Delivering disability services

The NDIA should support consumer decision-making by providing:

- *a centralised internet database of service providers that indicates the ranges of products and services, price, availability and links to measures of performance and quality*

- *well resourced and effective provision of advice and information to clients, as well as monitoring of their wellbeing, through local area coordinators. These services should be graduated in terms of the needs of the client and concentrated at key points, such as when entering the disability system or important transition periods*

- *funding for disability support organisations, on an individual basis according to assessed need, to provide additional assistance with brokerage, planning and administration.*

The Australian Government should, with privacy safeguards, fund and develop a national system for a shared electronic record of the relevant details of NDIA participants, including assessed need, service entitlements, use and cost of specialist disability services, outcomes and other key data items.

The NDIA should develop and implement a quality framework for disability providers, which would include:

- *the development of complete, nationally consistent standards that would apply to all funded specialist service providers and disability support organisations. The NDIA should monitor compliance with these standards and other regulations through a range of instruments, including graduated and rolling audits of service providers, community visitors, senior practitioners, independent consumer surveys, complaints, monitoring by local area coordinators and interrogation of the electronic disability record*

- *arrangements that encourage the diffusion of best practice throughout the disability sector*

- *providing consumers with information about the quality and performance of service providers on the national internet database of service providers*

- *establishing an innovation fund that providers would use for developing and/or trialling novel approaches to disability services.*

RECOMMENDATION 10.4

The Australian Government, through the Department of Families, Housing, Community Services and Indigenous Affairs should continue to provide funding for general advocacy by non-government organisations, with no involvement by the National Disability Insurance Agency in this funding role.

State and territory funding of disability advocacy groups should continue.

Chapter 11 Disability within the Indigenous community

RECOMMENDATION 11.1

The NDIS should provide funding for implementation, research and transparent evaluation of early intervention initiatives:

- *but to avoid duplication, should cooperate with the wide range of agencies and programs already targeting the preventable risks that generate higher rates of disability among Indigenous Australians.*

RECOMMENDATION 11.2

The Australian Government and state and territory governments should consider the feasibility of overcoming the barriers to service delivery in the NDIS for Indigenous people with a disability by:

- *block funding suitable providers where services would not otherwise exist or would be inadequate*
- *fostering smaller community-based operations that consult with local communities and engage local staff, with support from larger experienced service providers, in particular those with a high level of community ownership*
- *employing and developing Indigenous staff*
- *developing the cultural competency of non-Indigenous staff*
- *encouraging innovative, flexible and local problem solving, as well as conducting and publishing evaluations of trials in order to better understand what works and why*
- *developing an effective and cost-effective balance between bringing services to remote areas, and bringing people with a disability in remote areas to services*

- *working with state and territory governments, indigenous advocacy groups and other community groups to develop and refine funding strategies, better understand local and systemic issues as well as successful (and unsuccessful) approaches and diffusing this knowledge to other service providers, researchers working in this field and the broader community.*

In its initiatives for delivering disability supports to Indigenous people, the NDIS should be mindful of the wider measures addressing Indigenous disadvantage being adopted throughout Australia.

Chapter 12 Collecting and using data under the NDIS

RECOMMENDATION 12.1

Prior to the implementation of the NDIS, the NDIA should design and establish extensive and robust data systems, underpinned by the associated information technology and administrative systems. The systems should be used to develop a central database that would:

- *guide financial management of the scheme, and in particular, to continuously manage risks to scheme sustainability and to pinpoint areas of inefficiency*

- *inform decisions about disability services and interventions*

- *monitor and evaluate outcomes for people*

- *enable performance monitoring of service providers.*

Disability support organisations, service providers and participants would be required to provide timely relevant data to the NDIA.

RECOMMENDATION 12.2

The Australian Government should establish a national independent research capacity in the early stages of the implementation of the NDIS. The NDIA should determine how research is undertaken and the research agenda, following public consultation.

RECOMMENDATION 12.3

The NDIA should make relevant data, research and analysis publicly available, subject to confidentiality, privacy and ethical safeguards.

RECOMMENDATION 12.4

In implementing recommendation 12.1, the NDIA should determine, after consultation with relevant stakeholders, including the Australian Privacy Commissioner:

- *the key actuarial information needed to underpin sound scheme management*
- *data standards, definitions, terminology and collection processes*
- *data reporting standards, taking into account the Australian Government's initiatives for standard business reporting*
- *arrangements for achieving inter-connectedness of information technology systems among the NDIA, other relevant government agencies and service providers*
- *rules for accessing data, including confidentiality and privacy safeguards*
- *arrangements for integrating data and associated information technology and administrative systems with eHealth initiatives.*

The NDIA should then establish data collection and associated IT and administrative systems that link all agencies and service providers within the disability system.

Chapter 13 Early intervention

RECOMMENDATION 13.1

Early intervention approaches used by the NDIA should draw on evidence of their impacts and be based on an analysis of the likelihood of cost-effective outcomes. NDIS funding for early intervention should be additional to that allocated to people in the scheme for their ongoing care and support and should not be able to be cashed out under self-directed care packages.

RECOMMENDATION 13.2

The NDIA should build an evidence base on early intervention. It should commence this task by identifying, in consultation with stakeholders, existing or potentially promising approaches for further research.

Chapter 14 Where should the money come from? Financing the NDIS

The costs of supporting people with a significant disability from year to year through the NDIS should be viewed as a core funding responsibility of government and met from claims on general government revenue (a 'pay as you go' scheme):

- *but would be subject to the strong disciplines for certainty of funding specified in recommendation 14.2*

- *supplemented by payments from government to create reserve funds.*

However, the scheme should be managed and reported as if it were a 'fully-funded' scheme in which each year's funding is considered in the context of the scheme's expected future liabilities.

The Australian Government should be the single funder of the NDIS. It should direct payments from consolidated revenue into a National Disability Insurance Premium Fund, using an agreed formula entrenched in legislation that:

- *provides stable revenue to meet the independent actuarially-assessed reasonable needs of the NDIS*

- *includes funding for adequate reserves.*

If the Australian Government does not adopt that option, it should:

- *legislate for a levy on personal income (the National Disability Insurance Premium), with an increment added to the existing marginal income tax rates, and hypothecated to the full revenue needs of the NDIS*

- *set a tax rate for the premium that takes sufficient account of the pressures of demographic change on the tax base and that creates a sufficient reserve for prudential reasons.*

The Australian Government should seek offsets for the Australia-wide fiscal implications of the transfer of responsibility from state and territory governments by:

- *making no further special purpose payments to state and territory governments for disability supports, AND*

- *signing an intergovernmental agreement with participating state and territory governments that:*

> (a) *reduces state and territory stamp duties by the amount of own-state revenue they used to provide to disability and relevant community mental health services OR*
>
> (b) *transfers existing state and territory spending in these areas to the Australian Government.*

RECOMMENDATION 14.4

If the Australian Government does not accept that it should be the sole funder of the NDIS, then it should sign an intergovernmental agreement with state and territory governments that creates a pooled funding arrangement that:

- *provides a transparent and accountable basis for contributions by each jurisdiction*

- *uses the aggregate formula entrenched in legislation as spelt out in recommendation 14.2 to ensure the total pool size is sufficient to meet people's entitlements*

- *ensures that state and territory governments that provide less own-state funding for disability supports than the average should not be rewarded for doing so.*

RECOMMENDATION 14.5

The Australian Government should not provide additional funding to jurisdictions that do not participate in one of the arrangements spelt out in recommendations 14.3 and 14.4.

Chapter 15 Workforce issues

RECOMMENDATION 15.1

The NDIA should work with providers to identify likely areas of workforce shortages, and strategies to address them.

RECOMMENDATION 15.2

The Australian Government should attract further workers into disability support:

- *by marketing the role and value of disability workers as part of the media campaign launching the creation of the NDIS*

- *promoting careers in disability support in career advice to school leavers and job seekers*

- *by providing subsidies for the training of disability workers*

- *by encouraging the take-up of self-directed funding arrangements involving the flexible employment of people in the community, and not just people affiliated with specialised providers*

- *making people aware of the potential to use mainstream services as substitutes for specialised services*

- *through immigration of support workers, but only in the event that acute and persistent shortages occur, and drawing on the lessons from the Canadian Live-In Caregiver program and other similar programs.*

<div align="right">RECOMMENDATION 15.3</div>

Drawing on the system currently in place for working with children, Australian governments should ensure that police checks and other safeguards should be implemented that target the risk of abuse of vulnerable people with disabilities, and cover those relevant workers for a given period, rather than for a particular job.

<div align="right">RECOMMENDATION 15.4</div>

In order to sustain informal care and support, the NDIS should:

- *assess carer needs as well as those of people with disabilities (recommendation 7.6) and, where needed, use the assessment results to:*

  – *refer people to specialist carer support services including the 'Carer Support Centres' recommended in the Commission's parallel inquiry into aged care and to the National Carers Counselling Program*

  – *include the capacity for accessing counselling and support services for carers as part of the individual support packages provided to people with a disability*

- *assess the best training and counselling options for carers of people with disabilities as part of the NDIS research and data collection function.*

<div align="right">RECOMMENDATION 15.5</div>

- *The Australian Government should amend s. 65(1) of the Fair Work Act 2009 to permit parents to request flexible leave from their employer if their child is over 18 years old, but subject to an NDIS assessment indicating that parents are providing a high level of care.*

- *After monitoring the impacts of this legislative change, the Australian Government should assess whether it should make further changes to the Act to include employees caring for people other than children.*

Chapter 18 A national injury insurance scheme (NIIS)

RECOMMENDATION 18.1

State and territory governments should create insurance schemes that would provide fully-funded care and support for all catastrophic injuries on a no-fault basis, and that would collectively constitute a National Injury Insurance Scheme (NIIS).

The NIIS would include all medical treatment, rehabilitation, home and vehicle modifications and care costs, and cover catastrophic injuries from motor vehicle, medical (excluding cases of cerebral palsy associated with pregnancy or birth, which would be covered by the NDIS), criminal and general accidents. Common law rights to sue for long-term care and support should be removed, though access to damages for pecuniary and economic loss, and general damages would remain.

State and territory governments should develop a national framework in which the separate schemes under the NIIS would operate.

RECOMMENDATION 18.2

State and territory governments should fund catastrophic injury schemes from a variety of sources including:

- *compulsory third party premiums for motor vehicle accidents*
- *a small surcharge on passenger tickets of all rail transport regulated under the new rail safety national laws*
- *a modest levy on domestically registered passenger carrying vessels regulated under the Australian Maritime Safety Authority (as the proposed new safety regulator for all commercial shipping in Australian waters by 2013). A small levy on existing state-based registration for privately owned 'pleasure' vessels*
- *a small increase in municipal rates for catastrophic injuries arising for victims of crime and from other general accidents (excluding catastrophic medical accidents)*
- *contributions from the insurance (including self-insurance) arrangements of hospitals and the medical indemnity premiums of physicians for medical treatment accidents:*

  - *If the removal of the insurance costs associated with the lifetime care and support of cerebral palsy cases does not sufficiently outweigh the additional costs associated with the inclusion of no-fault catastrophic injuries, then any premium increases should be gradually phased in. State and territory governments should fund any gap between premium income and catastrophic medical injury claims.*

– Regardless, the Australian Government subsidy schemes should continue to safeguard the affordability of medical indemnity cover.

State and territory governments should fund NIIS claims directly to the extent that they choose not to fund catastrophic general accidents on a no-fault basis through local council rates.

The Australian Government should fund any catastrophic aviation accidents, until specific sources of funding related to accident risks are established.

RECOMMENDATION 18.3

The NIIS should be structured as a federation of separate state-based catastrophic injury schemes, which would include:

- *consistent eligibility criteria and assessment tools, and a minimum benchmarked level of support*
- *consistent scheme reporting, including actuarial valuations and other benchmarks of scheme performance*
- *shared data, cooperative trials and research studies*
- *elimination of any unwarranted variations in existing no-fault schemes*
- *a national reinsurance arrangement to pool coverage of high risks among the separate schemes.*

State and territory governments should create a small full-time secretariat to further the objectives outlined above. The NIIS and the NDIA should work closely together.

RECOMMENDATION 18.4

State and territory governments should consider transferring the care and support of catastrophic workplace claims to the NIIS through a contractual arrangement with their respective workers' compensation schemes, drawing on the successful experiences of Victoria's Worksafe arrangements with the Transport Accident Commission.

RECOMMENDATION 18.5

The NDIS should fund all cases of cerebral palsy associated with pregnancy or birth, and that meet the NDIS eligibility criteria. Common law rights to sue for long-term care and support needs for cerebral palsy should be removed, though access to damages for pecuniary and economic loss and general damages would remain, where negligence can be established.

RECOMMENDATION 18.6

The initial priority for the NIIS should be the creation of no-fault motor accident insurance schemes, which should provide services and support for catastrophic injuries arising from motor vehicle accidents in all jurisdictions by 2013. Other forms of catastrophic injury should be covered by at least 2015, with funding commencing by 2014 to establish a funding pool prior to any claims.

RECOMMENDATION 18.7

An independent review in 2020 should examine the advantages and disadvantages of:

- *widening coverage to replace other heads of damage for personal injury compensation, including for pecuniary and economic loss, and general damages*

- *widening coverage to the care and support needs of non-catastrophic, but still significant, accidental injuries, except where:*

  - *the only care needed can be provided by the health sector*

  - *the injuries arose in workplaces covered by existing workplace insurance arrangements*

- *the expert panel for medical treatment injury, evaluating the timeliness of its decisions, its independence and cost-effectiveness*

- *merging the NIIS and the NDIS.*

Chapter 19 Implementation

RECOMMENDATION 19.1

In the second half of 2011 or early 2012, the Australian Government and the state and territory governments should, under the auspices of COAG, agree to a memorandum of understanding that sets out an in-principle agreement:

- *that the NDIS should commence in stages, with:*

  - *regional rollouts undertaken in several states and territories commencing in July 2014*

  - *full national coverage in 2015-16 for some high priority groups*

  - *progressive coverage of all groups in subsequent years, with a fully operational scheme by 2018-19*

- *to follow the reform timetable for the NIIS specified in recommendation 18.6.*

RECOMMENDATION 19.2

To give effect to recommendation 19.1, state and territory governments and the Australian Government should create:

- *a full-time high level taskforce from participating jurisdictions and an expert project management team to commence work on the detailed implementation of the NDIS, including all transition arrangements*

  – *to be headed by a person with insurance or disability experience who has driven change successfully in a large organisation, appointed with the agreement of all jurisdictions*

  – *with a draft intergovernmental agreement to be prepared for final consideration and agreement by COAG in February 2013*

- *a full-time high level taskforce from all jurisdictions to commence work on the implementation of the NIIS by the states and territories*

- *the NDIA by June 2013.*

RECOMMENDATION 19.3

In the period leading up to the full introduction of the NDIS, the Australian Government should supplement funding under the National Disability Agreement to reduce some of the worst rationing of support services, particularly for supported accommodation and respite.

RECOMMENDATION 19.4

In 2020, there should be an independent public inquiry into the operation of the NDIS and its effectiveness in meeting the needs of people with disabilities. The review should also encompass the review of the NIIS as set out in recommendation 18.7.

1   Introduction

1.1   What has the Commission been asked to do?

In late 2009, the Australian Government announced that the Productivity Commission would commence a public inquiry into a long-term disability care and support scheme in April 2010. It said:

> This inquiry is an opportunity to rethink how we support people with disabilities so that they can engage with their community, get a job where possible, and live a happy and meaningful life (Sherry 2009).

The announcement followed a succession of reports that found that the current system to support people with disability and their families is deeply flawed and will increasingly be unable to meet people's needs. Examples include the 'Way Forward' report by the Disability Investment Group (DIG 2009a) and the 'Shut Out' consultation report by the National People with Disabilities and Carer Council (Australian Government 2009a). Such reports reflected continuing concerns about systemic and long-standing inadequacies in disability care and support across Australia, and the consequent impact on people with disabilities and their carers.

In its preamble to the terms of reference, the Australian Government said that it 'is committed to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers'. It noted that:

> … there remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers. Demographic change and the anticipated decline in the availability of informal care are expected to place further pressure on the existing system over the coming decades.

It added that:

> While Australia's social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services. … exploration of alternative approaches to funding and delivering disability services with a focus on early intervention and long-term care will be an important contribution to the National Disability Strategy. (terms of reference)

The Australian Government asked the Commission to consider how a national disability scheme could be designed, administered, financed and implemented. The Commission was asked to examine the feasibility, costs and benefits of replacing the current system of disability services with a new national disability care and support scheme that:

- provides long-term essential care and support

- manages the costs of long-term care

- replaces the existing funding for those people covered by the scheme

- takes account of the desired and potential outcomes for each person over a lifetime, with a focus on early intervention

- provides for a range of coordinated support options — accommodation, aids and appliances, transport, respite, day programs and community participation

- assists the person with the disability to make decisions about their support

- provides for people to participate in education, training and employment where possible.

This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries. The Commission was also asked to assess how these models would interact with Australia's health, aged care, informal care, income support and injury insurance systems.

1.2   Definitions and some key facts

There is no single definition of disability. Modern definitions of disability, including those drawn from the United Nations Convention on the Rights of Persons with Disabilities (adopted by the UN in 2006 and ratified by Australia in 2008), define disability as the interaction of long-term physical, mental, intellectual or sensory impairments, and attitudinal or environmental barriers that 'hinder ... full and effective participation in society on an equal basis with others'. The World Health Organisation (2009) similarly characterises disability according to the interaction between a person's body and features of the society in which they live.

This inquiry covers many issues that affect all people with disability. However, the terms of reference indicates that the scheme is intended to cover a subset of those affected by disability.

First, the terms of reference specify that the scheme should cover disability present at birth, or acquired through an accident or health condition, but not due to the

natural process of ageing. This means that the size of the relevant group is much smaller than all those with a disability. And, the numbers in this smaller group are projected to grow more slowly than those whose disability is ageing related. However, while this inquiry mainly considers people with disabilities aged under 65 years, population ageing will significantly raise the overall number of people with severe or profound disability, placing even more pressure on services, including for people who are not old. It will also affect the availability of unpaid carers.

Box 1.1   Some definitions

According to the Australian Institute of Health and Welfare, and as used in the Australian Bureau of Statistics (ABS) *Survey of Disability, Ageing and Carers*, 'disability' is defined as a limitation, restriction or impairment that has lasted, or is likely to last, for at least six months and restricts everyday activities. According to this definition, in 2009, just under one in five Australians reported having a disability.

The severity of people's disability varies significantly. At the more severe end of the spectrum people are classified by the ABS as having either:

- a profound core activity limitation, where an individual is unable to do, or always needs help with, a core activity; core activities are self-care, mobility and communication, and include washing, toileting, dressing and eating

- a severe core activity limitation, where an individual sometimes needs help with a core activity or task, and/or has difficulty understanding or being understood by family or friends and/or can communicate more easily using sign language or other non-spoken forms of communication.

While the above categories can be useful, as can the broader International Classification of Functioning, the appropriate definition of disability should take account of the policy context in which government is applying it and of the practical ease of identifying disability. For example, under the ABS's approach, many intellectual disabilities might not be categorised as severe or profound (reflecting the omission of learning as a 'core activity limitation'). However, in the Commission's view (chapter 3), there are strong grounds for a disability scheme to provide funded supports to people with an intellectual disability. On the other hand, some people suffering from short-lived but terminal diseases might well have severe disabilities, but governments could better support them through the health and palliative care systems.

Source: ABS (2010c); AIHW (2011a).

Second, the scheme is not intended to provide funding packages to all people with a disability, many of whom would need no or few supports, or who would get supports more appropriately from other government services. These matters are discussed in chapter 3.

Some key facts about disability

There are various measures of the number of people with the most significant needs (box 1.2). For example, among those aged under 65 years, there are around 680 000 people with a profound or severe core activity limitation (SDAC 2009), around 310 000 who have at least daily care needs (with mobility, self care and/or communication) (SDAC 2009), and about 172 000 who currently use specialist disability services (excluding Australian Government employment services) (SCRGSP 2011).

The estimates in box 1.2 are of the total number of people with severe or profound core activity limitation at a point in time ('prevalence'). Each year, there are also *new* cases of disability ('incidence'). Of the 680 000 people with severe or profound core activity limitation, about 80 000 were new cases and about 600 000 were people who acquired a disability at an earlier time. While new cases add to the numbers of people with disability, deaths and reductions in disability reduce the numbers. In many instances, people will experience temporary disability (as potentially in cases of depression, anxiety and attention deficit hyperactivity disorder), and will not necessarily require long-term care.

The health conditions of people under the age of 65 years who have a profound core activity limitation include diseases of the nervous system, intellectual and developmental disorders, mental illness, diseases of the circulatory, respiratory and digestive systems, cancers, and diseases of the musculoskeletal system (table 1.1).

Table 1.1   Health conditions of people who have a profound core activity limitation[a]

People under 65 years of age

Condition	Percentage
Intellectual and developmental disorders	15
Diseases of the nervous system	14
Diseases of the circulatory system, respiratory system, digestive system; endocrine, nutritional and metabolic disorders; neoplasms	14
Diseases of the musculoskeletal system and connective tissue	14
Mental illness	11
Autism	9
Congenital malformations, deformations and chromosomal abnormalities	6
Other mental and behavioural disorders	5
Injury, poisoning and certain other consequences of external causes	4
Diseases of the eye and adnexa; and ear and mastoid process	3
Other	5
Total	100

a Prevalence of main condition causing disability.

Source: SDAC (2009).

Box 1.2   How many people have significant needs?

While they share similar conceptual underpinnings, measures of significant disability vary markedly, depending on the data source and survey methods:

- Using the ABS Survey of Disability, Ageing and Carers, 2009 (SDAC 2009), around 263 000 people aged under 65 years had a profound core activity limitation in 2009 and 417 000 had a severe core activity limitation — or 680 000 in total.

- The ABS 2006 Census of Population identified a smaller group of people with a severe or profound core activity limitation (around 400 000 aged under 65 years in 2006), but this estimate is generally regarded as a less reliable measure than SDAC.

- Within the group of people classified as having a severe/profound core activity limitation there is a large spectrum of need for assistance. As an example, the 2009 SDAC indicates that approximately 310 000 people under the age of 65 years required at least daily assistance with one or more core activities (self care, mobility and communication). Within this 310 000:
  - about 23 per cent indicated that they needed assistance more than six times a day with at least one core activity
  - a further 24 per cent indicated that they needed assistance three to five times a day with at least one core activity
  - a further 17 per cent indicated that they needed assistance twice a day with at least one core activity
  - and a further 36 per cent indicated that they needed assistance once a day with at least one core activity.

- Usage of disability services provides other indicators of the numbers of people with the greatest need for support:
  - There were just over 265 000 people using specialist disability services under the National Disability Agreement (NDA) in 2008-09 (SCRGSP 2011). Of this 265 000, approximately 94 000 only used employment services. The NDA is directed at those whose disability was acquired before the age of 65 years.

- Around 200 000 people aged under 65 years used Home and Community Care (HACC) in 2008-09 for services such as nursing care, allied health, and the provision of aids and equipment that were not available under the NDA. People often use both NDA and HACC services, so the total number of users of NDA and HACC is not the sum of HACC and NDA services (approximately 20 per cent of people using NDA specialist services — excluding employment services — also access HACC services). Further, several people used very little HACC services (approximately one hour of care a fortnight).

Sources: ABS (2010c); DoHA (2009).

1.3 Ways of thinking about disability

Several participants drew attention to the (now very commonly expressed) social model of disability, which takes the view that 'disability' arises socially, rather than medically. In this case, disability reflects social barriers, such as prejudice, out-of-date practices, and poorly designed infrastructure. In other words, while a person may have an impairment, their disability comes from the way society treats them, or fails to support them. For example, the capacity for mobility of a person in a wheelchair is limited if buildings and transport are not easily accessible. Society could allow a much fuller participation by a person with a mobility impairment by changing the environment. The extent to which it does not do so may be seen as disabling.

Reflecting this view, the term 'disabled people' is widely used in official and other publications in the United Kingdom, while the term 'people with disability' is avoided (Glasby and Littlechild 2009, p. 3). However, in Australia, the opposite is true. This appears to reflect the notion that all people have a complex set of traits (their preferences, jobs, hobbies, personalities) and that an impairment is just one aspect of their lives. For that reason, many people do not want to be defined exclusively by their impairment *or* the way society adapts to or exacerbates it. Accordingly, in this report, we use the term 'people with disability', which is customary in the Australian context.

Terminology aside, the key insight from the social model is that disability will sometimes arise from society's responses as well as from impairments themselves. Many submissions to the inquiry argued that this provides a strong policy basis for achieving the highest practical degree of social participation for people with disabilities and for giving them much greater capacity to exert power. (The importance of person-centred approaches to care and support is discussed in chapter 8.)

Nevertheless, while society can facilitate participation in the way it responds, there are limits in the extent to which it can achieve the full participation of every person, regardless of their traits. Society could not realistically be seen to have the capacity to eliminate the obstacles to participation faced by a person with extreme intellectual or behavioural disabilities. Accordingly, a more scientific approach to disability would see it as both a social and medical phenomenon, but for which an important social objective must be to facilitate participation in the various aspects of community life where practicable.

Moreover, societies have scarce resources, which means that there must be tradeoffs between what can ideally, and what can actually, be achieved for any person. There

are costs associated with making social changes to improve the lives of people with significant disabilities and, given resource constraints, these costs have to weighed up against other social objectives of a society.

Accordingly, as in many other areas of social policy — public housing, income support, health care and education — there are reasonable limits to what government or society can do to address inequality. However, it is widely accepted in Australia that governments and society must increase resourcing for disability and that they should address discrimination where it arises (for example, turning down a person for a job because of a disability not related to their work competence).

The United Nations Convention on the Rights of Persons with Disabilities

These issues are also the concern of the United Nations Convention on the Rights of Persons with Disabilities (box 1.3). Many submissions to this inquiry pointed to the importance of any new scheme adhering to the principles and obligations contained in that Convention, which Australia has ratified.

One participant observed that 'ratification carries with it much more than mouthing the sentiments and writing the high sounding statement into a glossy document':

> As noted by the UN Convention handbook for parliamentarians, '... establishing a right is not the same as ensuring that the right is realised', and neither is it the same as States providing, ... 'appropriate enabling environments so that persons with a disability can fully enjoy their rights on an equal basis with others'. ... ... simply being a party to a convention is no guarantee the intent of the convention will be realised. ... if the report is to ensure the UN Convention is written into the NDS then the NDS must also ensure that an entitlement to service is ratified. (JacksonRyan Partners, sub. 30, p. 11)

In a similar vein, the National Disability and Carer Alliance said that, while ratification was 'an historic and significant moment', it was:

> … simply a first step on a long journey to ensure the rights enshrined in the convention are not only protected but, more importantly, able to be fully realised. While it is clearly not the only factor to be considered, it is important to acknowledge that rights can remain elusive if adequate resources are not provided. (sub. 413, p. 2)

Similarly, Catholic Social Services Victoria said that the United Nations Convention urges Governments to be proactive in identifying need and establishing more effective social support systems (sub. 453, p. 6).

Box 1.3   The United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities and its Optional Protocol entered into force on 3 May 2008 (with Australia ratifying shortly afterwards).

Guiding principles of the convention

There are eight guiding principles that underlie the convention:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

- non-discrimination

- full and effective participation and inclusion in society

- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

- equality of opportunity

- accessibility

- equality between men and women

- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The convention states that persons with disabilities enjoy the same human rights as everyone. Without being exhaustive, these rights include equality before the law without discrimination, the right to live in the community, and the right to education and work.

The convention entails certain obligations on parties ratifying it, such as adopting legislation and administrative measures to promote the human rights of persons with disabilities, eliminating discrimination in workplaces and society; providing information to people with disabilities, undertaking disability-relevant R&D and appropriate consultation with people with disabilities in developing and implementing legislation and policies and in decision-making processes that concern them.

The goal of achieving equal rights is tempered by two considerations: a resource constraint ("With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its *available* resources") and their progressive, rather than immediate, realisation.

In September 2009, Australia ratified an optional protocol to the convention which provides for a complaints handling process for people considering that their rights have been violated.

Source: United Nations (2006).

A commonly-held view was expressed by the Association for Children with a Disability NSW, which said that the current disability system is in violation of the United Nations Convention, 'if not in letter, then certainly in spirit':

We believe a National Disability Insurance Scheme will go a long way in addressing this. Our children are our future — including disabled ones! (sub. 297, p. 11)

Clarifying 'supports' versus 'services'

Different terms are used to describe the services and supports that are provided to people with a disability. In some instances, the terminology differentiates between services and supports.

For instance, sometimes the term 'services' is used to denote therapeutic services only (such as health care, physiotherapy and other interventions of this kind). Such services often do not involve much choice by the person with a disability. Some see these services as things that are 'done to people'.

In contrast, the term 'supports' is often used to describe measures that, combined with the person's own goals and motivation, makes it possible to live as full a life as possible. Supports are not 'done to people', but with them.

The underlying distinction between the idea of 'doing to people' and 'doing with people' is critical to an appropriate disability care and support scheme (and is a major reason for providing people with disabilities much more choice in a new system). However, while that distinction is a critical one, using the terms 'services' versus 'supports' to differentiate between the two approaches runs up against the common use of the word 'services', which does not usually carry any sense that people getting them lack power.

Accordingly, in this report, the Commission uses both terms, with the term 'services' used most commonly when referring to agencies that provide specialist services, such as attendant care or respite services, or when referring to mainstream services, like going to a movie. That usage is common to other reports on the disability sector, such as the annual review of government services (SCRGSP 2011) and the various reports by the Australian Institute of Health and Welfare. It is also common for providers of supports to be referred to as specialist service providers (for example, in the National Disability Agreement between the Australian Government and state and territory governments). Many submissions to this inquiry used the term 'services'.

However, the Commission draws particular attention to the distinction between disability support organisations (DSOs) and specialist service providers. The former are intended to provide support to people in using services — brokering, managing administration, mentoring and planning — and the term 'support' provides a useful way of distinguishing their role from that of traditional service providers.

1.4 Rationales and objectives

Various forms of care and support for people with a disability have long been a feature of the Australian social support system. Governments seek to enhance the quality of life and increase the economic and social participation of people with disabilities and their families, and to enhance and protect their rights. Those goals are reflected in a range of social, economic, regulatory and spending measures. These include equal opportunity regulation, building and other accessibility regulations, community education and — the key issue for this inquiry — the provision of care and support for people with disabilities and their families. This inquiry reflects the Australian Government's intention, as stated in the terms of reference, to explore better ways of meeting that goal, including perhaps through the creation of a new long-term disability care and support scheme.

The key rationales for a new approach stem from faults in the current system

In part, interest in a new approach has arisen from an awareness of the faults in the current system, which are documented in many submissions to this inquiry and covered in greater detail in the next chapter. Broadly, these are:

- There are insufficient resources and gaps in services in all jurisdictions and most locations, so that people with disabilities and their informal carers bear too much of the costs associated with disability.

- People with similar levels of impairment get quite different levels of support, depending on their location or the origin of the disability — what some call the 'lottery' of access to services.

- Under the current provider-centric model, the capacity for people with disabilities or their families to exercise choice about the services they use, and to have control over the financial resources allocated to them, is limited.

- Services are largely narrowly prescribed and lack participation goals, and there are insufficient opportunities for employment or participation in the community.

- People with disability and their families often do not have a reasonable level of certainty about the future (a particular concern of carers of children with a profound disability, who often worry about how their child will be supported when they get too tired, sick or die).

- There is a lack of coordination, showing up through duplicated and inconsistent assessment methods for allocating services or funding, inadequate links between

services provided by different governments, and insufficient information for planning and coordination.

- There is lack of portability of services between jurisdictions as people move.

- There are also some inappropriate models of support, such as care for young people with disabilities in aged care homes and people remaining in hospitals — and therefore blocking beds — because of insufficient funds for relatively minor home modifications.

There are strong grounds for governments to improve care and support arrangements for people with disabilities and their families. It is consistent with:

- community norms for upholding people's rights and for social justice, which are not fully recognised in current arrangements

- sharing the costs that fall on people with disability and their families among a wider group of people — through some form of social insurance — and the low likelihood that private insurance markets would function equitably or efficiently in this area

- the desirability of unlocking a poorly utilised source of productivity and social contribution (for example, through employment and community participation).

But the key test of a new scheme will be the extent to which it can address existing deficiencies in an equitable, efficient, cost-effective and accountable way.

Objectives

The shortcomings of the current system bring the objectives of a new system into sharp relief. The overarching objective should be, to the extent practicable, to enhance the quality of life and increase the economic and social participation of people with disabilities and their families. As shown throughout this report, current disability services are not meeting the needs of people with disabilities and their families. There is a widespread need for arrangements that will deliver better outcomes for clients, with services and support more readily and uniformly available and driven more by the preferences of the client. A key question is how to build a better scheme that supports and empowers people with disabilities by:

- providing long-term support for all forms of disability for those most in need, irrespective of the cause and who is at fault

- meeting the needs of people with disabilities and their families in ways that are timely and efficient

- providing national standards for assessment of need and provision of support

- providing a much greater role for decision-making by people with disabilities (and their families where appropriate and necessary)

- providing incentives for cost-effective delivery of support services

- making it sufficiently well-funded to provide timely assistance to all who need it, without unreasonably long waiting lists

- ensuring it is financially sustainable over the long term.

However, an objective is only genuinely useful if governments know whether they have succeeded in achieving it. This requires specific and assessable objectives and the means by which progress can be assessed (table 1.2).

Given the multiple objectives for a disability care and support scheme, the relative importance of these objectives will be crucial in the design of an effective scheme.

Nevertheless, it may be difficult to *fully* meet all the community's objectives of a new scheme, reflecting the need for any scheme to be financially sustainable and practical. There may also be tradeoffs between some goals. For instance:

- effective integration of support services may be costly if there is a large amount of supporting infrastructure required to do this, or significant implementation costs in changing from one type of approach to another

- giving people complete choice and power over the use of disability funding may raise accountability issues and may not always serve all people well

- more choice for individuals and families may also mean greater uncertainty for service providers and coordinators, possibly leading to less coordination and greater costs

- more broadly, governments face many other competing obligations — for example, in health care, education and infrastructure — together with the need to ensure that tax rates are set at fair and efficient levels. A new scheme which meets the above objectives is likely to entail a significant increase in funding for disability care and support. Given all the other competing claims on governments, it will not be possible to meet *all* the preferences of people with disabilities and their families.

1.5   Some design elements for a new scheme

There are many possible models for a national disability scheme. The models could vary in scope (relevant users, types and levels of support, generosity and duration), funding sources, decision-making arrangements and governance.

Table 1.2   **Objectives and (some) indicators**

Objectives		Some indicative measures of progress
To improve wellbeing through funding of more integrated, higher quality support — including appropriate early intervention, and measures to lower the incidence and impact of disability	→	Improved consumer satisfaction, better continuity of support, higher social and economic participation rates, lower disability rates, reduced duration of some disabilities, lower hospitalisation rates for some disabilities
Ensure that people's assessed reasonable needs are met in a timely way as they arise, with predictability of support over their lifetime	→	Measures of support provision, unmet need, waiting lists, sustainable financing approach
Provide more comparable long-term care and support to people with similar levels of disability, regardless of the source of disability or the location of the person	→	Lower regional and state variations in support service access rates by all disability types
Provide people with disability more appropriate levels of power over their lives, and specifically over the budgets allocated to them, and with choice of providers	→	An appropriate capacity to self-direct funding (and its uptake) and to choose providers; consumer satisfaction rates with control and choice of services
Provide people with disability with better options for education, jobs, independent living and community participation	→	Participation rates in education, employment, volunteering, sports; consumer satisfaction rates with living arrangements
Shift away from an excessive and unfair reliance on the unpaid work of informal carers	→	Greater share of hours from paid support; greater independent living rates, lower depression rates and higher participation rates among carers; lower respite bed block rates
Effective management of the scheme, including cost-effectiveness and sustainability	→	Improved technical efficiency, higher support service utilisation, lower rates of multiple assessments, savings on future costs, low management costs, lower number of assessment delays, cost-effective use of new technologies, dispute and mediation efficiency, long-term scheme sustainability

One option is to substantially increase disability funding, but otherwise largely preserve the current arrangements. That would have many beneficial effects, but it would fail to overcome many of the structural deficiencies of the current arrangements. Given this and our terms of reference, the inquiry has focused on designing a coherent national system for disabilities.

As in health and aged care, there are many choices about how to design a disability care and support system. The core issues relate to who makes the decisions, who

gets supports, what supports they receive and the associated funding amounts, service delivery and financing methods (figure 1.1).

Figure 1.1   Key design elements of a disability care and support scheme
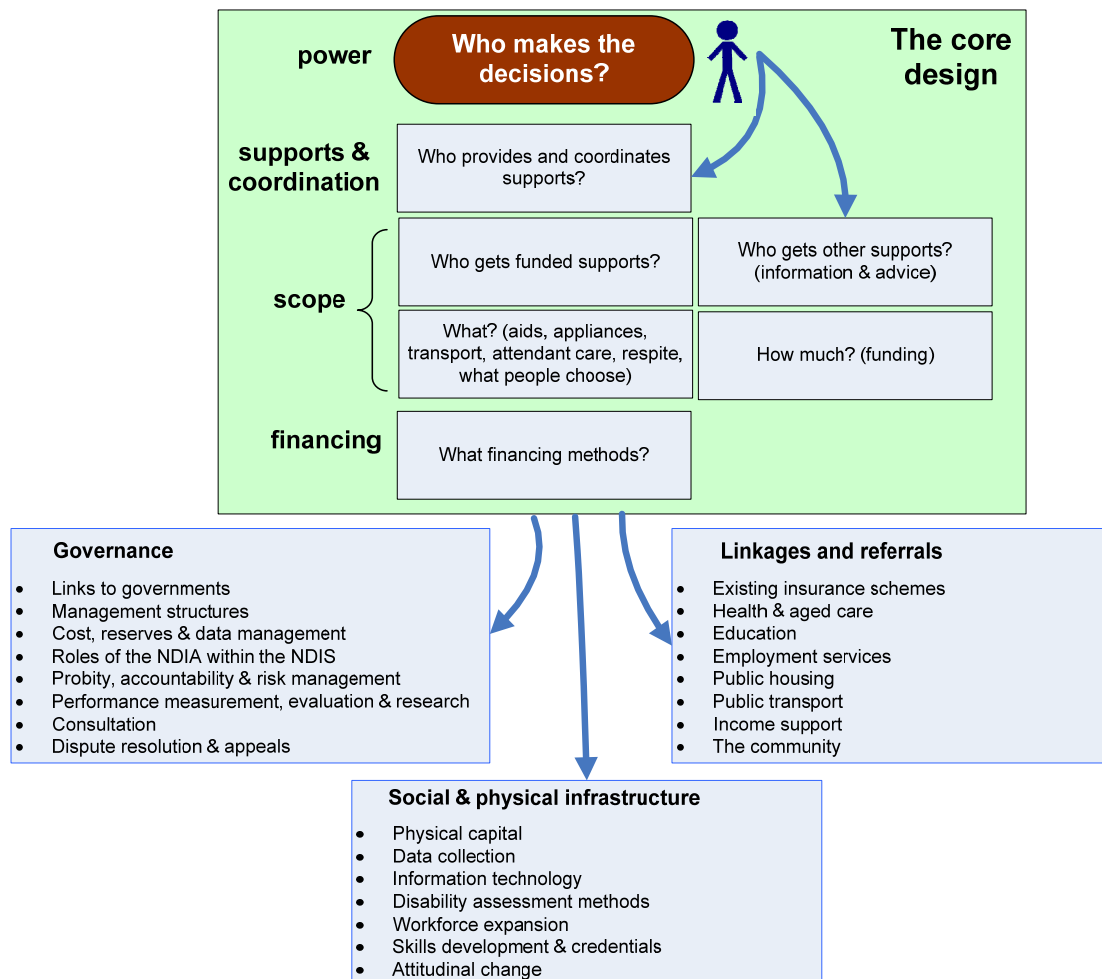
But realising a practically implementable and efficient scheme requires detailed attention to many other aspects of its design. Assessments of disability must be made (how?), the system must be organised and monitored (by whom?), linkages to related services and policies have to be identified and managed (which ones and how?), resources have to be built up (which ones?) and so on.

Failures in any one of these areas can undermine the capacity of a scheme to work well or meet people's reasonable expectations. For example, poor cost controls and risk management would limit the sustainability of the scheme, while a failure to consult with, and give more decision-making powers to, people with disabilities and their families would be contrary to the goal of enhancing people's independence.

These matters are discussed in detail in the relevant chapters throughout this report.

1.6   Inquiry processes

To help inform the approach taken in its issues paper, the Commission held early consultations with many people and organisations, including people with disability, carers, service providers, peak bodies, insurers and governments. These consultations provided insights into the key issues that would be involved in designing new arrangements for long-term disability care and support.

The Commission also held early discussions with the Independent Panel established by the Government to advise it and the Commission during the course of the inquiry (FaHCSIA 2010g). The panel comprises people with extensive expertise and knowledge of disability issues, and the Commission has continued to meet with the panel at frequent intervals during the course of the inquiry.

These early discussions also informed the Commission about appropriate ways to engage with people with disabilities and to make it as easy as possible for them to participate in the various stages of the inquiry (including making submissions and appearing at public hearings). The Commission is particularly grateful for the assistance provided to it on this matter by the Department of Families, Housing, Community Services and Indigenous Affairs.

In May 2010, the Commission released an issues paper to inform people about the key issues being examined and to advise them how best to provide their views to the inquiry. Participants were invited to send in formal public submissions, and/or to provide the inquiry with confidential responses outlining their personal circumstances and views. At the same time, the Commission released a short paper, together with Easy English and Auslan versions, which contained questions to elicit views about the desirable features of a national disability scheme.

We held initial public hearings in Hobart, Melbourne, Adelaide, Canberra, Brisbane, Sydney and Perth during June and July 2010. In total, people made 119 presentations over 12 hearing days. Participants did not wish to attend hearings in Darwin in response to the issues paper, but the Commission visited the Northern Territory following the release of the draft report to engage with a range of stakeholders. Consultations were held with a wide range of interested parties, including regional services and some Indigenous services. These are listed in appendix A.

The draft report was released on 28 February 2011. It contained the Commission's analysis, conclusions and draft recommendations as at that time, as well as requests

for feedback on particular issues. The draft report was distributed widely and made available on the inquiry website for downloading in whole or in part.

During April 2011, the Commission held a second round of public hearings to allow participants to respond to the proposals contained in the draft report. Hearings were held in Hobart, Melbourne, Canberra, Brisbane, Sydney, Adelaide and Perth, with 118 presentations over 11 hearing days.

Transcripts of the proceedings at all public hearings held during the course of this inquiry can be read on the inquiry website, and will remain there indefinitely.

Public involvement in this inquiry has been very extensive. Over its course, the Commission received more than 1000 public submissions, about half of which were from private individuals. This includes some personal submissions where the author was willing to make the submission public on a 'name withheld' basis. Many submissions were from people with disabilities or their carers. Also well-represented are the large and small organisations that support them. All public submissions can be read on the inquiry website, and will remain there indefinitely. In addition, the inquiry also received over 100 personal responses and completed Easy English questionnaires. The Commission thanks all those who have contributed to this inquiry. The information provided by participants was invaluable.

The Commission also wishes to thank the following organisations, which provided advice and data to the Commission on many occasions:

- the Accident Compensation Corporation (New Zealand)
- the Transport Accident Commission (Victoria)
- the New South Wales Lifetime Care and Support Authority
- National Disability Services
- the Australian Bureau of Statistics
- the MS Society of Australia
- Ageing, Disability and Home Care, Department of Human Services (NSW).

The Commission also thanks Vision Australia for assisting it to produce accessible documents for its website.

1.7 Structure of the report

The report begins with an introduction (chapter 1) and a discussion of why change is needed. Many participants (including providers, people with disabilities, carers and governments) think that disability services are often in crisis mode, with fragmented programs, inadequate provision of services and high levels of unmet demand. They argue that whether people get good services can be a 'lottery', based on where they live and how they acquire their disability, and that people often have little choice about what services they receive. These matters are discussed in chapter 2.

Chapter 3 looks at which groups of people would use a National Disability Insurance Scheme (NDIS) and how they would be referred to other services and supports as needed. The following five chapters look at how people with disabilities could interact with the NDIS. This includes the role of the community and community organisations (chapter 4), what support services people with disabilities should be able to get access to (chapter 5), how the Disability Support Pension might be aligned with the goals of the NDIS (chapter 6), how people would be assessed for assistance (chapter 7), and the question of who should have the power to decide what supports people get (including the role of person-centred approaches) (chapter 8).

The governance of the NDIS is considered in chapter 9, while the implications for service delivery are covered in chapter 10. Chapter 11 focuses on Indigenous issues, given the higher rate of disability in the Indigenous community compared with the broader population, their low rate of claims for some forms of services and supports, and the particular difficulties of delivering these in some areas.

As many clients of the NDIS will have various care and support needs over many years, it is crucial that the long-term financial viability of the scheme be a key objective. Good quality data and evidence will be crucial in managing the scheme's costs, learning about the efficacy of alternative services and generating good outcomes for people with disabilities. This is the subject of chapter 12, while the specific question of the appropriate use of early intervention strategies is discussed in chapter 13.

The following three chapters examine how the NDIS might be financed (chapter 14), workforce issues (chapter 15) and estimates of the likely cost of the scheme under different scenarios (chapter 16).

Many participants argued that there is little justification for the striking differences in current arrangements for insuring people for injury, with coverage varying

depending on the type of accident, its location and exact circumstances. Chapter 17 looks at the advantages and disadvantages of the current accident insurance arrangements, including the role of common law claims. Drawing on this analysis, chapter 18 proposes a National Injury Insurance Scheme, and discusses how it might be financed.

The measures proposed in this report are very significant and will require considerable care in their implementation. The national rollout of the scheme would require the Australian Government and all state and territory governments to be involved. And some changes would need to be sequenced. These matters are discussed in chapter 19. The final chapter looks at the benefits of making changes along the lines recommended in this report.

In preparing this report, the Commission has written several appendices, but only one, that concerning consultations undertaken (appendix A), is reproduced in this report. The remainder can be read on the inquiry website at www.pc.gov.au under 'projects'. A full list of appendices is contained in the table of contents.

The structure and performance of the current system is not covered in this report in great detail because comprehensive up-to-date descriptions by the Australian Institute for Health and Welfare (AIHW 2009b, 2010a) and the Steering Committee for the Review of Government Service Provision (SCRGSP 2011) can be readily accessed.

2   Why real change is needed

Key points

- People with disabilities and their carers are among the most disadvantaged groups in Australian society. This can be seen through measures of social isolation, financial status, as well as personal wellbeing. This disadvantage is linked to a lack of sufficient supports.

- While provision of support is generally lacking, it is also inequitable. The support people receive is influenced by where they live and the cause of their disability.

- There is significant unmet need for disability services in Australia, and this has been the case for decades. It has led to rationing and the growth of waiting lists, which leads to greater unmet demand. It affects a wide range of everyday activities including self care, mobility, communication, cognition, and transport.

- Two-thirds of people requiring assistance with core activities only receive informal support. People who only receive informal support make up the vast majority of those indicating that their core needs are fully met. If informal care can not be sustained, there will be increased demands on an already rationed formal system.

- Funding is insufficient across all jurisdictions, and improvements could be made in terms of both service coverage and the spending per service user. Underfunding is worse in some regions than others. Current funding efforts are unlikely to reach a reasonable and necessary level of support, as doing so would have major fiscal implications for states and territories.

- Underfunding is only part of the problem. Systemic failures include:
  - the fragmented structure of the disability system, and a lack of coordination, have made it extremely difficult for service users and their families to access services.
  - a lack of portability of disability supports between states.
  - outdated service models which distort allocation decisions.
  - a lack of person-centred planning and a general lack of consumer choice.
  - a lack of certainty around waiting times and the availability of supports mean that families can not plan for the future.
  - more timely and forward looking service delivery could save the system money.
  - the lack of essential frameworks that would allow the system to identify and solve its problems. These include a strong governance structure and data systems.

2.1　Introduction

Throughout the consultation process of this inquiry, there has been no question among stakeholders (including government) as to whether support for people with disability needs to be improved. This presumption is also reflected in the terms of reference for this inquiry:

> The Government is committed to finding the best solutions to improve care and support services for people with disability.

One of the roles of this inquiry is to consider what scope of change is required. For example, changes can come from small, well targeted reforms or larger scale structural change.

This chapter considers the evidence surrounding the view, held by many, that the disability support system requires large-scale systemic changes. The analysis is based on a wide range of evidence which includes population-wide statistics, information from the disability support sector, as well as the experiences of individuals and families.

The first sections of this chapter look at the poor outcomes of the disability support sector as a whole. This involves evidence of disadvantage among people with disability and their families (section 2.2). It also involves evidence of poor outcomes of the disability support system, including the lack of service provision and unmet need (section 2.3).

The subsequent sections consider the potential reasons behind these poor outcomes. Section 2.4 outlines the evidence regarding the underfunding of disability supports. Section 2.5 looks beyond funding at various structural elements of the system and sources of inefficiency.

This chapter is only a brief summary of the major issues motivating reform. The chapters that follow focus more on providing solutions to the comprehensive problems facing the disability sector.

2.2　Disadvantage and disability

People with disability and their families face many social and financial challenges and, as a group, are among the most disadvantaged in Australia. This makes support services all the more important for their wellbeing. While this disadvantage may not be entirely attributed to unmet need for services and supports, there appears to be a strong link between observed disadvantage and a lack of support services. The

evidence suggests that large scale support is warranted over and above what is currently provided.

Social isolation

Social isolation affects people with disability and their families at a disproportionally high rate — this was one of the major findings of the Shut Out report (Australian Government 2009a). More than half of the submissions to the Shut Out report cited 'exclusion and negative social attitudes' as critical issues (p. 3). The point has also been made strongly by participants to this current inquiry (subs. DR791, DR771, DR830, DR999).

At the extreme end, some people with disability do not participate in any activities outside of home — people with profound core activity limitation were nine times more likely to be in this group than the general population (figure 2.1). While most people with disability do participate in at least some activity outside of the house, this does not imply that only a minority of people with disability experience isolation.

Figure 2.1 **Proportion of people aged under 65 years not participating in activities outside of home, 2009**[a]
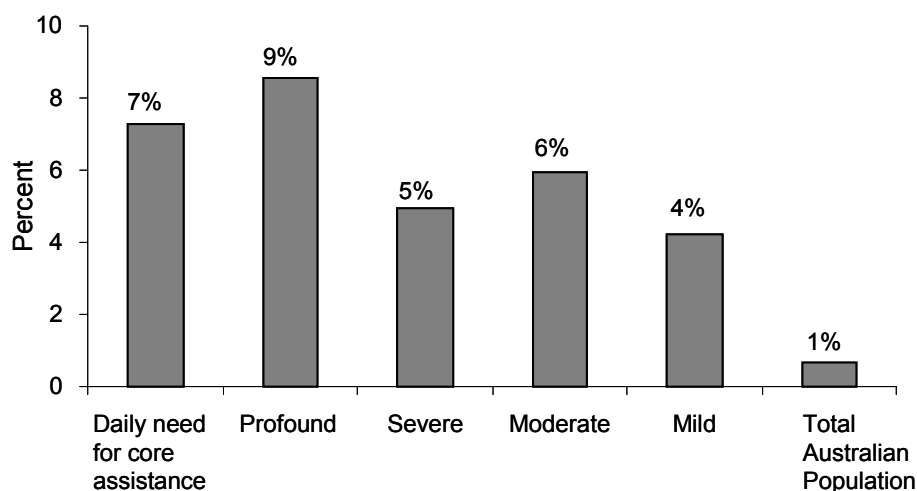
a Activities include: visiting a museum or art gallery; visiting a library; attended theatre or concert; attended cinema; visited animal or marine parks or botanic gardens; took part in sport or physical recreation; attended sporting event as a spectator; visited relatives or friends; went to restaurant or club; church activities; voluntary activities; performing arts group activity; art or craft group activity; other special interest group activities; other activity not elsewhere specified

Data source: ABS (unpublished).

Further evidence suggests that isolation affects a much wider group. For instance, people with profound limitations were also likely to miss out on social activities at home:

- only 16 per cent had been visited by friends or family in 3 months, and around 59 per cent had not had a telephone call in 3 months

- around 18 per cent had not had any social contact in the last 3 months

- around 44 per cent had not used the Internet in the last 12 months (ABS 2010d).[1]

Social isolation can be particularly pronounced for people who require support to access the community.

> One common factor is that people who are deafblind are becoming more isolated due to insufficient support to assist them getting out and about. They have to rely heavily on human support options (eg; interpreters, communication support people, guides and carers), communication devices and social networking online services to interact with the 'outside' world. Many deafblind people do not have access to these devices nor are trained to use social networking options. (Able Australia, sub. DR791, p. 5).

The social isolation experienced by people with disability is evident in various other indicators discussed more fully in chapter 4.

Many participants also highlighted the isolation felt by carers (subs. 177, 249, 259, DR634). These accounts accord with findings from the Families Caring for a Person with Disability Study. The study shows that around 18 per cent of carers only had face-to-face social contact either once every three months or less often (Edwards et al. 2008).[2]

Lower levels of education, employment and income

There are significant differences in the levels of education and training among people with disabilities, particularly those with higher support requirements. Around 80 per cent of all Australians over the age of 25 years progress past year 10, compared to two thirds of people with disability and half of people with severe or profound core activity limitations (ABS 2010d).

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[1] One of the main data sources used by the Commission is the ABS *Survey of Disability, Ageing and Carers, 2009*. Given the timing of the release of this dataset, the Commission has used unpublished data as well as the publicly released confidential unit record file (ABS 2010d) and the published summaries (ABS 2010c, 2011).

[2] The Edwards et al. (2008) estimates were based on the Families Caring for a Person with Disability Study (FCPDS). The sample size was 1002 carers, all of whom were selected from Centrelink lists of recipients of either Carer Payment or Carer Allowance.

People with disability and their carers are also less likely to participate in the labour force. Around 31 per cent of people with severe or profound core activity limitations were in the labour force, compared to 54 per cent of people with disability, and around 83 per cent of people without disability (figure 2.2).

The relatively lower rates of education and employment among people with disability may be attributed to several factors besides disability itself (chapter 6 and appendix K). High quality educational and employment outcomes require an appropriate mix of supports, community and business receptiveness to the involvement of people with disabilities, good economic incentives to work, and expectations of social and economic participation. The current system has not sufficiently promoted these features.

Further, the aggregate rates of employment is affected by demographic differences. The population of people with disability is older than the general population, given that disability prevalence is higher at older ages. Generally, participation rates fall with age for any group.

Figure 2.2   **Disability employment for people aged 15–64 years, 2009**
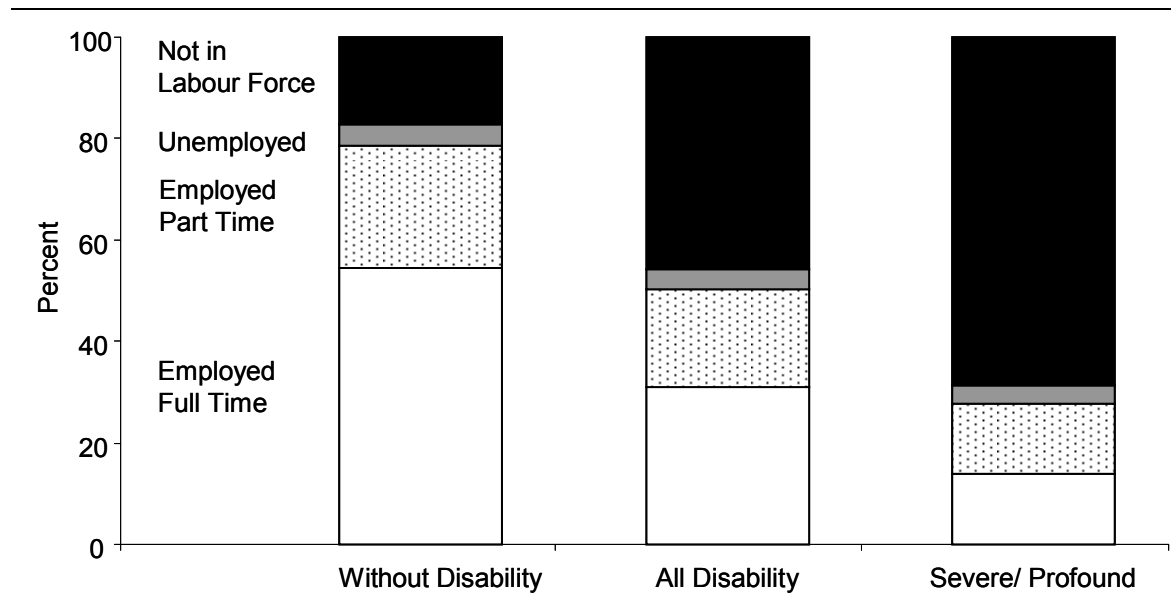
Data source: ABS (unpublished).

Informal carers tend to have less capacity for paid work than non-carers — in 2009, around 42 per cent of primary carers spent on average 40 hours or more per week providing care (ABS 2010d).[3] The labour force participation rate for primary carers is only 54 per cent compared to 77 per cent for non-primary carers and 80 percent

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[3]   Calculation includes primary carers and main recipients of care who live together.

for non-carers. In addition, carers were more likely to work part time. This inevitably leads to carers receiving lower incomes on average than the rest of the population — over 60 per cent of carers were in the lowest 40 per cent of income earners (ABS 2008a).

As a result of poor employment outcomes, people with disabilities are also among the most disadvantaged groups financially. The distribution of income for people with disability differs greatly from that of the wider population (figure 2.3). Still, this is likely to understate the differences, as people with disability generally have additional costs of living associated with their condition.

Employment in paid work not only has implications for income levels, skill development and participation — it also affects people's ability to save for retirement. As such, both people with disability and their carers are less likely to have superannuation or other retirement savings.

Figure 2.3 **Distribution of weekly cash income for people aged 15–64 years, 2009**[a]
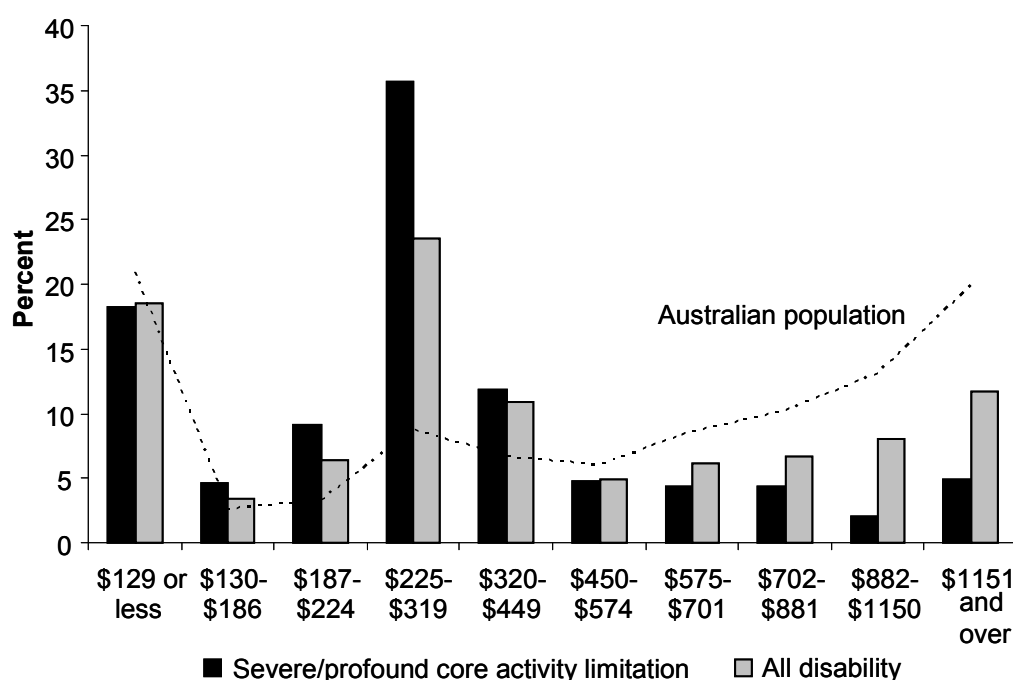
a Data on weekly cash incomes are personal incomes rather than households, and exclude people on zero incomes. The 2009 SDAC is not ideally suited to examination of income distribution, and estimates for the Australian population may not align with those of the ABS Household Income Survey.

Data source: ABS (unpublished).

Difficulties with housing

Housing has implications for people's access to services, natural support networks and transport. People with disability are much more likely to live in public housing than the wider community (figure 2.4). However, many are also part of the private rental market or own homes with mortgages. In these private housing markets, people with disability are also likely to face constrained accommodation prospects due to lower than average income levels (Beer and Faulkner 2008).

Figure 2.4   **Housing situation ages 15–64 years, 2009**[a]
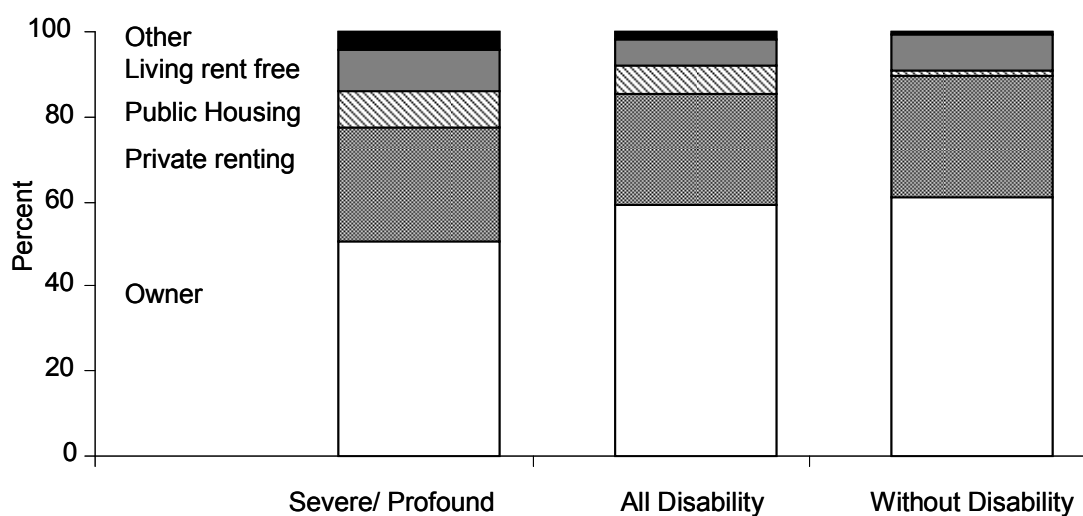
a People classified in 'other' accommodation include those not residing in private dwellings, as well as those whose answers did not fit other classifications.

Data source: ABS (unpublished).

Underlying this current state of housing for people with disability are severe constraints, particularly the shortages of supported accommodation and support for community living (VAGO 2008b, AIHW 2007a). As a result of these constraints, many people with disability live in inappropriate forms of housing.

- Shortages in supported accommodation mean that there is little choice in terms of where the accommodation might be, or whom it might be with. The latter becomes an important issue when vulnerable people with disability are housed with co-tenants who have violent behavioural issues (subs. 11, 225).

- One of the most common results of a lack of supported accommodation options is the continued stay in the family home (Beer and Faulkner 2008). Such arrangements are often preferred by families, and it would not be appropriate for people to be forced out of family homes (sub. DR648). However, people with disability often remain living with their parents in spite of their preference for some form of independent living (subs. 89, 299, 584).

- Where it is not possible for a person with disability to stay in the family home, people under the age of 65 years are often housed in residential aged care facilities (AIHW 2009a). At June 2010, almost 6500 people with disability under the age of 65 years were living in aged care facilities, including 133 people in their 20's and 30's (table 2.1).

- Private boarding homes or caravan parks are often used to house people with disability if they have particularly challenging behaviour, or if other options are simply not available (subs. 149, DR651, DR880, DR981). These arrangements are generally not designed for people with disability, and often leave people with insufficient support and at risk.

- Homelessness also affects people with disability, and is a highly inappropriate situation for a person who requires assistance with everyday activities. People with disability made up roughly one-quarter of clients for the Supported Accommodation Assistance Program (SAAP), which is Australia's primary support response to homelessness (AIHW 2005). The support needs of these people can be severe; participants referred to the case of a person with both severe vision and hearing loss who was homeless (sub. DR791). Psychosocial disability is also heavily associated with homelessness (subs. DR1042, DR1057, AIHW 2007b).

Table 2.1 **People with disability aged under 65 years living in aged care homes by age, June 2010**

	20-29 years	30-39 years	40-49 years	50-59 years	60-64 years	Under 65 years
	No.	No.	No.	No.	No.	No.
NSW	16	49	239	959	1 100	2 363
Victoria	12	21	112	634	749	1 528
Queensland	<5	26	102	509	648	1 285
South Australia	<5	9	42	201	221	473
Western Australia	<5	<5	47	201	283	531
Tasmania	0	<5	13	54	94	161
Northern Territory	0	<5	6	15	29	50
ACT	0	<5	<5	28	37	65
Australia	28	105	561	2 601	3 161	6 456

a Where there are between one and five people in a category, the number has been suppressed in order to protect confidentiality. The category is marked <5, and does not form part of the sum totals.

Source: YPINH (2011)

Poorer personal wellbeing of carers and families

Disadvantage is also observed in the wellbeing of carers. Both survey data and other research by the Australian Institute of Family Studies (Edwards et al. 2008) found significant differences in physical and mental health between carers and non-carers. For instance, carers were almost twice as likely to be in poor physical health than the general population. Around half of female carers and almost a third of male carers had also suffered from a depressive episode of at least six months since they had begun caring.

Many families caring for people with disability experience relationship breakdown. While this also occurs in the wider community, its prevalence among carers illustrates the fact that primary carers can often be the sole provider of informal care. For example, around 30 per cent of all female carers between the ages of 30 and 50 years had either separated or divorced since they had started their role as carers (Edwards et al. 2008). For carers, the probability of separating is higher in the first ten years of caring, (3 per cent each year on average), which is consistent with data showing the frequency of arguments and the likelihood of depression are also higher in the first years of caring.

These results are consistent with the findings of Cummins et al. (2007b), who found that carers had the lowest level of wellbeing of any group that they had studied, including people who were unemployed, or people earning low wages and living alone.[4] Other groups showing low levels of wellbeing in this study included unemployed people who lived alone, and people earning very low incomes.

2.3   Insufficient support provision

The disadvantage outlined in the previous section is compounded by a lack of supports. Support levels are generally insufficient and the provision of support is often inequitable — this places greater costs on people with disability and their families.

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[4] Cummins et al (2007b) used a survey of subjective wellbeing. The sample of carers included those caring for people whose condition fit the following classifications: 'disability'; 'chronic condition'; 'aged and frail'; 'mental illness'. The final sample contained 3766 carers. The Personal Wellbeing Index for carers was compared to scores reported in Report 16.1 of the Australian Unity Wellbeing Index (Cummins et al 2007a), which included a sample of the general population of around 30 000 people.

The disability support system and no-fault insurance schemes

The lack of supports relates most directly to those under the NDA (formerly CSTDA) and HACC services, rather than people who are supported by no-fault accident insurance schemes. In most cases, the level of care and support received through no-fault accident insurance systems is significantly better than the more general 'safety net' system.

- In no-fault motor accident schemes, such as those run by the Tasmanian Motor Accident Insurance Board, the NSW Lifetime Care and Support Scheme (LTCS scheme), or the Victorian Transport Accident Commission, people receive supports on a needs basis that is not arbitrarily constrained.

- Workers' compensation schemes provide supports (including some income replacement) for a wide range of injuries, although the accident must have occurred at the workplace.

These accident schemes are able to provide a greater level of supports, partly due to their relatively narrow target group. However they also receive a greater and more stable source of funding through income from insurance. Differences between the various accident schemes are discussed more fully in chapter 17.

This current system sees many people with the same level of disability receiving varied levels of support, depending on whether they were injured in a road accident, at work, or elsewhere. The absurdity of the situation is summed up by the Hon. Bill Shorten when he said:

> It has been said to me that the best thing to do for someone who has fallen off the roof of their home and suffered a spinal injury, is to bundle them into the car and drive it into the nearest lamppost. That grim piece of gallows humour reflects the sad truth that getting adequate compensation for a person with a serious injury is still a lottery. State borders, the whim of the courts, and the cause of the injury play a far greater role than need, fairness or justice. Yet people injured in accidents at least have the chance for some kind of compensation, and treatment that is whole-of-life and centred on the individual. They are the comparatively lucky ones. (Shorten 2009)

In the current system, people who are not covered by a fully funded accident scheme must fall back on a much more heavily rationed system, or rely entirely on unpaid support. They include the vast majority of people with disability, including (but not limited to) people with disabilities linked to a medical condition, genetic cause, or acquired in the pre-natal period. They would also include people whose injuries are not covered by insurance schemes, such as those incurring serious injuries at home.

Unmet need

Unmet need for disability supports can be defined in several ways. It generally refers to situations where people:

- receive some support but require more than they currently receive
- receive some support but require some other types of support that are not available
- do not receive any of the support they require.

Supports can be formal and informal, and unmet needs can relate to either or both. However, in most instances, the main policy concern is where the provision of formal publicly-funded supports fails to meet people's reasonable needs, placing unreasonable reliance on informal care.

It is also important to note that unmet need does not simply refer to any instance where support is provided by an informal carer. Informal carers would have an important role in any functional disability system, and the Commission does not imply that informal care is an inherently poor outcome in each situation. Rather, unmet need refers to situations where informal care is relied on to an unreasonable extent.

Shortfalls in disability supports are widely recognised (Ohlin 1999, AIHW 2007a). The National Disability Agreement raises the significance of unmet need, and gives a high priority to improving how need is measured (Australian Government 2009b). These improvements are expected to be incorporated in the ABS Survey of Disability, Ageing and Carers (SDAC), and the Disability Services National Minimum Data Set. However, the issue has been identified in previous surveys and recognised by previous governments:

> It was a matter of concern for Commonwealth, State and Territory governments for some time, but was probably crystallised into public consciousness following the 1993 National Survey of Disability and a subsequent Australian Institute of Health and Welfare study. (Ohlin 1999, p. 1)

Although there have been many significant policy changes in recent decades, the extent of unmet need continues to be a major concern. There was a strong consensus among all participants to this inquiry that the level of unmet need is unacceptably high.

Estimates of unmet need

The ABS SDAC (2010d) provides an overall picture of unmet need for core and non-core activities of daily living, but one which needs to be interpreted carefully. The use of survey data is vital to gaining population-wide estimates of various aspects of unmet need. Although the data are not perfect, the caveats associated with the survey data are reasonable.[5][6]

Most people who require assistance with core activities, (comprised of self care, mobility and communication), indicated that their needs were fully met (figure 2.5). The vast majority of this group had their needs met by informal support alone, without receiving any formal supports. The presence of informal supports will often conceal an underlying unmet need for formal supports since, absent appropriate formal supports, informal support will often 'fill the gap'. Many families in this situation face desperate unmet need for respite, supported accommodation, and other supports.

Many people indicated that their needs were partly met, and this can mean many different things. For instance, they may be receiving some support for one core activity, while not receiving support for another core activity. In consultations and hearings, the Commission heard many instances where assessed need was not matched by supports because of rationing. These included people whose needs for assistance with self care were 'partially met', including insufficient assistance with toileting and bathing (trans., p. 553). Similarly, where a person's mobility needs are partially met, it can mean spending days or weeks at a time in bed. As such, some of the most urgent shortfalls of support are for people whose needs are 'partially met'.

A much smaller proportion of people requiring assistance with core activities indicated that these needs were not met at all, by either formal or informal supports.

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5 Given the surveys are based on self-assessment, some people will underestimate their needs, while others will overestimate their needs. Low formal service levels may also set a norm that provides a low benchmark that affects people's judgments about the adequacy of formal supports and that inappropriately accentuates informal care, even if that support is not sustainable over the longer run. Furthermore, it is possible that a person's responses may differ at different points in time — particularly if the availability of support varies.

6 Close to the time of publication for this report, the Commission was notified by the ABS of some corrections to the SDAC 2009 CURF. While it is unclear what effect (if any) this would have on the estimates presented in this report, the Commission has not been advised of specific problems with any variable used for its analysis.

Figure 2.5 Unmet need for assistance with core activities, 2009

Core activities include self care, mobility and communication.

Needs partly met
21%

Needs not met at
all 3%

Needs fully met, receives at
least some formal support
20%

Needs fully met
through informal
support (receives
no formal support)
56%
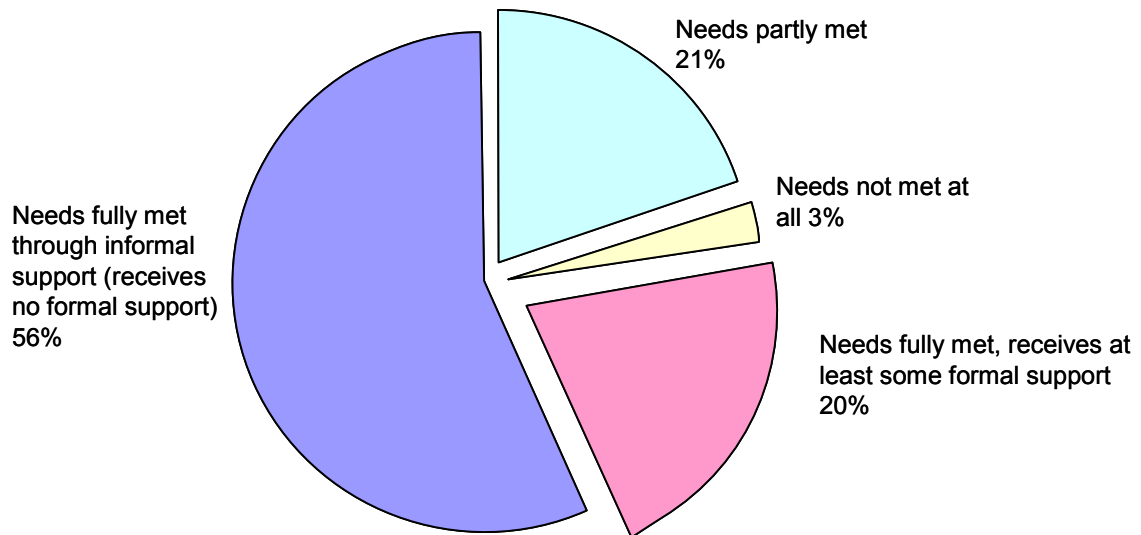
Data source: ABS (2010d).

It is important also to consider people's unmet needs for *non-core* activities (which include cognition or emotion; health care; paperwork; transport; housework; property maintenance; and meal preparation). Of the group with core activity limitations, around 42 per cent had their non-core activity needs only partly met or not all. For those whose needs were fully met, informal supports were the principal source of support (which again may hide insufficient provision of formal supports in this area of need).

Figure 2.6 **Unmet need for assistance with non-core activities, for people with severe or profound limitations, 2009**

Non-core activities include Cognition or Emotion; Health Care; Paperwork; Transport; Housework; Property Maintenance; Meal Preparation

Needs fully met through informal support (receives no formal support) 31%

Needs partly met 40%

Needs not met at all 2%

Needs fully met, receives at least some formal support 27%
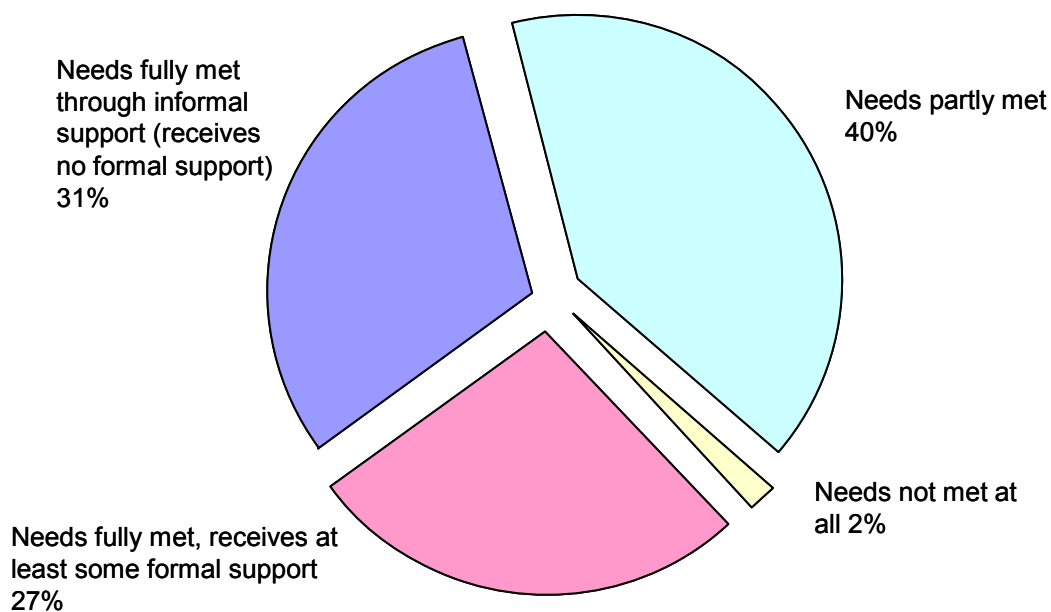
Data source: ABS (2010d).

The Commission also examined areas of unmet need for specific activities of daily living (table 2.2). The numbers of people who require more assistance with self-care are particularly high compared to other areas of support.

Table 2.2   **Many basic needs are not met**

Type of support	Profound core-activity limitation	Severe core-activity limitation	Moderate core-activity limitation	Mild core-activity limitation
Numbers of people not receiving assistance when needed				
	000's	000's	000's	000's
Self-care	41.7	45.2	—	—
Mobility	31.2	50.9	—	—
Communication	14.6	6.3	—	—
Cognitive or emotional tasks	19.3	17.3	18.5	15.0
Reading or writing tasks	15.2	7.9	4.3	4.2
Transport	19.7	27.0	25.8	22.5
Meal preparation	7.9	7.5	2.0	1.1
Share of people with support needs who do not receive assistance				
	%	%	%	%
Self-care	14.5	23.4	—	—
Mobility	7.6	13.0	—	—
Communication	11.2	8.6	—	—
Cognitive or emotional tasks	8.9	9.1	18.9	13.8
Reading or writing tasks	10.6	9.8	19.4	13.8
Transport	6.9	11.0	31.5	23.7
Meal preparation	4.4	9.8	10.9	9.1

Source: ABS (2010d)

Since informal support is often the major contributor to meeting people's daily living needs, there is an important question as to the extent of unmet need experienced by primary carers. Questions regarding unmet need were asked directly to primary carers in the SDAC 2009. Among primary carers where the main care recipient was under 65 years of age and had severe or profound assistance needs, around 52 per cent of carers indicated that they needed more supports, ranging from emotional and financial support to respite (figure 2.7).

Figure 2.7   **Unmet needs for carers' supports, 2009**

Primary carers for people under the age of 65 years with severe or profound activity limitations
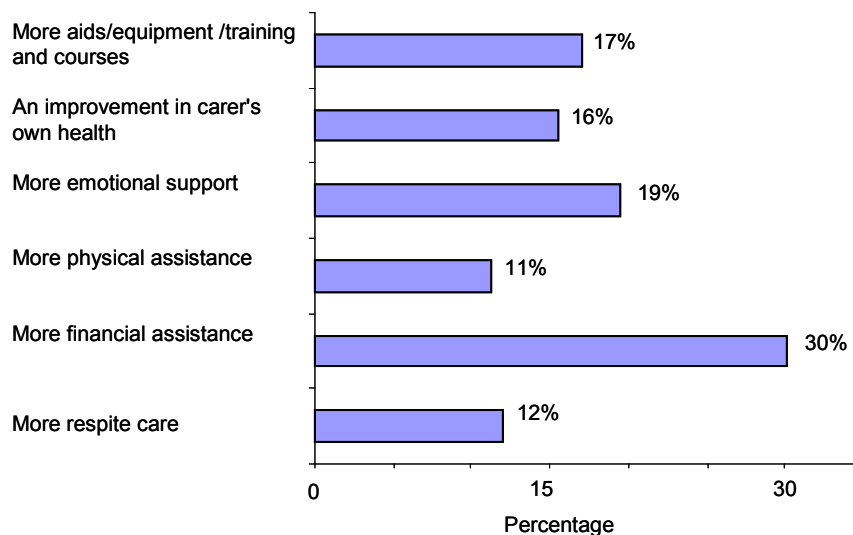
Data source: ABS (2010d)

Waiting lists and other evidence for unmet need

The AIHW (2007a) used both survey and waiting list data to compile estimates for unmet need for different disability supports (table 2.3). These estimates are not based on current data, although they are useful in highlighting accommodation and respite as a particular area where unmet need is high. As an overall picture of unmet need, the estimates in table 2.3 are likely to be an underestimate. For instance, ABS (2010d) estimates almost 42 000 primary carers who had indicated a need for more assistance with respite alone.

More recent waiting lists show that unmet need continues to grow, particularly for respite and supported accommodation, as the number of applicants consistently outweighs the number who are granted support.

- In Victoria, the number of people waiting for supported accommodation in 2008 was around 1370 people. To meet this level of unmet demand, the supply of supported accommodation would have to increase by 30 per cent. The unmet demand for supported accommodation was growing by 4-5 per cent per year. (VAGO 2008b)

- In NSW, there were 1596 people waiting for supported accommodation in 2008, of which 85 received support that year (Constance 2008, p 6829). There were also 1592 people who sought respite. At the latest count, there were 1729 people

requesting supported accommodation in 2010 (Standing Committee on Social Issues, NSW 2010).

Although these waiting lists show evidence of growth in unmet need, they are still likely to offer an underestimate of overall unmet need. This is because many people do not apply for supports due to the excessive and uncertain waiting times, or because the appropriate service is simply not available. Moreover, waiting list data is simply not well collected in many service areas, as many support programs do not maintain or report such lists.

Table 2.3   **Waiting list data and AIHW estimates of unmet need, 2005[a]**
Number of people

	Accommodation and Respite	Community Support	Community Access	Employment	Total
Waiting List Data					
Victoria	4 254	—	507	—	4 761
Queensland	—	—	—	—	3 578
Western Australia	409	—	77	—	486
South Australia	2 147	589	533	—	2 619
Tasmania	284	122	70	—	476
AIHW Estimate					
Australia	27 800	—	5 900	2 200	—

a Data where available.

Source: AIHW (2007a, table 4.2).

Waiting lists may also fail to capture people who receive disability supports from other, less appropriate service systems such as Health and Aged Care. A good example of this is the number of younger people with disability in aged care homes. For instance, in NSW, there were 2363 younger people with disability living in aged care facilities in 2010 (YPINH 2011). It would be reasonable to assume that all such people should be on waiting lists for more appropriate accommodation. However, the evidence suggests that most would not be reflected in existing waiting list data. First, the actual waiting list for supported accommodation is less than the number of people accommodated in inappropriate settings. And many on the waiting list would not be in aged care accommodation.

Further evidence of unmet need for disability supports can be found in the number of long stay hospital patients. A lack of appropriate disability supports, (such as supported accommodation, home modifications, or even appropriate transport), can result in longer stays in hospital than would otherwise be necessary.

• In Western Australia, for example, there were 14 patients with disability in 2010 who were 'medically stable' and ready to be discharged. Some were awaiting

funding from the Disability Services Commission while others had applied or had been assessed (by DSC or ACAT). Between them, the 14 patients had stayed a total of 1503 bed-days (Western Australian Government correspondence).

- In South Australia, data shows that at any time there is a cohort of 32 to 48 patients with a disability who are ready for discharge to a more appropriate setting (South Australian Government correspondence). The average length of hospital stay for these patients in acute care was 207 bed-days in June 2010, with one patient currently at 1298 bed-days (three and a half years).

In the absence of time series data on bed blocking, information on the total number of hospital separations and bed days for *all* long-stay patients,[7] may provide an indication of whether the incidence of excessive hospital stays is falling (figure 2.8). The numbers of long stay patient separations and bed days appear to vary from year to year, showing no long term downward trend. Hence, the issue of bed blocking in hospitals is likely to continue unless further action is taken.

Figure 2.8   **Hospital separations and bed days for long stay patients under the age of 65**

Separations and bed days per year
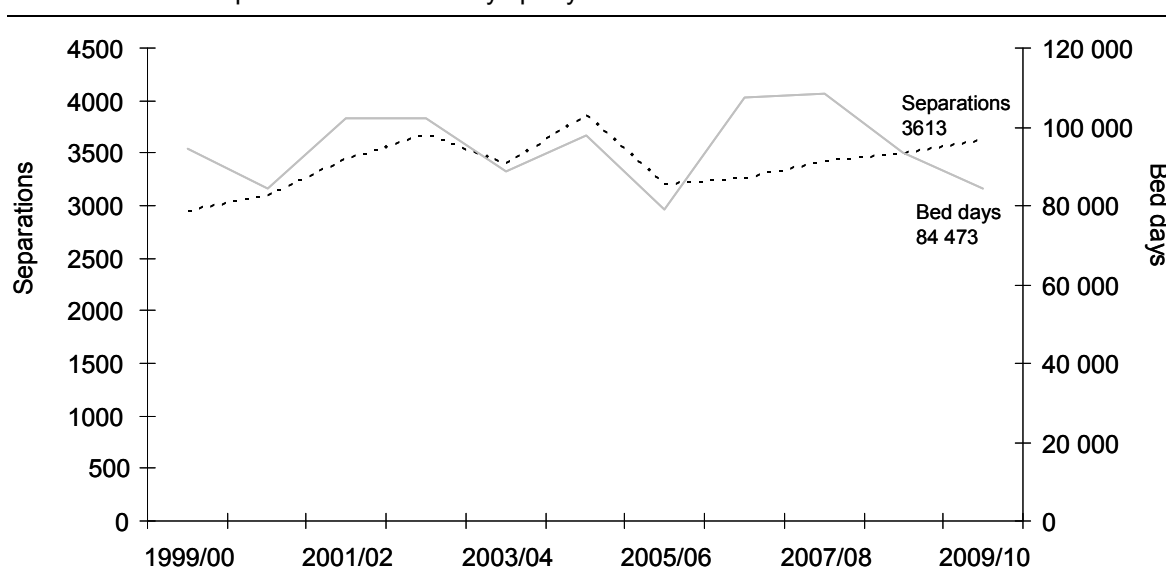
a Long stay patients are defined as admission with a principal diagnosis of either Z74 (problems related to care-provider dependency) or Z75 (problems related to medical facilities & other health care).

Data source: Department of Health, unpublished statistics.

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7   Data on long stay patients will include people whose stay duration is appropriate, and others whose stay could be reduced by improving disability supports.

Unmet demand, excessive waiting times and uncertainty

An important aspect in describing the extent of unmet need is the excessively long periods of time people spend waiting, and the uncertainty involved. Evidence observed through waiting lists and prolonged hospital stays show that unmet need is not short term and does not simply reflect lead times for supports. People often wait for services indefinitely, since there is no certainty about when their support needs will be adequately met:

- In severely rationed systems, families in crisis are given priority over others in waiting lists. This means that people are often bumped down the list over time, which makes their progression very uncertain.

- When particular parts of the system are budget constrained, or lack certainty over future budgets, the scope for meeting unmet need in the future is unknown. For some supports, there is uncertainty as to whether they will be available in future periods at all.

If a person's circumstances improve, or if they move between regions, they may find themselves starting again at the bottom of the waiting list. Conversely, moving up a waiting list may require people to describe their situations in the most pessimistic terms, as if bidding competitively for supports through the 'misery Olympics'.

The waiting times encountered by participants for basic supports are often several years (subs. 94, 425, 462, DR1006, DR1009). Longer waiting times tend to apply for supported accommodation, with examples including people waiting eight years (sub. 26), or over ten years (sub. DR1009). Waiting times for therapies are often 12 to 18 months, which is sufficiently long to affect therapeutic outcomes (sub. 405).

The lack of certainty means that people are unable to plan for the future. This is particularly important as people's needs change over time, and there is no guarantee that the appropriate supports will be available at a later date. A stark example is the uncertainty carers face regarding the care arrangements that will eventually be needed when they will no longer be able to provide care (subs. 22, 96, 595, DR726).

Indirect estimates of unmet need

An alternative way of measuring the *dollar* value of unmet need is to examine the detailed characteristics and needs of people in the SDAC, and estimate the total costs of support to meet those needs (net of support reasonably provided by people's families). The level of unmet need can then be estimated as the difference between existing funding and the measured value of total support needs. Based on

the Commission's cost estimates for the NDIS, it is likely that only around half of people's needs are currently being met.

The roles of informal and formal care

Informal care is vital to the care needs of people with disability — this will continue to be the case in the future, regardless of improvements in the provision of formal supports. One of the aims of reform would be to ensure that the balance between formal and informal supports is reasonable and sustainable.

The vast majority of people with disability under the age of 65 years only receive informal care. Around 66 per cent of people who live in households and need assistance with core activities receive only informal support (figure 2.9). A further 20 per cent receive both formal and informal care. Given the magnitude of informal care, any withdrawal of informal care would place further demand on the already overburdened formal support.

Figure 2.9   **How core needs are met for people under 65 years, 2009**

Formal and informal care for people needing assistance with core activities
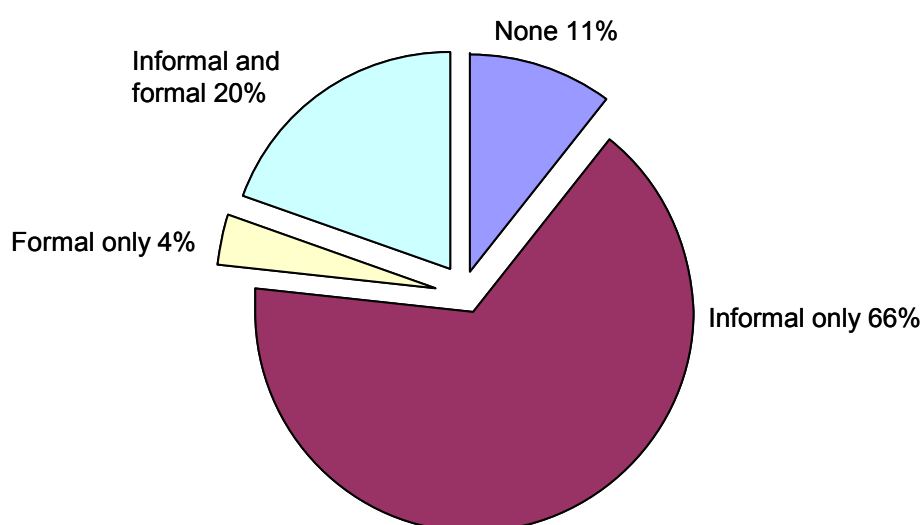
a Around 11 per cent indicated that they received neither formal nor informal support for their core activity needs. This includes 7 per cent who received no support and indicated their needs were fully met; 1 per cent who received no support and indicated their needs as partly met; and 3 per cent who received no support and indicated their needs as unmet. Questions regarding the receipt of care and unmet need were answered by the same population.

Data source: ABS (2010d)

Currently, the formal supports provided to informal carers is insufficient. This is perhaps most visible in the unmet need for supported accommodation and respite.

The need for more supports for carers has been made strongly by many participants (subs. DR718, DR981, DR1045).

The potential for withdrawal of informal care through crisis

There is expected to be a downward trend in the availability of informal care in Australia (see PWC 2010a, Access Economics 2009, NATSEM 2004, and Jenkins et al 2003). This is attributed to situations where carers reach a point where they stop providing care — associated either with carers' ageing profile, or the inability to provide care due to a lack of supports. Given that the majority of disability care is provided informally, any ongoing reductions of informal care would exacerbate demand for formal supports, particularly for supported accommodation and attendant care.

Inadequate formal support for people with disabilities places greater demand for supports on informal carers, and can precipitate a crisis for the carer and the person with a disability. Many participants to this inquiry have made this point strongly. Survey evidence also shows a link between the support received by carers and their health outcomes:

> There is a clear and consistent pattern, with carers who indicated that the support they received was "about right" having significantly better mental health and vitality than carers who needed a lot or a little more support…

> Carers who needed a little more support had an incidence rate [of depression] 1.58 times that of carers who said the support they received was about right (54.6 per cent versus 34.5 per cent). Moreover, carers who needed a lot more support had an incidence rate 1.88 times that of carers who indicated the support they received was about right (65.0 per cent versus 34.5 per cent) (Edwards et al. 2008 pp. 79–80).

It should be noted that a person's ability to provide care, and the effect it has on their health, is also determined by the carer's own physical abilities and psychological resilience, the family context, income, and the complexity of needs and extent of any behavioural problems of the person with a disability. However, better support provision is likely to have a positive effect on a carer's capacity for ongoing informal support, and could reduce the likelihood of crisis.

The potential for withdrawal of informal care through ageing

As carers age, their ability to provide care tends to reduce, particularly as they may require care themselves. Aged carers have varying views about the kind of support they need. Some aged carers have expressed a need for supports to help them continue to provide care. Others expressed a need for a viable alternative to their

care. In fact, the number of aged carers is partly a reflection of a lack of alternative care.

> Many have been in circumstances where they had no choice but to assume the sole responsibility of care for children with disabilities without a real prospect of those circumstances ever ending. … [The] realization that their ability to care for their children is diminishing with age and that in the not too distant future their ability to care will have disappeared… adds enormous anxiety to the already significant anxiety and stresses of their situation. (National Seniors Australia, sub. 595, p. 9)

As the support system improves, some older carers will continue in their role as primary carer, in accordance with their preferences. However, the main effect of a better support system would likely be a shift towards formal care as carers age.

There are varying estimates of the number of aged and ageing carers: SCRGSP (2011) shows around 8100 primary carers over the age of 65 who are caring for a recipient of CSTDA/NDA services; Centrelink data for 2010 shows that among recipients of Carer Allowance, around 11 200 were over the age of 65 years and caring for a child.[8]

Increased life expectancy and increasing reliance on ageing carers

The evidence suggests that the reliance on ageing carers is growing. Centrelink data shows that the number of Carer Allowance recipients over the age of 65 caring for a child has increased over the last five years by 10 per cent per year on average. In addition, PWC (2010) estimated that between 2006 and 2036, the proportion of carers over 65 years would rise from 16 to 24 per cent. This ageing profile is due in part to the general ageing of the population, but also to changes in life expectancy. Over the last 50 years, the life expectancy of people with intellectual disabilities has increased by many decades.

> In the 1950s, for instance, someone born with Down syndrome could expect to live to around 15 years of age (Thase 1982). In the current decade life expectancy is approaching 60 years and continues to rise (Torr et al. 2010). (Tracy 2010, p. 83)

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[8] PC (2011) reports that there are around 8100 people over the age of 65 years acting as a primary carer for someone receiving CSTDA services, based on the National Minimum Data Set from the AIHW. Centrelink data on carer allowance recipients shows around 11 500 carers over the age of 65, with around 10 500 caring for people younger than 65 years. However, not all people with disability receive CSTDA/NDA services, and not all carers receive carer allowance. So while this estimate is internally accurate, it may be lower than the true number of aged carers. Alternatively, ABS SDAC (2003) indicated around 10 000 primary carers over the age of 65 years, however standard errors are much higher for survey data.

Hence, the factors contributing to the increased reliance on ageing carers are likely to continue.

Evidence on relinquishment

The Commission received considerable testimony of parents struggling with care, and reporting that their last resort was to place their adult child into state care (box 2.1). This anecdotal evidence suggests that the relinquishment of care is a very difficult and reluctant decision, and is generally made after years of attempting to cope as primary carers in the context of a lack of formal supports.

Box 2.1 **Withdrawal of informal care is a last resort**

These families simply couldn't cope any longer — both lived some distance from the city — but would have, and wanted to continue their role, if only the necessary services, respite, transport, emotional and physical support had been available. They were not 'unwilling' to care — they were 'physically, financially and emotionally unable to care'. (Mary Walsh, sub. 118, p. 6)

The only way to get help, we were told, was to relinquish our little girl to DoCS (community services). Eventually we could not cope and found ourselves in a world where authorities find it hard to distinguish loving parents from those who abuse their child. It was wrong. (Mad as Hell, sub. 153, p. 7)

We are now back to lobbying for a package, and have been told we will only access one if we go into crisis or relinquish care. I used to wonder how parents could do that, but I see it's the only option. (Mad as Hell, sub. 153, p. 8)

34 per cent [of] sole carers in a 2005 study considered relinquishing care, and a small number of carers do relinquish the care of their son or daughter because the care load is beyond family resources. They are generally offered inadequate family and assistance. The irony is that substitute care families are generally offered a higher level of formal support. (Carers Australia, sub. DR981, p. 20)

The process of relinquishment places great stress on parents, and further demands on formal supports:

Legal responsibility then transfers from one Department to the other, but requires a full legal process of the parents being "served with papers" and seeking a 'protection order' before the Court system The child is now, legally 'abandoned', and in 'need of protection' because of that family abandonment. This is an emotionally destroying process, with the parents having to deal with their appearance before the magistrate, the court-room processes and overwhelming sense of guilt. (Mary Walsh, sub. 118, p. 6)

In Qld the pressure on families often results in families making the heartbreaking decision to relinquish their disabled child or young adult to the Dept of Child Safety or DSQ. This puts further pressure on these agencies to provide support that they are not really equipped to provide. (Redland District Special School Parents and Citizens Association, sub. 463, p. 4)

No jurisdiction other than the ACT have estimates of relinquishment available, although the Commission was advised informally that respite is increasingly comprised of permanent residents. For instance, around 30 people in NSW were using respite as long-term accommodation in 2008 (NSW Auditor General 2010). In 2010, around 40 children were in state care in Victoria, having had their informal care relinquished (Nader, 2010). These numbers in NSW and Victoria represent snapshots at particular points in time, but moreover, the numbers are not complete snapshots. It is entirely likely that many more people with disability have had their informal care withdrawn due to inadequate supports.

A much higher rate was estimated by Disability ACT, comprising around 22 situations each year where informal care is withdrawn in the ACT alone (Disability ACT 2010). This leads to around 11 to 16 extra places required in supported accommodation (Kenney 2011 p. 752). These instances may result from either the natural ageing of the carer or from crises.

Extrapolating this incomplete evidence into a national estimate is difficult for several reasons. PWC (2011) indicate that the tendency towards crisis is affected not only by the level of support in a jurisdiction, but also the service mix. The level of supports and the mix of services differs in each jurisdiction.

The role of formal care and insurance

There are limits to the amount of informal care that can reasonably be provided, and many participants attested to this (sub. 210). These limits depend on the appropriateness of care relationships, the carers' own abilities, and the need for expertise or equipment. The costs of formal supports, such as attendant care, therapy, and aids and appliances, are more than many people could generally afford by themselves.

Moreover, having a disability or becoming a carer often has serious implications for the cost of living and the ability to work, which further reduces people's ability to pay for further costs of support. Given the importance of disability supports, and people's inability to afford reasonable levels of support, there is a direct role for governments to provide formal disability care (a matter further raised in chapter 14).

The value of a functional system of formal care is also in its ability to pool risks. As in other areas of life, there is a benefit to society from pooling financial risks to reduce their impacts on individuals — this is the value of insurance. Even for people who never have to make a claim, there is a benefit from knowing that there will be sufficient funds available to ensure that people receive necessary care and support, if required.

Spreading the risks of these costs is usually the role of insurance companies, however for a number of reasons discussed in chapter 14, commercial insurance markets will not operate well in the area of long-term care and support for people with disabilities. Therefore, people with disabilities are left to rely on the government system to spread risk. As a result, the government must determine the ideal level of insurance, which is difficult. Among other things, it will be affected by:

- the level of risk aversion people possess

- the cost of raising funds through taxes.

While it is hard to determine the optimal level of insurance, the current arrangements do not provide enough risk pooling, with significant portion of disability-related costs borne by the people with disabilities and their carers (section 2.2). Redistributing these costs more evenly across the community is not just a transfer of wealth, it spreads risks more efficiently. As discussed in chapter 20, insurance is a highly valued economic service.

2.4 Underfunding in the current system

A functional disability services system requires both adequate funding and the efficient use of that funding. While there is great potential for improvements to efficiency (see section 2.4), it is generally also agreed that much more funding would be required to meet the current demand for services. For instance, according to some State Government submissions:

> Such a scheme would have significant cost implications — given the funding required to meet unmet demand. It is only likely to be feasible with Commonwealth involvement due to the scale of the funding required, and the states' limited revenue sources. (Victorian Government, sub. 537, p.3)

> Given current funding levels fall well short of the type of care expected to be paid for by a social insurance scheme, the level of overall funding, and its growth over time, will need to be significantly greater than what is currently contributed by state and federal governments. This is especially the case if a national insurance scheme extended entitlement to the population currently not in receipt of formal disability services. (South Australian Government, sub. 496, p. 17)

> Alternative revenue sources need to be considered to address disability budget pressures and effectively meet the needs of people with a disability in NSW. (NSW Government, sub. 536, p. 39)

The extent of underfunding in the disability support system is in itself a major argument in favour of change. However, it is not straightforward to quantify underfunding accurately, particularly given the lack of data on the current need and

usage of supports. That said, all sources of data currently available reinforce the view that systemic underfunding has contributed to the shortfall in supports and continues to do so.

Disability funding within the current framework

Funding for NDA and HACC services comprised almost $6 billion nationally in 2010. The states and territories provide the vast majority of funding, although the proportions of federal and jurisdictional funding differ across Australia (table 2.2). Much of this diversity is likely to reflect variations in the adequacy of funded service provision across jurisdictions (a view supported by many participants), rather than other factors:

- differences in disability spending per capita among jurisdictions do not, to any great degree, reflect differences in disability rates

- cost variations across jurisdictions do not credibly explain the substantial divergence in resourcing for disability. Many costs such as attendant care (which is also included in the cost of supported accommodation), are likely to carry a similar per unit cost. Attendant care is generally a major contributor to costs of support (80 per cent of costs in NSW LTCS).

- in theory, variations in spending may also partly reflect the relative efficiency of different jurisdictions in providing supports, but there is no evidence that higher spending jurisdictions are less efficient (and indeed the contrary may be true).

Table 2.4 Government spending on disability services by jurisdiction, 2009-10

NDA supports and employment services

Government/ Jurisdiction	Total expenditure[a]	Share of expenditure financed by jurisdiction's own funds[b]	Total direct service delivery (excluding administration, payroll tax)	Total direct service delivery per potential recipient[c]
	$000	%	$000	$
NSW	1 687 006	82	1 521 724	6 813
Victoria	1 374 150	85	1 247 346	7 737
Queensland	876 748	80	801 271	5 582
Western Australia	491 631	84	463 102	7 497
South Australia	373 013	74	335 780	6 737
Tasmania	131 403	79	125 225	5 666
ACT	75 040	82	66 722	7 386
Northern Territory	53 159	82	50 619	8 320
Australian Government[d]	774 572	—	723 107	1 068
Total	5 836 721	71	5 334 896	7 881

a Significant amounts are spent by way of capital grants to non-government organisations. They occur irregularly and at differing levels. **b** Calculation excludes payroll tax expenditure. **c** Potential population includes people with severe or profound core activity limitations, and is adjusted for Indigenous underrepresentation. **d** Australian Government expenditure includes direct service provision, largely comprised of employment services. It does not include transfers to jurisdictions.

Source: SCRGSP (2011).

Variation is also observed in the amount of funding per service user and service coverage (table 2.5). Coverage is calculated as the number of people using each type of support as a proportion of the potential population.[9] In jurisdictions where coverage is lower, the amount of expenditure per service user is generally higher. This reflects different approaches taken to manage trade-offs given a fixed budget — by providing more supports to fewer people, or less support to more people. No single jurisdiction has an absolute advantage in both coverage and funding per service user, suggesting that each jurisdiction sacrifices one or the other due to insufficient funding.

The combined coverage for all state and territory provided disability supports also varies significantly between jurisdictions (table 2.5). It shows that a considerable majority of the potential population do not receive any such services.

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[9] Overall coverage of disability supports calculated from SCRGSP (2011) may not accord closely with population estimates of the coverage of formal supports made using SDAC 2009. The estimates were made using two different datasets in different years. The SCRGSP (2011) calculations include numbers of actual users rather than estimates of the population, and they exclude formal supports provided by the Commonwealth Government.

Table 2.5   **Funding per service user and service coverage, 2007-08**

CSTDA/ NDA services

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Accommodation								
$ per user	114809	80340	62786	65523	40425	68598	105562	79546
% coverage	3.1	4.6	3.7	4.6	8.5	6.3	2.9	2.4
Community Support								
$ per user	6878	5730	6844	5579	3342	4329	4199	6601
% coverage	9.3	20.9	8.3	15.4	26.2	13.7	27.9	14.0
Community Access								
$ per user	15899	14533	14815	8606	4545	11705	14769	9657
% coverage	5.0	8.0	5.2	5.0	10.6	8.6	3.8	2.9
Respite								
$ per user	16505	5276	12140	8734	6581	26539	18689	11190
% coverage	2.7	7.5	3.1	3.8	3.1	1.7	2.7	2.0
All services								
$ per user	34440	19404	26640	21261	13244	24294	16296	15384
% coverage	14.6	29.0	13.2	20.4	30.1	22.9	30.6	20.5

Source: SCRGSP (2011) Tables 14A.5, 14A.12, 14A.15.

Regional disparities within jurisdictions

Further to the variation observed at state level, a more direct proof of underfunding within jurisdictions is the varied level of funding provided to different regions. An example is HACC services in Victoria, where funding per potential population varied between regions by as much as 35 per cent (Victorian Auditor General 2009). For historical reasons, one region was 15 per cent below the mean, while another was 20 per cent above. People in remote areas were also less likely to use NDA funded services. In outer regional or remote areas, there were about 32 service users per thousand of the potential population, compared to 43 users per thousand in major cities and inner regional areas.

In a similar audit of NSW respite, it was found that people's access to respite is influenced heavily by regional location.

> There is no consistent needs-based approach for determining who gets respite and how much they get. For historical reasons, respite centres are distributed unevenly across the state and the chances of getting centre-based respite depend, in part, on where you live. For example, only 2.3 per cent of the potential users in the southern part of the state get centre-based respite. (NSW Auditor General 2010, p. 3)

Several participants have indicated that rural and remote areas face poorer provisions of support than would be available to cities and metropolitan areas.

Often barriers to services delivery are created by inflexible and "accountable" city centric models of service delivery. In an attempt to ration services or to target the most needy recipients, funding bodies risk not providing any services to people with disabilities in country areas. (Wattle Range Council, sub. 572)

The Commission also heard in public hearings and consultations that often people in non-metropolitan areas either have to go without supports, or travel long distances at considerable expense to receive supports. Given the issues with cost efficiency and population density, it may not be feasible to have the same bricks-and-mortar infrastructure in each area. Even so, the fact that disability supports are likely to be lacking in the same areas where other human services and infrastructure are also lacking means that alternative sources of support would be unavailable.

Rectifying this inequity would require a redistribution of funds (which would see services decline in many areas), or a substantial increase in funding.

By DHS [Victoria]'s own reckoning it will take up to 25 years to achieve funding equity between regions using the current approach. In 2006 DHS calculated that an additional injection of $11.6 million would be needed to achieve equitable [per capita funding]. (VAGO 2009, p. 2)

This example also shows that moves towards interregional equity are constrained by the overall funding level.

Increases to disability funding

All levels of government are aware of the need for better service funding (subs DR922, DR996, DR1031, DR861, DR683, DR1032). There have been several recent funding initiatives aimed at trying to meet the current levels of unmet need (box 2.1). Many initiatives, such as the Better Start early intervention program, deliver a considerable injection of funds on a focused area. While positive, they tend (by their nature and design) not to address system-wide needs. Moreover, some smaller initiatives may only have funding guaranteed for a short period.

An example of a broader and longer-term initiative is *Stronger Together* in NSW, which involved planning over ten years and guaranteed funding in five-year blocks. Stronger Together focuses on building capacity in disability supports in various areas such as early childhood services, respite, case management, and accommodation. It also involves some systemic changes, such as more person-centred approaches, greater transparency and efficiency. However, on the sustainability of such increased funding, the NSW Government has said:

As the investment under Stronger Together shows, it is not sustainable for specialist disability services to continue to be funded solely from existing budgets. (NSW Government 2010a, p. 13)

The National Disability Agreement involves significant increases in general funding from the Commonwealth. However, under these arrangements, the majority of funding will still come from state and territory budgets. This means that jurisdictions would need to provide the majority of ongoing funding increases that are required to cover current unmet need as well as future demand for support.

Box 2.2   **Examples of recent funding initiatives**

The new National Disability Agreement replaces the existing Commonwealth State and Territory Disability Agreement. Under the new Agreement, the Commonwealth will provide more than $5 billion in funding over five years to the States for specialist disability services. The Agreement means that in 2013 the Australian Government's contribution will exceed $1.2 billion, compared to $620 million in 2007.

Stronger Together is an initiative by the NSW Government to boost their expenditure on disability supports over ten years, from 2006 to 2016. Funding was guaranteed in five-year blocks, involving an additional $1.5 billion in the first phase, and a further increase of $2.02 billion in the second phase. Its focus is on building capacity in various areas of support, as well improving operational efficiency.

The Australian Government implemented the Better Start program (to begin in July 2011), which committed an extra $122 million funding for early intervention over four years. The program, which begins from July 2011, will involve subsidies for allied health services up to the value of $6000 per year, to a maximum of $12 000 total.

The Younger People with Disability in Residential Aged Care (YPIRAC) program is a five year agreement between the Australian Government and State and Territory governments. The Program was established by the Council of Australian Governments (COAG) in February 2006. Funding of up to $122 million from the Australian Government matched by up to $122 million from States and Territories is available. This program aims to reduce the number of younger people with disability living in residential aged care, and to provide additional support to those who remain in residential aged care.

Sources: NSW Government (2010a) and FaHCSIA website.

Maintaining present funding efforts will not close the funding gap

A key point made by a number of jurisdictions is that expenditure on disability services is growing at a faster rate than state revenue and other items of expenditure aside from health. Disability support is comprising an increasing share of the non-health budgets of many jurisdictions, and this increase is not seen as sustainable.

A useful conceptual approach would involve assuming the economy is in a steady state, removing variables such as population and GDP trend growth (figure 2.11). In this system, it is possible to consider average disability spending as remaining constant in real terms, albeit with cyclical fluctuations. This level of spending can then be compared to the Commission's hypothesised level of reasonable and necessary disability spending.

To reach the level of reasonable and necessary spending alone, jurisdictions would need to significantly increase disability spending as a proportion of their budgets. In total, it would require around 6 per cent of the collective state and territory budget spending as opposed to the current 3 per cent.[10] Given that states and territories currently differ in terms of their disability spending, the increases required in different jurisdictions would vary. Due to the quantum of this increase in expenditure, the Commonwealth is likely to be better placed to fund this reform than State and Territory Governments.

Figure 2.10 **Conceptual illustration of disability funding in a steady state economy**

Based on expenditure levels for NDA services
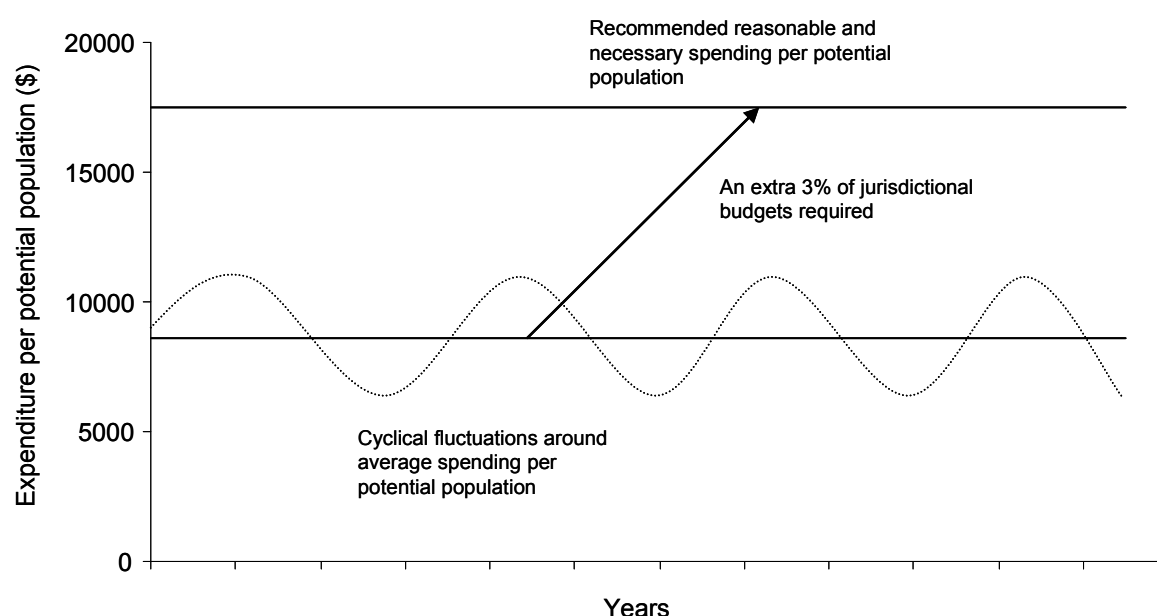
a Cyclical fluctuations shown in this diagram are illustrative only, and are not macroeconomic projections. Does not allow changes in costs from technological changes.

Data source: PC Calculations

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[10] Based on expenditure on care and support as covered currently by the NDA.

Cycles of underfunding in the current system

Underfunding of disability supports can lead directly to *greater* costs in other areas of state and territory spending. This is because rationing in one service area can lead to the use of less appropriate, less efficient services. This results in greater strain on state and territory budgets, and hence on future disability spending.

Rationing is effectively a limit on the services provided at any one time. Yet, many people who miss out during one budget period would still require support in the next budget period. For example:

> Chronic underfunding in recurrent budgets causes a shortfall in programs which operate a subsidy, or funding to run out before the end of the financial year, for example.

> In the Western Sydney region of NSW, all funding for Level 2 Home Modifications for 2010 was allocated by mid 2009. Extensive waiting periods have resulted, leaving people isolated, at risk, and unable to complete daily activities or leave their house, in addition to those who have endured unnecessary periods of hospitalisation. (Occupational Therapy Australia, sub. 510, p. 7)

Where rationing persists over successive periods, greater unmet need can build up over time. Insufficient funds also mean there is less scope for forward planning or investment to meet future demand.

Underfunding (such as in home modifications) often leads to even greater costs in other service areas. These costs are often exacerbated by the fact that the most appropriate and efficient supports are not being used. For example:

> I spent over 12 months as an inpatient in the Hampstead Rehab Centre because government funding would not help with a bathroom so I could go home to my mum. The one bathroom that we did have was probably as big as that table and it just wasn't going to be wheelchair-friendly, so we had to get one added on the back.

> One area of government then spent over $300 000 keeping me in the Hampstead Centre and would not give us $15 000 tops to help renovate a bathroom so I could go home. (trans., p. 318)

Several other participants have noted the greater use of hospital and health expenditure due to a lack of disability supports. Considerable costs are hospital beds are used in lieu of more appropriate disability supports, this often results in a larger cost (box 2.2).

Box 2.3   **Approximate costs of blocked hospital beds**

- In South Australia, hospital and sub-acute settings range from $451 per day for basic care and $3859 for ventilated patients within an Intensive Care Unit. The average stay for prolonged use of hospital beds (212 days) would cost around $96 000. The single current longest stay (1298 days) would have cost $585 000.

- In Western Australia, the hospital bed-day cost of caring for medical stable younger patients is about $1000 per day, not including additional costs of consumables for tracheotomy care and enteral feeding. In 2010 there were 14 such patients with a collective 1503 bed days — this is likely to have cost around $1.5 million.

- Applying these unit costs to the national estimates of long stay patients, the estimated annual cost to hospitals of long stay patients is between $38 million and $84 million.

Source: Western Australian Government correspondence, South Australian Government correspondence, Department of Health unpublished data.

Bed blocking also leads to further service shortages. Data available on the NSW respite system shows that in 2008, around 30 people with disability were using respite as longer term accommodation (in the absence of better arrangements), simply because there was no other option (NSW Auditor General 2010). When the number of people was reduced from 30 to 12 in 2009, this allowed 130 more people to use respite services (i.e. 18 beds blocked meant 130 people missed out on respite services).

If we can assume that the cost of accommodating 18 long term users of respite roughly equates to cost of supporting 130 regular respite users, then the annual cost of prolonged respite use is around $119 000 per person. This is 3.8 per cent more than the average supported accommodation place in NSW.[11]

The potential future costs of the withdrawal of informal care

As noted earlier, the withdrawal of informal care has great potential to increase support costs in the future. Incomplete data (particularly on the rate of withdrawal of informal care) makes estimates in this area difficult. However, it is possible to use scenarios to illustrate the magnitude of the problem. The potential for carer withdrawal to increase future costs may depend on:

- the rate at which informal care is withdrawn

---

[11] Using numbers of service users and expenditure from 2007-08, and potential population from 2008.

- Assuming care is relinquished at a yearly rate of 0.2 per cent of the potential population (as estimated by Disability ACT), this extrapolates to around 1300 people nationally in 2011, growing to around 1830 in 2050.

- Alternatively, if the rate were 0.3 per cent of the potential population, this would extrapolate to around 1950 people nationally in 2011, and 2750 in 2050. If the rate were 0.5 per cent of the potential population, this would equate to 3250 people in 2011, and around 4580 people in 2050.

- how people's needs are dealt with after care is withdrawn.

  - the cost of extra places in supported accommodation

  - the cost of using less appropriate systems such as prolonged stays in hospital or respite beds

The cost differences between supported accommodation and less appropriate settings are significant. Where care is relinquished at the rate estimated by Disability ACT, the current annual cost of carer withdrawal would be $107 million if supported accommodation is used; $153 million if respite is used; and $211 million if long stay hospital beds are used. In all, likelihood, a mixture of the three accommodation settings would apply and, either way, the long-term costs of carer withdrawal would amount to hundreds of millions of dollars.

In the alternative scenarios where the rate of relinquishment is 0.3 (or 0.5) per cent of the potential population, the annual cost of carer withdrawal is around $160 million (or $267 million) if supported accommodation is used, $230 million (or $383 million) if respite is used, and $317 million (or $528 million) if long stay hospital is used. Hence, the rate of carer withdrawal will also determine the costs associated with carer withdrawal.

Carer withdrawal is often associated with inadequate provision of supports in people's homes. Depending on the ability of systems to avoid crises and implement appropriate supports, the withdrawal of informal care is likely to be a significant factor in determining future costs. These costs represent a growth in needs above those already unmet.

The high costs involved with crises can impede funding for other support services. This is because when faced with budget constraints, systems have little choice but to give priority to families in crisis. The lack of funding for supports (such as early intervention and respite programs) further increases the number of families falling into crisis, hence leading to an ongoing causal relationship between respite shortages and crises. In effect, the carer withdrawal rate estimated above (0.2 per cent of the potential population) would rise over time. A stark representation of this problem was modelled for the NSW Government by

PWC (2011): it assumes that all crises are met with supported accommodation, but the disability system does not receive *any* funding increases (box 2.3). Disability funding was subsequently increased in NSW through the reforms of Stronger Together 2, which would have changed the trajectory significantly from that modelled in box 2.3.

Box 2.4   **Hypothetical projections of underfunding, rationing, and crisis based support**

One of the main responses to underfunding is to prioritise between areas of support. This involves some people missing out on supports (rationing), while resources are focused on those most in need (i.e. families in crisis). This is not a sustainable approach to the provision and management of supports.

The figure below shows what could happen if real funding were kept constant (as a proportion of real GDP in that jurisdiction), and demand for supported accommodation were to increase at a rate modelled by PricewaterhouseCoopers (unpublished analysis). Due to the increasing number of families in crisis, more resources would be diverted towards more costly crisis supports and away from other less costly areas of support. As a result, fewer and fewer people would receive supports over time.
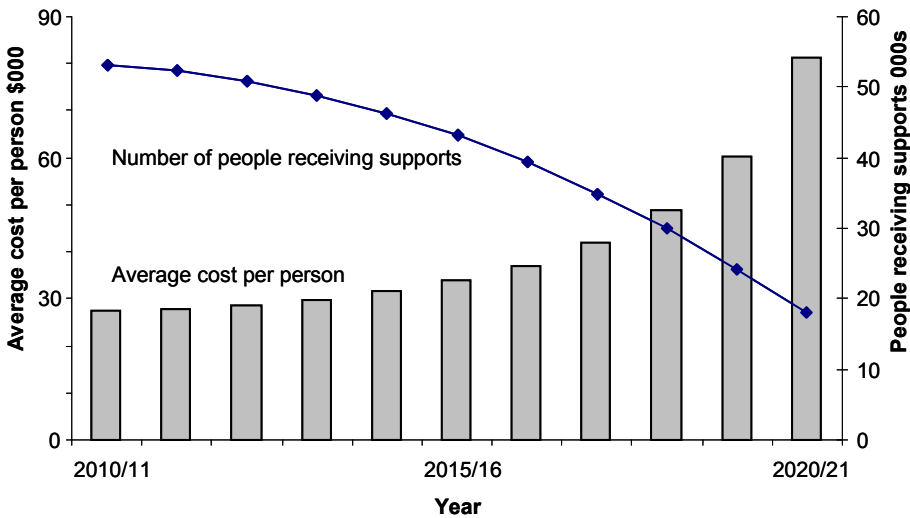
Source: Figure adapted from PWC unpublished analysis.

2.5   The need for structural change

The disability support system is inefficient. Structural elements, legacy practices and unresponsiveness constrain an already underfunded system, contributing directly or indirectly to unmet need. The evidence suggests that often, funding

increases alone would not be sufficient reform. Rather, widespread structural change would be required.

This section attempts to outline the major inefficiencies affecting the sector, which stem from structural and historical elements and are not criticisms of individual agencies or governments. The term 'inefficiencies' in the context of this section refers to a wide range of flaws in the current disability support system.

Jurisdictional borders

With the exception of employment services, the majority of disability support services are governed by states and territories. This means that regulation, budget management and delivery management occurs at the state/ territory level. This has potential advantages for governance such as:

- closer contact with families and the sector. This should facilitate coordination and feedback when making policy changes or running pilot programs

- greater potential for coordination of policy in other areas of social services such as public transport or education

- the ability to innovate without a one size fits all approach.

A reality of the current system is that each jurisdiction has its own budget limitations, and accordingly must set its own:

- eligibility criteria

- assessment tools and procedures

- conditions of service provision

- the suite of services, aids and appliances on offer

The duplication of these factors across jurisdictions means that the portability of services, funding, aids and appliances is not guaranteed. Effectively, transaction costs are heightened by the uncertainty at jurisdictional borders. People can spend considerable amounts of effort to secure supports, only to find that they could lose these supports by crossing state and territory borders. This leads to barriers to economic and social participation for people with disability, as described by several participants (box 2.4).

> **Box 2.5   The lack of portability is a real barrier in people's lives**
>
> Several participants noted their personal experience of barriers to interstate portability of supports.
>
> > Currently, if you are receiving services in one state and have to move interstate for any reason, you automatically go to the back of the queue. When you have waited for many years to gain access to services, you are basically trapped, especially if your son/daughter is part of a block-funded service. If, as a parent, you have the misfortune to fall ill and need to move or simply wish to retire interstate, you are in the invidious position of losing everything you have achieved over many years. The states must be able to reach some agreement over portability. We are one nation after all. (M. Dewar, sub. 317, p. 2)
> >
> > I have previously sought employment interstate to maximise my career development and opportunities. However, this was prevented by incompatible state-based disability support arrangements and an inability to transfer my current state-based disability equipment (wheelchairs, etc) and support hours to other Australian states. As a person with high support needs, I would have been unable to cover the costs of this support and equipment from my own income. This situation prevents me from moving interstate to take up career opportunities as financially I would be worse off than being on the DSP. (B. Lawson, sub. 103, pp. 2–3)
>
> A lack of portability is not just an issue for people moving between jurisdictions. People are also concerned about losing their supports when moving between support programs.
>
> > A significant issue facing people with blindness or vision impairment is the barrier preventing the transfer of equipment when they are undergoing periods of transition, such as primary school to high school, and school to work or post-school activities. When moving between different programs and/or funding environments, it is inefficient, unproductive and inequitable to demand that a person return customized and familiar equipment, and then go on a waiting list for new equipment (or simply have to manage without it). (Australian Blindness Forum, sub. 438, p. 11).

Furthermore, since case management systems do not span jurisdictional lines, there is little direct management of people moving interstate. There are currently efforts to improve the management of portability within the context of diverse systems, mainly in the form of greater information provision (box 2.5).

This is not to say that some instances of national coordination have not been possible within the current governance model. Some good examples include the Australian Disability Parking Scheme and the National Companion Card Scheme, which both include nationally uniform minimum arrangements, while still being administered by the relevant state and territory authorities. However, these represent coordinated efforts on particular issues, which are relatively simple when compared with the more extensive full suite of services. The harmonisation of parking permits alone took several years before a national model was agreed.

| Box 2.6 | **Current initiatives on portability of aids and appliances** |

More consistent access to aids and equipment is one of the national reform priorities agreed to by Community and Disability Services Ministers under the National Disability Agreement. As part of this initiative, the Commonwealth is working with state and territory governments to release an information sheet in 2011 for people with disability. The information sheet will help ensure consistent application of existing portability arrangements between states and territories and ensure individuals have continuity of access to equipment they need when moving interstate.

It is proposed that when people with disability move interstate, the guidelines of the equipment scheme of the receiving state or territory will apply, including equipment available and any co-payments, eligibility, prioritisation, environmental need and waiting list conditions. The key principle will be that people should contact their current equipment scheme prior to moving to confirm what equipment can be taken.

Source: Correspondence with FaHCSIA.

Navigating the maze

Fragmentation is also evident within jurisdictions, as services are delivered by a multitude of programs that are funded and managed separately. This has implications for how efficiently the service delivery system can operate, and how complex it may be for users to navigate. Issues of governance structure are discussed more fully in chapter 9, while service delivery is discussed in chapter 10.

Due to the lack of structural coordination, improvements that are attempted within the current system often take the form of isolated programs and pilots. This not only adds to the complexity of the system, but it also lacks certainty over which programs will continue to receive funding in the future. Moreover, there is a lack of a coordinated effort to ensure programs do not have excessive overlap, or have gaps between them.

People often deal with a number of programs and agencies to receive a full suite of services. For instance, an audit of NSW respite services found:

> The absence of a coherent system across the sector and barriers to the exchange of information between and within disability providers can cause delay. It also results in carers making multiple applications with, and undergoing multiple assessments from, a range of providers. (NSW Auditor General 2010, p. 4)

Figure 2.13 below shows how complicated the arrangements can be for respite care alone, which comprises one small section of disability support. The experience is similar for other types of support (sub. 301).

Figure 2.11 **Respite arrangements in NSW**

RESPITE FUNDING LANDSCAPE

Applicable to NSW
Copywrited to Interchange Respite Care NSW c2008

COMMONWEALTH

Dept. of Health & Ageing

Families, Housing, Community Services, & Indigenous Affairs

Veteran Affairs

HACC   Aged Care   NRCP

NGO's

CRC

National Respite Development Fund

Employed Carers
O'night for Older Carers

Residential   CACP
EACH
EACH Dementia

o'night respite

cottages. 1 in every HACC region

60% Federal
40% State

MHR   RCYPSD   RYC

NGO's

National Disability Agreement (NDA)
(formerly the CSTDA)

incorporating the former programs of:

Respite for Older Carers of Children with a Disability (ROCCDP)
Older Carers Bilateral Agreement
The Disability Assistance Program   (DAP)
Respite Capacity Building Contracts
Support Co-ordination

Veterans Home Care

STATE

Department of Ageing Disability and Home Care

Department's Respite Houses

HACC

Stronger Together

Flexible Respite;   Centre Based Respite   Teen Time

Disability Services

Life Choices

Active Ageing

Ageing Parent Carers Respite

Code: NRCP = National Respite for Carers Program;   HACC = Home & Community Care;   MHR = Mental Health Respite;
RCYPSD = Respite for Carers of Young People with Severe Disabilities; RYC = Respite for Young Carers; ROCCDP = Respite Older Carers Children with
Disabilities Program; DAP = Disability Assistance Program; CSTDA = Commonwealth States & Territories Disability Agreement;
CRC = Carer Respite Centres;   NGO = Non-Government Organisations;   CACP = Community Aged Care Packages;   EACH = Extended Aged Care at Home

Data source: Interchange Respite Care NSW

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Not surprisingly, the system as a whole is often referred to as a maze. Often, there is no one to help navigate the system and as a result it is often difficult for people to determine what services exist, let alone whether they are appropriate or of high quality. Case management services can help in this navigation, however they are not always available (see chapter 10). This creates large transaction costs, borne by the people who access the system. Worse still, they are borne not only by people receiving support, but also people still seeking support.

Gaining access to services is often a process of trial and error with large amounts of time spent researching and filling applications only to find out that a service is either not appropriate or not available due to limited funding.

> Whilst living in rural Victoria my daughter and younger son were assessed for services and support, by DHS, three times in six months. Each assessment consisted of twenty five pages to fill in (twice) and each time there was a change of coordinator thus requiring the next assessment, form filling in (twice) and still no services or support. (sub. 380, p. 1)

> I had a wedding and I needed someone to look after my son so I could attend. I firstly rang [the local council]. They came out to the house… and interviewed me for two hours. Result was that yes I was eligible but they could only offer 2.5 hours. They advised me to ring Villa Maria or Yooralla. Both agencies requested an interview in the home. Two workers from each agency came to the house with car and interviewed me for two hours plus. After six hours of interviewing, I was placed on several waiting lists but got no respite time. For the cost of that process I could have hired someone myself to look after my son for at least a week. Two years later I am still on waiting lists for two of the aforementioned agencies (sub. 90, p. 4).

Thus, the duplication of assessment combined with general under-provision of services can mean that people receive more assessment than service.

People with rare conditions may also find further hardship in accessing information or supports. Eligibility for programs and trials is often highly rationed and, at times, medical conditions are used as eligibility criteria. An example would be the Better Start program:

> … eligible children diagnosed with a sight or hearing impairment, Down syndrome, cerebral palsy or Fragile X syndrome will have access to funding and Medicare rebates under the initiative (FaHCSIA 2010a).

On these grounds, people with less common conditions have noted difficulty in receiving information and support (see subs. 9, 319, 414, 455, DR699 for example). In many cases, the level of care received will depend on whether or not a person qualifies for a particular program.

The importance of choice

Choice is important in many aspects of life: choice about jobs, where to live, how to spend one's time and what services to buy. In the latter area, 'consumer' choice is a way for people to signal what they value. However, choice is generally not a common aspect of the disability support system — many decisions are made by support workers, service providers and by governments. Choice in the disability system is discussed more fully in chapter 8.

Allowing people control over the decisions that affect their lives is important in its own right. Consumer choice also generally leads to more efficient outcomes, as people are usually better placed to know what would meet their needs than service providers — as one participant noted, a support provided at the wrong time is like 'sending a bald man to a barber'. Consumer choice can also give service providers the incentive to innovate and provide higher quality services. In these ways, the lack of choice adds to inefficiency in the current disability support system.

The personal importance of choice

The concept of choice is central to the lives of many people with disability. It relates to the control they have over aspects of everyday life, such as when to go to bed and what to eat. The importance of these decisions are particularly apparent in the context of personal care.

> Having a disability is less about physical limitations, and more to do with a lack of choice. Everything in my life is very clinical, get up at this time, eat this time, have a shower at this time, go to bed at this time. Whilst I acknowledge this is and will always be the reality for my entire life a minimal [amount] of funding would allow me a great deal more freedom than I have access to now. The autonomy that a few more hours a week would give me should not be underestimated. (sub. 346, p. 1)

Even small degrees of decision-making power can lead to large improvements to a person's quality of life. Increasing the degree of choice available to people may not even require more funding — in some cases, it can lead to more efficient choices which can reduce costs.

Block funding and consumer sovereignty

In the current system, the capacity for choice relates closely to the method of government funding of support services. Block funding is the process by which governments directly fund service providers with lump sum payments. These payments are then used by the providers to deliver support services. The alternative is 'individualised' or 'self directed' funding, where government funds can be given

directly to service users to then purchase services. This would mean service providers receive funding only after being approached (chosen) by the service user. Various models are possible under these two broad descriptions, and it is possible for funding schemes to have elements of both approaches (chapter 8).

Block funding is currently the dominant form of funding model, although some jurisdictions have provided more individualised approaches (particularly Western Australia and Victoria). The potential advantages of a block funding arrangement include:

- service providers are known to government, and potentially more easily regulated

- certainty of funding for service providers, and more scope for large asset grants.

Participants have raised major concerns about several aspects of block funding. It is not consistent with consumer choice and can lead to weaker market competition (chapters 8 and 10 respectively).

Where governments purchase services from providers (through block finding), it creates incentives for providers to 'please' governments, and weaker incentives to please service users, since the government agency will decide whether to renew funding.

Block funding arrangements offer less scope for service users to take their 'portion' of funding and go to a new provider. This means that in the event of poor quality service provision, there may be no scope for service users to replace their provider.

> HACC funding is provided to the care service, out of which my funding is provided, in my case it goes to RCHCS. I have been supported by many years by such service. There have been times where I have had to suffer whatever this service provided or otherwise, quality care or otherwise, the ups and downs. There was no option, whatever this service provided, good and bad, and all in between, I had to wear it; I was in effect held hostage because I dare not depart for fear of losing funding support.

> There were times I became despondent. I do not intend to illustrate specific instances of bad care or good care. The fact is, I was held virtual hostage to one service because of HACC being the nature it is, not supporting portability. (sub. 120, p. 1)

Furthermore, an improvement in consumer choice may benefit service outcomes due to the natural asymmetry of information — service users generally know their preferences.

Opportunities for efficiency gains

Some of the most significant inefficiencies in the disability support system are clear opportunities to improve service outcomes, affordability, and the quality of life for service users. While not exhaustive, the issues covered in this section are indicative of the kind of efficiency gains that could be achieved with a coordinated reform agenda.

Timely support that is forward looking

The current disability system does not generally account for people's future needs. This is not surprising given that it is difficult for the system to provide enough support to even meet current needs. However, there are potentially large efficiency gains if assessments were forward looking (discussed in chapter 5) and the delivery of services were timely.

The timeliness of support can, for example, have a direct influence on the effectiveness of the support. In some cases, it can reduce or prevent further injury or ill health.

> Long delays in service provision often result in avoidable ill health which results in unnecessary presentations with trauma and other illness to tertiary hospital emergency departments (with or without an associated admission). Furthermore, long delays result in reduced independence and participation in the community and associated feelings of depression and helplessness. (Friedreich Ataxia Clinic, sub. 423, p. 3)

People with disability and their families are sometimes able to contribute to the costs of supports, either in part or in full, in order to reduce waiting times. However, this is often discouraged by poor incentives or uncertainty regarding their eligibility for subsequent reimbursements.

> In some cases public patients travel interstate and or visit a private provider and pay for the cost of the [prosthetic] limb up to $20 000 out of their own funds to avoid waiting times even though they are eligible for government funded prosthetics. In cases such as this individuals forego any opportunity for funding support. (Limbs 4 Life, sub. 301, p. 12)

In cases such as this, there are strong grounds for a greater capacity for people to augment existing (reasonable) funding with their own money to buy a more preferred aid or other support.

In some instances, timely supports may potentially save money from the disability services budget over the longer term. A good example of this relates to pressure ulcers:

While not all pressure ulcers can be prevented, many are caused by inadequate equipment, notably seating and mattresses. Providing the correct pressure relieving equipment is not optional for the individual, however the waiting times and limits on types of products make it so.

It is common for people with MS with pressure ulcers unable to get the right equipment to spend up to 6 months in hospital recovering. Such a stay costs in the vicinity of $80-100 000, and can result in increased community care costs and carer burden upon discharge. The purchase of an $8000 mattress and good seating in addition to self management support can prevent such episodes. Saving just one hospital admission per lifetime for a person at risk of pressure ulcers justifies the investment. (National Aids and Equipment Reform Alliance, sub. 530, p. 7)

Often these kinds of potential savings are not realised due to the separation between the service area that bears the cost and the service area that would benefit from the saving. At other times, aids and appliances are not available to take advantage of these benefits.

Supporting carers' employment

There is considerable potential to encourage carers' employment. Any improvements in care and respite support would clearly improve the ability of carers to participate in the workforce. However, a more direct approach may also help to ensure that incentives are not misaligned. For instance, high effective marginal tax rates, as well as inflexibilities regarding current transfer payments, may reduce the incentive to participate in paid work:

There is no capacity for dividing Carer Payment as an incentive to sharing the care between more than one person; income and assets tests are based on couple rather than individual income.

For Carer Payment recipients, the 25 hour maximum work, care or study and travel rule may result in a reluctance to loose income security and health card benefits. (Carers Victoria, sub. 475, p. 23)

Similar issues regarding other transfer payments, such as the Disability Support Pension (which supports around 793 000 people), may deliver large and widespread efficiency gains (chapters 6, appendix K). The benefits of supporting carers' employment are also discussed more fully in chapter 20.

Improving data systems

Several areas of governance, regulation and research could benefit from greater collection and availability of data. Currently, the availability of data in the disability

sector is not sufficient, especially given its importance to efficient management and policy development. As characterised by the Insurance Council of Australia:

> … there is a lack of robust actuarial data in regards to the cost of care. There is also a lack of data concerning the prevalence of the various disabilities potentially covered by the scheme. (Insurance Council of Australia, sub. 553, p. 15)

Data in all areas of disability could be improved, particularly data on the experiences and outcomes of service users, on unmet need, and on the costs and efficiency of providers (subs. 270, 237, 371, 571). The current deficiencies in data collection are discussed fully in chapter 10.

The scope for data collection has sometimes been reduced by concerns about people's privacy. Under the Home and Community Care (HACC) scheme, the emphasis on *needs based* supports involves a decision not to collect information regarding the cause of disability. This protects from the potential for support allocation to become *condition based*, but at the same time limits the potential for management, research and policy development.

Often, the absence of data collection is not a deliberate decision. Rather, it is a continuation of historical practice. For instance, with regard to NSW respite:

> AHDC does not maintain information on how NGOs prioritise clients and allocate respite. Under the funding agreements established before 2006, NGO's determined who they give respite to and how much they give. (NSW Auditor General 2010, p. 13)

Clearly, the lack of data systems has important implications for transparency and efficient management. As a result, NSW ADHC is to implement an online booking system for respite in 2011, which will 'consider client mix and staffing requirements to maximise occupancy and ensure quality of care' (NSW Auditor General 2010, p. 13).

Moreover, the current system structure does not lend itself to the collection of data across different support programs, different regions or different jurisdictions. A more coordinated delivery system, or perhaps better coordination between current administrative systems, could lead to more comparable and valuable data. The possible role of the NDIS in data collection is also discussed in chapter 10.

2.6 Conclusions

People with disability and their families often experience severe social, financial and personal disadvantage over their whole lives. While some of this is due to disability in the first place, much is also due to the dysfunctional nature of the

'system' providing them with support. The problems in the system appear to be so widespread and severe, that effective large scale reform is justified.

One partial solution would be additional funding to address the high level of unmet need, but it is clear that underfunding is not the only contributor to the poor outcomes of the system. Several systemic inefficiencies are also responsible for the lack of support, as well as constraining people's decisions on where (and how) to live. The inefficiencies often stem from structural elements of the system. Broad structural change is as important as adequate funding in improving outcomes for people with a disability and their families.

3   Who is the NDIS for?

Key points

- The Commission proposes that the NDIS have three main functions and associated with them, three different populations of 'customers':
  - providing insurance against the risk of acquiring significant disability and promoting opportunities for people with a disability and creating awareness of the issues that affect people with a disability
  - providing information and referral services
  - funding individualised supports.

- All Australians would be potential beneficiaries of the first tier of services, while the second tier is targeted at all people with, or affected by disability. The third tier is targeted at people with support needs that would otherwise not be reasonably met without taxpayer funding, and that are not more appropriately met by other systems.

- In many cases, the NDIA would work collaboratively with the community sector to meet the needs of individuals, including through community capacity building.

- A person receiving funded support from the NDIS would have a disability that is, or is likely to be, permanent. The definition of 'permanence' would include people with long-term functional limitations who may only need episodic support. In addition, people would have to meet at least one of the following conditions. They would:
  - have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support (3a). For example, this would include people who need support in toileting, who require significant support for mobility and/or communication or who require supports in self-management and planning to live successfully in the community (such as those with significant and enduring psychiatric disabilities or those with intellectual disabilities)
  - be in an early intervention group (3b). This would encompass people for whom there is good evidence that the intervention would be safe, cost-effective and significantly improve outcomes. This would include those for whom interventions would improve functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments) or delay or lessen a decline in functioning. This might include people with newly diagnosed degenerative diseases, such as Multiple Sclerosis and Parkinson's disease.

- The Commission estimates that these criteria would cover around 411 000 people. There would also be scope to include people who have large identifiable benefits from support that would otherwise not be realised (3c).

3.1   Introduction

The Australian Government is committed to enhancing the quality of life and increasing economic and social participation of people with a disability. It is against this backdrop that the Commission has considered the functions and potential users of a National Disability Insurance Scheme (NDIS).

People with a disability have different needs and aspirations and encounter different barriers. So different approaches for realising participation and quality of life goals are appropriate for different people. More inclusive social attitudes, accessible buildings and transport, disability-inclusive education and employment policies, and addressing deficiencies in the health care system, will assist many people with disabilities. They may be all that is needed by many people with less restrictive disabilities.

For others, information and referral services or broader community support (including by not-for-profit organisations) may substantially increase their wellbeing. For a smaller group of people, often those with more severe disabilities, individually tailored, funded supports may be the key to increased social participation and an improved quality of life.

Given this diversity, the Commission proposes that the NDIS have a number of functions, each aimed at achieving better outcomes for different groups of people.

3.2   A tiered approach to providing supports

The Commission considers that the NDIS should have three main functions, and associated with them, three different populations of 'customers' and costs (with the costs inversely related to the size of the populations concerned) (figure 3.1).

Tier 1: Everyone

In one sense, the NDIS is for every Australian, since it provides insurance against the costs of support in the event that they acquire a significant disability. Insurance is valuable, even if someone does not make a claim. (Many people for example, insure their house against loss. Most never make a claim, nor do they expect to, but they willingly pay premiums each year to cover the risk). People in the community could take comfort in knowing that a strong support system exists for their loved ones if they were ever to need it.

As well as offering insurance, the NDIS would seek to minimise the impacts of disability for all Australians. This includes:

- promoting opportunities for people with a disability

- creating awareness within the general community of the issues that affect people with a disability and

- drawing on its data and research capabilities to engage with other agencies to improve public health and safety.

In the awareness area for example, the NDIS could recognise and encourage employment of people with a disability and try more generally to combat stereotypes that reduce opportunity. The potential benefits of a more inclusive society extend to the wider community. While the 'tier 1' function would involve the whole community (chapter 4), the associated costs would be small and in some cases would come from existing resources.

Tier 2: People with, or affected by, disability

Anyone with, or affected by, disability could approach the NDIS for information and referral services (as distinct from individually tailored funding). This would include providing linkages with relevant services for which the NDIS was not directly responsible, such as mainstream services and community support groups. The scheme would also provide general information about the most effective care and support options. However, it will be critical to provide any referral and information services cost-effectively, with strict cost limits. As in tier 1, the population of potential 'customers' would be very high, but the overall costs would not be large.

Tier 3: People with disability for whom NDIS-funded, individualised supports would be appropriate

Individualised supports, provided under tier 3, would be targeted at people with ongoing support needs that would otherwise not be reasonably met without taxpayer-funded services. The extent of the funded support would depend on:

- assessment criteria that would identify whether there was a need for NDIS-funded support

- given the existence of sufficient needs, a careful assessment process that would determine the nature and level of support needs, and the individual budget required to fund those supports.

These assessment processes would not be ad hoc, but would reflect the framework for categorising support need (the International Classification of Functioning, Disability and Health) and would provide objective assessment of the types of needs that require funded support. (The exact assessment arrangements and their underlying framework are addressed in chapter 7.)

The number of people accessing funded supports would be a small fraction of those people who access (or are the targets of) tiers 1 and 2. Even so, this tier would account for the majority of scheme costs.

Figure 3.1   **The three tiers of the National Disability Insurance Scheme**

Tier 1

Social participation, minimising the impact of disability, insurance (target = Australian population) **22.5 million**

Tier 2

Information, referral, web services, and community engagement. Target = all people with disabilities (**4 million**) and their primary carers (**800 000**)

Tier 3

People receiving funding support from the NDIS Target = people aged 0 to the pension age with sufficient needs for disability support and early intervention

(3a) People with intellectual, physical, sensory, or psychiatric disabilities who have significantly reduced functioning (330 000)

(3b) Early intervention group (80 000)

(3c) Others optimally supported (unknown, but modest)

(3d) Funded support for some carers

Total = around 410 000

This chapter considers a range of practical issues that affect how the three tiers of the NDIS would operate. Section 3.3 considers the role of the scheme in respect of minimising the impacts of disability. Section 3.4 outlines the scheme's role in assisting individuals to navigate the spectrum of mainstream and specialist services both public and private.

The remainder of the chapter is dedicated to the design of tier 3 — the provision of NDIS-funded, individualised supports. Accounting for a significant majority of the scheme's budget, the design of tier 3 will be particularly important and will need to canvass:

- assessment criteria for funded support, including how to ensure that the scheme takes full advantage of opportunities for cost-effective early interventions (section 3.5)

- the role of the NDIS compared with other government services used by people with disability, such as those for aged, health, mental health and palliative care and the proposed National Injury Insurance Scheme (section 3.6)

- how many people might access individualised supports (section 3.7)

- practical issues that affect the transition to a new scheme (section 3.8).

The wider community will play a vital role across all tiers of the NDIS and across a wide range of activities, from specialised service provision to community participation and inclusion. Not-for-profit organisations, in particular, will make a valuable contribution in terms of community engagement, common sense and grass roots contact. For example, they will be able to harness philanthropic fund-raising, the efforts and creativity of volunteers, and community networks and connections to freely provide activities of benefit to people with disabilities. The role of not-for-profit organisations and others in the community is discussed further in chapter 4.

The more comprehensive assessment process that would determine the nature and level of supports, and the individual budget required to fund those supports is covered in chapter 7.

3.3 Tier 1 — minimising the impacts of disability

Public campaigns that promote opportunities for people with disability have the potential to benefit the entire Australian population. Currently, several bodies including government departments and agencies, and not-for-profit organisations carry out broad disability awareness campaigns. The NDIS would not duplicate the campaigns provided elsewhere. Rather, where appropriate, it would provide information to the government and not-for-profit organisations running such campaigns. In cases where it had a clear advantage in doing so, the NDIS would directly fund and carry out such programs. This would constitute a very small proportion of the scheme's budget.

The NDIS is likely to be a valuable vantage point for both widespread general campaigns and more targeted messages on awareness and inclusion. Given its connection with a wide range of people with a disability, the scheme would be well placed to seek information and feedback on people's experiences of social inclusion. It may then be possible for the NDIS to direct such campaigns to areas where problems of discrimination are common or to find and promote examples where inclusion has clear beneficial outcomes for both parties. In practice, this will involve working closely with the community sector (chapter 4). It might also

involve working with other agencies such as the Australian Human Rights Commission.

The NDIS would also be well placed to recognise and encourage the inclusive practices and initiatives of private enterprise. The NDIS could, for example, publicise examples of inclusive, non-discriminatory environments and their outcomes. This work may involve coordination with the Department of Education, Employment and Workplace Relations, as they will continue to deliver most disability employment supports.

Awareness of the scheme and its staged roll out

The general community, people with disabilities and their carers, and service providers will need to be informed about the new scheme. A public information campaign will need to occur before the commencement of the scheme. Given that the NDIS will effectively provide insurance cover to everyone, broad-based awareness of the scheme will be important. People seeking information, referrals or funded assistance, will need to know what services are available from the NDIS. The NDIS should work with disability organisations to promulgate messages about the scheme through their own networks. Information sessions held for stakeholder groups would inform them of the new scheme and the staged rollout. Information would be made available to support groups and through a range of publications, free media and contact points such as Post Offices, Centrelink offices, Medicare offices, medical practices and health centres.

Participants were generally supportive of the NDIS having an awareness-raising role:

> Awareness campaigns regarding disability in Australia to date have not been conducted from a particularly rigorous evidence base or included: a strong impact evaluation framework; a close connection with other policy tools; or a sufficient resource base for large scale and sustained effort. Institutions administering an NDIS or similar scheme would be expected to be in a position to do better in each of these respects (directly and through funding of and co-operation with activity by disability organisations and other relevant government and non-government organisations). (Australian Human Rights Commission, sub. 72 p. 20)

> The Scheme could conduct public awareness activities designed to provide information relating to the availability, benefits, appropriateness, and costs of care and support. (Royal Australasian College of Physicians, sub. 506, p. 8)

3.4 Tier 2 — ensuring appropriate support from any system

The current system of disability services has often been described as a maze (notably, the Association for Children with Disability's guide to services and support is entitled 'Through the Maze'). Even within a jurisdiction, people deal with multiple programs and agencies, few of which coordinate or share information (chapter 2).

Bringing specialist disability services under a single umbrella — the NDIS — will go a long way to streamlining the system. But regardless of the size and scope of the NDIS, it will always be just one part of a broader suite of services that are potentially relevant to people with a disability. There will, for example, continue to be a need for mainstream services in such areas as health, housing, education, transport and employment. The community and not-for-profit organisations will also continue to play a valuable role (chapter 4). As such, information and referral services and broader support are likely to be of great value to people with disabilities, their families and carers.

For all the services for which the NDIS is not directly responsible, the Commission proposes that the scheme provide a referral service, so that people can more easily connect with appropriate services. Referrals would take account of people's needs and locality (though would not be qualified the same way that a GP's referral would). One aspect of this — discussed in chapter 10 — is a centralised electronic database of service providers that would indicate the ranges of products and services, their availability and links to measures of performance and quality (recommendation 10.3).

The scheme should also provide general information about specific disabilities including their expected impacts and the most effective care and support options. Some participants in this inquiry commented that they did not have adequate information on which to base decisions. Others reported spending considerable time and effort undertaking their own research. As one participant in the Canberra hearings observed:

> In the weeks after diagnosis, families are asked to make these massive clinical decisions … families have to come to grips with all of this material and try and make these decisions for themselves without being given — you know, they don't have the skills to read the research and understand what it's about and yet that's the only way that they have any chance of actually dealing with this. So what we need to do is actually have centres that actually offer all of the reasonable options and give parents the real information in an unbiased way. People who are not involved in particular

ideologies about how to deal with disability need to be actually giving the information to families and then the families can make the choices. (Bob Buckley, trans., p. 377)

The Commission considers that information and referral processes should be available to anyone with, or affected by, disability. In the main, participants supported the scheme providing referral and information services to a broad group of individuals:

> IDEAS is pleased to see the high level acknowledgement (described as one of the three main functions of the NDIS) of the role of information in determining the quality of life for people. (IDEAS, sub. DR939, p. 5)

> We particularly support the notion of 'warm referral' in that people who are not eligible for the NDIS are actively connected in to services outside of the NDIS system. (Arthritis Victoria, sub. DR736, p. 5)

While there was some consensus among participants that the NDIS should have a role in awareness raising and in providing information and referral services, some participants were concerned about how this might work in practice. A number of participants were keen for the Commission to spell out more clearly how the NDIS would work with the community sector, particularly not-for-profit organisations, to achieve these aims. Not-for-profit organisations have considerable experience in these areas and it will be crucial for the NDIS to build upon, rather than displace, their valuable efforts. The Commission discusses this issue more fully in the following chapter.

A maze with extra barriers

Finding the most appropriate services, support groups or organisations is often made more complicated by cultural barriers. This was noted in both the Shut Out report (Australian Government 2009a) and in submissions to this inquiry:

> For families from different ethnic backgrounds, the issues are compounded. Many people from different ethnic backgrounds are not aware of their rights — to benefits, services, supports or respite. Due to the isolation felt by many carers and people with a disability from different ethnic backgrounds, language barriers or low levels of English proficiency still mean that these families do not access information and are unaware of what is available. (Australian Government 2009a p. 57)

> [A] targeted promotion strategy aimed at people from NESB [Non-English Speaking Backgrounds] with disability is needed to ensure that awareness of available support and programs is increased. This is particularly necessary when the new scheme is introduced. (Multicultural Disability Advocacy Association of NSW, sub. 604, p. 18)

As highlighted in a number of submissions, the provision of information and referral services should take account of cultural and lingual diversity (see, for

example, subs. 390, DR926 and DR679). The scheme could do this in a variety of ways, for example, by working with existing community liaisons, particularly in non-English speaking and Indigenous communities. The importance of these contacts would be paramount during the implementation of the NDIS, as well as any other time of service and scheme reform.

3.5 Tier 3 — individually tailored funded supports

In its terms of reference for this inquiry, the Government makes clear that it does not intend for the scheme to address the care and support needs of all individuals, but rather should focus on those where such needs are greatest.

Such a focus is consistent with the fact that risk pooling through insurance tends to focus on higher-cost, less frequent events, like early death, serious injury and property loss. Many families and individuals have an ability to bear and finance some risks themselves, and this is often a more efficient and flexible way of addressing smaller and more common risks than formal risk pooling through insurance.

Of the 3.8 million people with a disability living in households, some 41 per cent reported that they do not require assistance (SDAC unpublished). For others, the supports provided under tiers 1 and 2 of the NDIS will be all that is needed. To that extent, it is not credible that the true potential population for individually tailored, NDIS-funded supports amounts to 4 million — though as discussed later, it could well exceed the existing population of people receiving publicly-funded services.

Moreover, the Government has indicated that it intends for the scheme to cover those with *long-term* care and support needs. The terms of reference for the inquiry direct the Commission to assess an approach which 'provides long-term essential care and support for eligible people … [and] includes a coordinated package of care services available for a person's lifetime'.

Participant's expressed mixed views on whether the provision of individualised, funded supports, under tier 3 of the scheme, should be targeted at those with ongoing and significant disability or be available to all people with a disability (box 3.1).

Box 3.1   The scope of tier 3 supports

Some participants considered that the provision of individualised, funded support should extend to all individuals with a disability:

> DANA does not support the restrictions to eligibility for individualised supports that are contained in this recommendation … We support Tier 3 of the Scheme being available to all those people with disabilities who need specialist disability supports to live their lives and participate and be included in society on an equal basis with others. (DANA, sub. DR1010, p. 3).

> The proposed NDIS does not adequately capture all those who could benefit from long term support … The NDIS should broaden eligibility to support the "equal right of all persons with disabilities to live in the community, with choices equal to others" and "take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community" as per Article 19 CRPD. (Australian Federation of Disability Organisations, sub. DR982, p. 6)

> … [Consistent] with Novita's verbal submission to the Commission, we urge that all children and young people with a disability should be deemed eligible. (sub. DR936, p. 5)

While other participants saw merit in targeting tier 3 supports to those with significant, long-term disabilities:

> Arthritis Victoria agrees that people with a moderate or mild core activity restriction will generally receive appropriate support from the NDIS through Tier 1 and Tier 2 services. (Arthritis Victoria, sub. DR736, p. 3)

> The MHCA agrees that any long term disability care and support scheme must focus on those people with a disability most in need of services and that under the terms of the Inquiry, the target group for the NDIS will be a subset of the broader community of people with a disability. The MHCA also understands the Commission's decision to limit this group to those people who require considerable support. The solution of a tiered system for the NDIS, providing supports to three different populations of people through the strategic approach is also endorsed as a good way of providing services … (Mental Health Council of Australia, sub. DR961, p. 11)

> While the three tier structure proposed by the Productivity Commission means that more people would be eligible to benefit from the scheme we agree that those individuals falling into Tier 3 would account for the bulk of the funding. (Valued Independent People, sub. DR932, p. 2)

The Commission is of the strong view that (in contrast to the other tiers of the NDIS), the delivery of individualised, funded support under tier 3 of the scheme should be targeted at people with significant and ongoing support needs that:

- would otherwise not be reasonably met without NDIS-funded services, and

- are not more appropriately met by other systems, like the National Injury Insurance Scheme or health care.

The question of whether the support needs of some individuals are best addressed by other systems is examined in the following section. The remainder of this section

grapples with how to translate the first notion into workable and 'balanced' assessment criteria.

On the one hand, the assessment criteria will need to be clear and precise. If the NDIS used wide or vague criteria for individualised, funded support it would create inconsistencies, divert resources away from greatest need, undermine community acceptance of adequate public funding and threaten scheme sustainability. But, on the other hand, the criteria should not be unduly prescriptive, such that individuals who did not neatly 'slot' into categories missed out on much needed supports.

Using severe and profound as a basis

The terms of reference for the inquiry indicates that the scheme is broadly intended to address the long-term care and support needs of individuals with a 'severe and profound' disability. However, it does not indicate what criteria individuals would need to meet in order to be regarded as having such a disability. That said, the ABS employs these terms in its Survey of Disability, Ageing and Carers (SDAC), as follows:

- *Profound core activity limitation*: where a person is unable to do, or always needs help with, a core-activity task (communication, mobility or self-care).

- *Severe core activity limitation*: where a person sometimes needs help with a core-activity task; has difficulty understanding or being understood by family or friends; or can communicate more easily using sign language or other non-spoken forms of communication.

While the terms severe and profound, as used by the ABS, are suggestive of high-level disabilities, this is not necessarily the case. There are many people *defined* as having disabilities, but for whom the NDIS is not needed. For example, a person whose periodic back pain sometimes prevents them from picking up an object from the floor without assistance, or a person with asthma who could not communicate while having an attack are all defined as having a disability using current disability classification systems.

Indeed, these individuals would be defined as having a severe disability, since they 'sometimes' need help with 'core' mobility, communication or self-care activities. But these individuals would not typically need (or want) funded supports. While the limitations they experience relate to 'core activities', given their nature, frequency and intensity, they could nonetheless be self-managed (perhaps assisted by family or friends), or addressed by other publicly funded services such as those provided by the health sector.

This does not mean that assessment criteria for the provision of individualised supports should disregard the notion of core activity limitations. But rather, that existing ABS definitions are intended for classification purposes and are unlikely to equate with people's usual understanding of severe and profound or be an appropriate definition for access to such services.

A further limitation of adopting an ABS-based definition of severe and profound relates to the expected duration of the disability. The current definition of disability covers people whose limitations have lasted, or are expected to last, more than six months, and so would include people with disabling conditions that last for relatively short periods. For example, the ABS classifies around 2000 women with a menopausal disorder as having a disability (ABS 2004). However, this condition tends to be relatively short-lived, with symptoms lasting from several years to a month.

Not only has the Australian Government indicated that it intends for the NDIS to address long-term support needs, characterising people with shorter-term core activity limitations as 'disabled' can pose problems. Labelling a condition a disability and treating it as such might prolong recovery. A number of studies have found that positive expectations about recovery are associated with better health outcomes for a number of conditions, even after controlling for symptom severity (see, for example, Gross and Battié 2005 and Turner et al. 2006).

Using existing state and territory definitions of disability

State and territory definitions of disability (for the purposes of identifying potential service users) are slightly more nuanced, as was the definition employed in the (now superseded) CSTDA. (The current inter-governmental agreement covering disability services, the National Disability Agreement, contains no such definitions.)

In addition to requiring that individuals have a *significantly* or *substantially* reduced capacity in a number of areas — typically communication, self-care, learning and mobility — the reduction in capacity must also give rise to a 'need for support'. Most jurisdictions go further and specify that the need for support must be 'continuing', 'ongoing' or 'long-term'.

While Tasmania, the Northern Territory and the ACT only make reference to communication, learning and mobility limitations, the remaining jurisdictions take a broader perspective, adding variously, self-care, self-management, decision-making and social-interaction. South Australia takes a slightly different approach, covering those individuals who experience: 'significantly reduced functioning in most of the following areas: communication; self care; mobility; community access; health and

safety; domestic activities; social; self direction; work and leisure' (Disability SA 2008).

All states and territories include some reference to permanence in defining disability, typically represented as 'permanent or likely to be permanent' that 'may or may not be of a chronic episodic nature'. South Australia goes on to say 'and is not likely to resolve with medical treatment', while Queensland provides the following guidance:

> … permanent or likely to be permanent refers to the irreversible nature of the disability, even though it may fluctuate in severity over time — that is, it may be of a chronic episodic nature. (Disability Services, Queensland 2010, Eligibility Policy, p. 2)

State and territory definitions are a useful starting point — they take broad account of the nature, frequency, intensity and duration of care and support needs. However, one major limitation is that they place undue emphasis on an individual's present state of functioning. In its draft report, the Commission advocated a more forward-looking approach and proposed extending scheme coverage to those for whom there was a reasonable potential for cost-effective early interventions.

Capturing the gains from early intervention

The Australian Government regards a focus on early intervention as an important contribution to the National Disability Strategy. The Commission, as part of this inquiry, has been asked to examine options that provide incentives to focus investment on early intervention. Such an approach is consistent with the 'Wellness approach', which focuses on optimising an individual's functional and psychosocial independence with a view to achieving positive and long reaching benefits.[1]

By focusing on an individual's present state of functioning and/or the current resources of government, opportunities to help avoid rising levels of need and costs at a later stage are often ignored. As the Victorian Government observed:

> Incorporating a strong commitment to early intervention will need to address a number of challenges, particularly in relation to eligibility boundaries and cut-offs. Individuals with degenerative conditions, for example, may not qualify for support initially if the scheme is limited to people who have catastrophic, severe or profound disability. Early intervention, however, could assist in delaying deterioration of their condition and therefore reduce the downstream support needs. Similarly early intervention for those children and young people with congenital disabilities supports improved outcomes and supports families. (sub. 537, p. 18)

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[1] An overview of the wellness approach is included in the report 'The Active Service Model: A conceptual and empirical review of recent Australian and International literature (1996–2007)' authored by the Australian Institute for Primary Care.

The view expressed by the Victorian Government is consistent with experiences in the United Kingdom. The Commission for Social Care Inspection found that when access to individually funded social care services was restricted to only those with the very highest needs, it leads to a short-term dip in the number of people eligible for social care, followed soon after by a long-term rise (Commission for Social Care Inspection 2008, p. 41).

Few states and territories include specific early intervention criteria, though in practice they are pursuing this as a policy direction (chapter 13). The South Australian Government reports that it extends access to disability services to children under five years with a significant global developmental delay (Disability SA 2008). The Victorian Government advises that it also makes provision for children with a developmental delay (DHS Victoria 2009c). (Services for this group are also the responsibility of the Victorian Department of Education and Early Childhood Development and form part of a program of early childhood services.)

People often equate early interventions with interventions that occur in the first few years of life or when a disability first arises. However, early intervention can also involve making investments around specific transition points, such as leaving school or home, or entering the workforce. Hence, in its draft report the Commission proposed an early intervention group that was not bound by age. Specifically, the early intervention group:

> … would include two groups of people. One group would be those for whom there was reasonable potential for cost-effective early therapeutic interventions that would improve their level of functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments). The other would be those with newly diagnosed degenerative diseases, such as Multiple Sclerosis (MS) and Parkinson's disease, for whom early preparation would enhance their lives. For instance, assisting in retaining bladder control can benefit people with worsening MS. (p. 16)

Participants were generally supportive of extending tier 3 supports to this group:

> In particular we believe the Commission is right to… recognise the importance of early intervention for 'those with newly diagnosed degenerative diseases, such as Multiple Sclerosis and Parkinson's disease, for whom early preparation would enhance their lives.'… Such an approach would be very beneficial for people with younger onset dementia and support their carers in maintaining their long-term care role. (Alzheimer's Australia, sub. DR962, p. 2)

> Delivered at the right time services such as speech and physical therapy and specialised equipment such as communication aides can dramatically improve learning potential and social outcomes for children/people with a disability. In some specific diseases such as MS early diagnosis, treatment and support may even mean that the recipients never become severely disabled. (People with Multiple Sclerosis Victoria, sub. DR715, p. 2)

Early intervention is vital for people living with MND. Early access to information and counselling creates a solid base upon which the needs of people diagnosed with degenerative disease can be addressed through appropriate levels of support. (MND Australia, sub. DR783, p. 4)

However, the Commission considers that this criteria could be further refined to make clear that all early interventions should be cost-effective and to allow for non-therapeutic interventions. (An example of a non-therapeutic intervention could include orientation and mobility training for people with vision impairment.) Moreover, interventions would be focused on reducing the impacts of *long-term* disability.

The Commission proposes the early intervention group encompasses people for whom there is good evidence that the intervention would be safe, significantly improve outcomes and be cost-effective. Early interventions would seek to reduce the impact of disability for the individual and the wider community. They would typically be of a given duration and occur as soon as the disability is first identified or appears, where there is a discrete change or deterioration in the disability, or at particular transition points in an individual's life.

Early interventions would include interventions designed to improve an individual's level of functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments). They would also encompasses interventions, which seek to delay or lessen a decline in functioning. This latter form of intervention might be relevant for those with newly diagnosed degenerative diseases, such as Multiple Sclerosis and Parkinson's disease, for whom early preparation would enhance their lives. For instance, assisting in retaining bladder control can assist people with worsening Multiple Sclerosis.

The treatment of intellectual disability

Around 40 per cent of individuals with intellectual disability with life-long care and support needs do not face a core-activity limitation (AIHW 2008a). Even so, their actual capacity to participate in society may be lower than those identified as having such limitations. As noted by the AIHW:

People with intellectual disability encounter special challenges that are different from people with other types of disabilities in a number of important aspects. For example, they have difficulty learning and applying knowledge and in decision making. They may have difficulty identifying and choosing options at key life transition points. They often have difficulty adjusting to changed circumstances and unfamiliar environments and therefore need high support during times of change.

Need for help with core activities may not fully reflect the level of support that an individual with intellectual disability requires to participate in society. Even though they may function relatively well in the familiar routines of self-care and domestic life, and be independently mobile … It is therefore important to also consider the level of support that is needed in non-core activity areas, especially making friendships, maintaining relationships and interacting with others. (2008a, pp. 1–2)

These views were echoed by the NSW Council for Intellectual Disability:

We think that support is really important for transitions and life changes. This is when big changes in your life happen. It might be moving from one stage of life to another. Or it might be moving from one type of support to another. Some examples of life changes are: Moving from school to work; Moving out of home; Learning how to deal with loss. (sub. 546, p. 11)

While participants were generally supportive of including a specific criterion relating to early intervention, the Commission's proposal to include 'intellectual disability' as a specific criterion proved to be far more contentious (box 3.2).

It is clear that those with intellectual disability have both significant and ongoing support needs. As the National Council for Intellectual Disability made clear:

For over 10 years NCID, our Agency Members and the intellectual disability community have demonstrated through a strong evidence base that ALL people with intellectual disability have complex and significant support needs.

Intellectual disability is the only disability group that has objective criteria that is not graduated through a spectrum; the definition has a clear boundary and everyone within that definition requires support. (sub. DR1000, attachment, p. 1)

In the Commission's view, the question is not whether individuals with intellectual disability have significant and ongoing support needs. Rather, the relevant question is how to best design criteria which captures this group of individuals, without inadvertently capturing a broader group. There are a range of options, each with their own potential benefits and drawbacks.

- *The use of diagnostic criteria*: This was the approach partially employed by the Commission in its draft report (and reflects current practice in Victoria). The Commission does not favour broad reliance on diagnostic criteria. However, it can be a more precise way of capturing some individuals, where the nature of their condition is such that it is clear that they have significant and ongoing support needs. The potential benefits of this approach are that individuals would know if they were covered. Further, since criteria for identifying intellectual disability are clear and broadly accepted, it minimises the risk of inadvertently capturing more or less than the target group (false positives and negatives).

The Commission received considerable feedback on the desirability of including intellectual disability as a stand-alone criterion. Some participants argued that the Commission should use functional, rather than diagnostic criteria:

> Deaf Children Australia does not agree with the inclusion of Intellectual Disability as to do so will likely result in applications being made under the ID category when other more specific categories would be more appropriate. We believe this distortion has occurred with the recent Autism Early Intervention packages. A broader category of brain function impairment or simply using the remaining categories — perhaps specifically the 'large identifiable benefit ….' would suffice. (Deaf Children Australia, sub. DR998, p. 1)

> Of my 2 daughters who have disabilities, the one with a chronic illness is far more disabled by her condition than the one with a genetic disorder, an intellectual disability & a host of other physical & psychiatric conditions… The list of those covered by the 3rd Tier includes "intellectual disability not already included". The reason for this is unclear. Why should a person with an intellectual disability be eligible for NDIS support unless the impact of his or her disability was to limit core activity? (Melinda Jones, sub. DR941, pp. 5–6)

While other participants favoured including intellectual disability as a criteria:

> In particular, we commend the report for the … recognition of people with intellectual disability as a group that has need of ongoing support… NCID is strongly supportive of Intellectual Disability being maintained as an eligibility criterion in the National Disability Insurance Scheme (NDIS). (National Council on Intellectual Disability, sub. DR1000, p. 6)

> PDCN supports the eligibility criteria identified in tier 3 as it provides a more representative sample of the different disability types, looks more broadly than just functional need and recognises the different causes of disability. (Physical Disability Council of NSW, sub. DR832, p. 2)

- *The use of functional criteria*: This approach typifies most current practice and underpinned the draft report. If well crafted, this approach can be more equitable than a purely diagnostic approach. As a number of participants noted, individuals with other cognitive disabilities such as chronic schizophrenia and acquired brain injury can also experience significant and on-going non-core limitations.[2] Criteria that specify functions such as self-management, decision-making and/or self-direction, might better capture all relevant individuals. But the risk of false positives is high. Limitations in self-direction or decision-making are common, so much would rest on the interpretation of 'significant' and 'ongoing'. Such broadly cast, functional criteria might not have proved problematic in the context of rationed state and territory disability schemes, (since the provision of supports does not rest solely on whether individuals meet the relevant criteria). However, broadly cast functional criteria could prove more problematic in an entitlements based, fully-funded scheme such as the NDIS.

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2   See for example submissions DR958, DR811 and DR836.

- *The use of functional criteria with examples of those likely to be captured:* This is similar to the approach the Commission adopted with respect to the early intervention group specified above. (For example, the Commission signalled likely candidates might include those with, say, autism or Multiple Sclerosis). This approach is equitable and also provides potential scheme users with some certainty without being unduly prescriptive. However, the NDIA would still need to manage the risk of false positives. Accompanying guidelines, which clearly spell out the scheme's boundaries, would help minimise this risk.

NDIS assessment criteria

On balance, the Commission considers that assessment criteria should use the mixture of indicators that best measure support needs. Combining functional criteria with examples of relevant condition-based criteria can sometimes identify the group needing help better than using functional tests alone, despite the latter's apparent theoretical elegance. Having regard to this, the Commission has developed the following assessment criteria.

A person getting funded support from the NDIS would have a disability that is, or is likely to be, permanent. 'Permanent' refers to the irreversible nature of the disability, even though it may be of a chronic episodic nature. For example, this would include people with significant and enduring psychiatric disabilities, who periodically rely exclusively on support from the clinical services of the mental health system, but at other times are able to live in the community provided they have appropriate supports.

In addition to the above requirements, people would have to meet at least one of the following conditions. They would:

- have significantly reduced functioning in self-care, communication, mobility or self-management[3] and require significant ongoing support. For example, this would include people who need support in toileting, who require significant support for mobility and/or communication or who require supports in self-management and planning to live successfully in the community (such as those with intellectual disabilities or those with significant and enduring psychiatric disability). This group comprises around 329 000 people (3a in figure 3.1), and/or

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3 'Self management' is a term employed in the Victorian *Disability Act 2006*. According to the Victorian Department of Human Services (2009), self management includes being in control of one's behaviour, insight, memory and decision making. For example, the ability to independently make decisions, including decisions with medium to long-term implications or to make long-term plans.

- be in an early intervention group (3b) (around 82 000 people). This would encompass people for whom there was good evidence that the intervention would be safe, significantly improve outcomes and would be cost-effective. For example, this would include those for whom interventions would improve functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments). This group would also encompasses people for whom interventions would delay or lessen a decline in functioning. This might include people with newly diagnosed degenerative diseases, such as Multiple Sclerosis and Parkinson's disease.

A research arm of the NDIA would build an early intervention evidence base to guide the development of protocols governing the optimal intensity, timing and duration of interventions. In many cases, this would involve other key stakeholders such as health departments and research institutions. The role of the scheme in identifying and funding early intervention initiatives is discussed fully in chapter 13.

Safety nets

As noted earlier in this chapter, the assessment criteria should be clear and precise without being unduly prescriptive such that individuals who did not neatly slot into categories missed out on much needed supports and services. The Commission has tried to cast the above assessment criteria as clearly as possible, so that potential users know if they are likely to receive funded supports. But it is hard to anticipate all of the circumstances under which it would be appropriate for the NDIS to provide individually-tailored, funded supports let alone capture them in relatively simple criteria.

The Commission considers that there needs to be sufficient flexibility, albeit with concomitant checks and balances to ensure sustainability, so that the scheme has the scope to provide people with individualised supports where it makes sense to do so.

Hence, the Commission proposes that there would also be scope to include 'people who have large identifiable benefits from support that would otherwise not be realised' (category 3c). This category takes account of the difficulties of slotting everyone into the specific groups above.

The NDIA would apply this third criterion judiciously rather than routinely. It would be constrained by guidelines, and monitored rigorously for its effects on scheme costs. If the agency were to use this criterion loosely, it could pose a risk to the overall financial sustainability of the scheme.

At their simplest, the guidelines might call for annual reporting on the criterion's use and the associated costs. More comprehensive approaches might require that the NDIA weigh up the costs and benefits of using the criterion on a case by case basis or take account of the 'precedence' effect of extending support to a given individual.

Participants were generally supportive of the idea of a safety net (see, for example, subs. DR737, DR809 and DR958).

In some cases, carers would receive their own supports, such as counselling or training (3d in figure 3.1). This issue is discussed in greater depth in chapters 7 and 15.

Should non-permanent Australian residents be able to access tier 3 supports?

Disability supports are generally available to Australian citizens and permanent Australian residents who are also permanent residents of a particular state or territory. Similar to the position outlined in the draft report, the Commission recommends that individualised funding under the NDIS should be available to Australian citizens and permanent residents such as refugees, and applicants for permanent residency. In all cases, people will need to be within Australian borders to receive supports from the NDIS.

Given the move to a national entitlement system, the Commission also considers that the treatment of residency under the NDIS should be broadly comparable to approaches used by Medicare as well as for social security payments. This involves a further issue of extending coverage to some New Zealand citizens, which is perhaps more complex given the current agreements around health and social security. As a starting point, arrangements could be aligned with those that currently operate in social security:

- New Zealand citizens who were Australian residents on the 26 February 2001 would be able to access the full range of NDIS supports.

Reciprocal arrangements with New Zealand could be negotiated at a later date.

Reciprocal arrangements

The Australian Government is party to several international agreements for reciprocal healthcare. The establishment of a national scheme for disability supports would open up opportunities to consider international arrangements for reciprocal

disability support. This would initially require comparisons in terms of eligibility, assessment and service provision. Any agreement would also have to consider the likely effect on NDIS resources.

The Commission does not consider that reciprocal arrangements should be pursued while the NDIS is still in the process of being rolled out, as successful rollout should be the focus. Once trials are completed and the NDIS is functioning nationally, the government would be better placed to consider reciprocal arrangements.

How disability may be treated in residency decisions

Disability and health more generally has historically been considered in residency and immigration decisions. These decisions are the responsibility of the Department of Immigration and Citizenship, rather than the NDIA. Moreover, it is beyond the scope of this inquiry to consider immigration policy — this issue has been subject to its own separate inquiry (Joint Standing Committee on Migration 2010).

The NDIA may have an ongoing informational role in supporting the Department of Immigration and Citizenship. For instance, many visa types have health examinations and health waivers, which consider the health needs of new immigrants and the likely costs attached. The NDIA would be a natural source of general cost information.

Initial assessment could often be simple

Assessment should be multi-layered, with the ultimate goal of directing people to the right supports, inside or outside the NDIS, and where inside, the quantum of support. A short upfront assessment module would establish whether an individual would benefit from funded support. In many cases, this stage would be waived for:

- individuals who unambiguously experience significant limitations in mobility, self care, communication or self-management, such as those with quadriplegia, or diagnosed as having intellectual disability

- where the scheme had already identified opportunities for cost-effective early interventions across a group of individuals.

Having an initial assessment would reduce the overall costs of detailed follow-up assessment, as the NDIS would not be the appropriate source of support for some people.

3.6 Taking account of the broader context of service delivery

Not all individuals who meet the criteria will receive individualised support from the scheme. For example, some will be supported by aged care, others will be captured by the 'sister scheme' of the NDIS, the National Injury Insurance Scheme (NIIS). It will be important to make clear where these boundaries lie. The Commission proposes that the NDIS proactively seek memoranda of understanding with the health, mental health, palliative and aged care sectors, so that individuals do not 'fall between the cracks' of the respective schemes.

Intersection with accident-based schemes

As noted in chapter 18, the Commission recommends the creation of a National Injury Insurance Scheme (NIIS). Some participants (including some state governments) considered that two schemes were unnecessary and that the NDIS should capture individuals with catastrophic injuries. However, given the timeframe for transition to any coherent injury scheme and other practical reasons, the Commission considers that the NIIS should run parallel to, rather than be incorporated into the NDIS. The rationale for separate schemes is discussed in more detail in chapter 18.

Ultimately, the NIIS would cover (nearly) all causes of catastrophic injuries, including those related to motor vehicle accidents, medical treatment, criminal injury and general accidents occurring within the community or at home. One exception to this would be cerebral palsy arising from pregnancy or birth. In this area, there are compelling grounds for funding future care and support from the NDIS rather than the NIIS. This reflects several factors.

- The scientific evidence suggests that most cases of cerebral palsy are not accidents in the typical sense of the word. Most do not involve cases where clinical practices could avoid the disability, but are more akin to other birth defects, which would be covered by the NDIS.

- It is particularly hard to reliably determine medical treatment or care by the physician as the cause in any individual case. Individually risk-rated insurance is not an efficient way of moderating risks compared with other approaches, such as training programs, clinical protocols and other measures aimed at the relevant group of physicians.

The Commission has also flagged arrangements for state and territory governments to transfer the care and support of catastrophic workplace claims to the NIIS

through a contractual arrangement with their respective workers' compensation schemes. This reflects the fact that the incidence of catastrophic injuries under workcover schemes is low and that their systems are not well geared to provide coordinated lifetime care for such cases. These individuals would not therefore receive individually tailored supports from the NDIS. Those individuals covered by no-fault, non-catastrophic Workcover arrangements would also be excluded, as these appear to operate reasonably well in each jurisdiction and reforms are already underway in the areas where changes are needed.

Aged care is a particularly important parallel support system

The aged care system is responsible for meeting the care and support needs of those who acquire disabilities later in life. And the Australian Government has made clear, in its terms of reference for this inquiry, that it intends for this arrangement to continue. The terms of reference state that the NDIS 'is intended to cover people with disability not acquired as part of the natural process of ageing'. Even so, a number of participants called for the NDIS to include individuals who acquire their disability after Age Pension age (box 3.3).

While there are many similarities between the conventional disability system and aged care, there are also many differences, such as in philosophy, employment goals, and the appropriateness of co-contributions, which mean that two systems are required (appendix C). A reformed aged care system, such as that proposed recently by the Commission in its parallel inquiry into aged care, would be a more appropriate system for addressing disability resulting from the natural process of ageing. The Commission has recommended that individuals be able to access a broad range of supports, determined by a comprehensive assessment of needs upon entry to the system. This assessment would include consideration of a wide range of supplementary care needs and supports.

A second group of individuals, who acquired their disability earlier in life are concerned that, as they age, they may 'fall between the cracks' of the two systems (box 3.3). They want to preserve the continuity of their support arrangements and ensure the adequacy of funding. For example, many people want the capacity to stay in their own homes (say a group home), to stay with the support workers they like and to use the service providers that best meets their needs, regardless of the system that accredits these providers.

| Box 3.3 | **Participants' views on the interface with the aged care system** |

A number of participants considered that individuals who acquire their disability after Age Pension age should be able to access the NDIS:

> People who lose their vision after the age of 65 should receive the same access to services and supports as people under that age. Blind Citizens Australia recommends that the NDIS be open to people aged over 65 as this provides the best chance of preventing discrimination and inequality. If two schemes are adopted, Blind Citizens Australia recommends that both schemes must apply the same rules for access, provide equivalent access to supports and deliver resources proportionate to the numbers of people requiring access in each scheme. (Blind Citizens Australia, sub. DR758, p. 7)

> For people who lose their hearing after age 65 the divide between NDIS and aged care is a problem. These people need supports as much as people younger than age 65 and they should not be excluded from NDIS supports. (Deaf Australia, sub. DR934, p. 5)

> The report states that the needs of those who acquire a disability after age 65 would be best met by the aged care system. This is not the case. Most people with progressive neurological diseases over the age of 65 will need services from both systems. (Neurological Alliance Australia, sub. DR938, p. 2)

Other participants, who acquired their disability early in life, were concerned about continuity of care upon reaching Age Pension age:

> Alzheimer's Australia particularly welcomes the recognition of the need to ensure, not only that people with a disability who pass the pension age should have the choice of which system they wish to be in, but that 'There would also be scope for people with a disability who are aged less than the pension age to use the services and features of the aged care system, with the costs being met by the NDIS until the person reached the pension age.' (Alzheimer's Australia, sub. DR962, p. 2)

> It would be useful to provide a stronger statement about the right of people with a disability to choose to age in place if their home is some form of disability supported accommodation such as a group home; such a statement would make the right to increased costs and additional resources to enable aging in place unequivocal. (Professor Christine Bigby and Dr Chris Fyffe, sub. DR933, p. 12)

The Australian Government has agreed to fund the disability support needs of such people under the National Health and Hospital Network Agreement with state and territory governments. It has agreed to fund specialist disability services provided under the National Disability Agreement for people aged 65 years and over (50 years and over for Indigenous Australians). This agreement is already factored into the Australian Government's budget commitments, and therefore does not need to be incorporated into the estimated costs of the NDIS. (The only variation to the Agreement we are recommending would be that the NIIS would fund people over the Age Pension age who acquire catastrophic injuries, such as from a motor vehicle crash.)

That nevertheless leaves the practical issue of achieving the continuity of support as people with disabilities get older. The Commission proposes that, upon reaching the Age Pension age [4] (and at any time thereafter), a person with a disability could elect either to stay with the NDIS or move to the aged care system.

- If a person elected to move to the aged care system, they would be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches).

- If a person elected to stay with the NDIS care arrangements, their previous support arrangements would continue, including any arrangements with disability support organisations, their group accommodation, their local area coordinator, or their use of self-directed funding. The NDIS assessment tool would be used to determine their entitlements.

- If a person over the Age Pension age required long-term residential aged care then they would move into the aged care system to receive that support, regardless of the age at which they acquired their disability.

The advantage of these flexible arrangements is that the NDIS would — from the perspective of any person — become a lifetime scheme if that was preferred.

Regardless of which system organised the supports, *after* the Age Pension age people with a disability would be required to make a capped co-contribution to their care on the same basis as the general population, if they had the financial means. This is consistent with the co-contribution arrangements recommended in the Commission's parallel inquiry into aged care. The co-contribution reflects that the likelihood of disability in old age is high, can be anticipated, and that people can save to meet those costs.

This proposal would not affect most people who acquired a disability earlier in life because they would not have earned enough income or acquired enough assets to trigger any requirement for co-contributions after the Age Pension age. However, some people who acquired a disability prior to the pension age may have built up sizeable assets and entitlements to retirement income. These would mostly be people who acquired a disability just a few years before the Age Pension age, but it could include others. Like any other aged person, people in these circumstances would be expected to contribute to their care. Moreover, it would prevent people with assets or high incomes from attempting to enter the NDIS prior to the Age Pension age to escape the co-contribution arrangements in the aged care system. To provide an additional impetus for workforce participation, it may be appropriate for

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[4] A younger age threshold would apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

there to be a lower co-contribution for people acquiring a disability early in their life. The Commission considers that the Australian Government should determine the appropriate aged co-contribution level as part of the implementation arrangements for the NDIS and changes to the aged care system.

For people with disabilities who are eligible under the NDIS and who are below the Age Pension age but need to access aged care services, those costs would be met by the NDIS, without any co-contribution being required.

Intersection with the health system

The Commission recommends that primary care and hospital (in-patient and outpatient) based services and medical and pharmaceutical products remain outside the scope of the scheme (chapter 5). Even so, it is likely that some ambiguity will remain around the respective responsibilities of the health and disability system. For example, which system is responsible for undertaking early intervention and, more particularly, which system is responsible for meeting the support needs of individuals with a chronic health condition.

Current arrangements for individuals with chronic health conditions

According to the Department of Health and Ageing:

'A chronic medical condition is one that has been (or is likely to be) present for six months or longer. It includes conditions such as asthma, cancer, heart disease, diabetes, arthritis and stroke.' (DoHA 2010b)

Chronic medical conditions can be disabling. The Department described chronic diseases elsewhere as:

illnesses that are prolonged in duration, do not often resolve spontaneously, and are rarely cured completely. Chronic diseases are complex and varied in terms of their nature, how they are caused and the extent of their impact on the community. While some chronic diseases make large contributions to premature death, others contribute more to disability. Some may last indefinitely, whereas others may resolve over time. Features common to most chronic diseases include:

- complex causality, with multiple factors leading to their onset

- a long development period, some of which may have no symptoms

- a prolonged course of illness, perhaps leading to other health complications and

- associated functional impairment or disability (DoHA 2010c).

As they do with mental health, state and territory governments take slightly different approaches to determining which individuals with chronic health

conditions are eligible for specialist disability supports. Most jurisdictions rely on the concept of permanence to distinguish between the respective roles of the health and disability systems. The Queensland Government, for example, offers the following guidance:

> … the disability will not be considered permanent where there is a need for specific health services for a defined period following physical trauma or the onset of an acute episode of illness. A person in this situation may only become eligible for disability support services once their medical needs have stabilised and the long-term nature of their disability becomes apparent. (Disability Services, Queensland 2010, Eligibility Policy, p. 2)

In other jurisdictions, such as South Australia, a diagnostic approach helps differentiate the responsibilities of the two systems. For example, individuals with cancer and heart disease are covered by the health system (sub. 496). In its submission on the draft report, the South Australian Government noted:

> This group [people with functional limitations resulting from chronic health or other health conditions] currently are not eligible for NDA [National Disability Agreement] funded disability support, but have been supported to a certain extent through HACC funding, particularly through assistance provided by Domiciliary Care, RDNS and Country Health. (sub. DR861, p. 3)

But gaps between disability and health services persist. Individuals with chronic health conditions note that in some cases, they simply cannot access the services they need. The Chronic Illness Alliance said:

> There is an assumption that the costs of such care for people with chronic illnesses are met through the health and medical system. But this is not entirely the case. Often people with chronic illnesses find they cannot access the services they need which are related to living in the community rather than to their health needs. They are not eligible for some disability services and the services they need are not available from medical services. An example of this is that some people with chronic illnesses do not fit the criteria of eligibility for aids and equipment from state-based services, which are poorly funded and inadequate to meet the needs of those who require them. (sub. 215, pp. 2–3)

It also contended there is little distinction between 'disability' and 'chronic illness':

> These distinctions between disability and chronic illnesses are largely historical and over time some chronic illnesses have been recognised in terms of their impairments while others have not. There is little appreciation by the public and in policy for instance of the debilitating effects of arthritis, Meniere's disease, Crohn's disease and epilepsy. We would urge any review of disability services to ensure that these attitudes towards chronic illnesses and the impairments related to them be included in that review with a view of doing away with such false distinctions. (sub. 215, p. 3)

Coverage of chronic health conditions under an NDIS

Both the South Australian and New South Wales Governments made recommendations about the division of responsibilities between the NDIS and the health system in their initial submissions. The South Australian Government proposed that coverage under the NDIS extend only to those disabilities that are not the result of chronic disease processes and that a diagnostic, as well as functional definition, be applied to exclude people with chronic health conditions (sub. 496). It went on to note that:

> Any extension of the eligibility criteria to other groups (aged or chronic health) will make the scheme too complex and will increase the risk of the scheme failing to meet the needs of people with disabilities. (sub. 496, p. 4)

If interpreted literally, that would have the implication that stroke, early onset dementia, muscular dystrophy and a variety of degenerative diseases would not be covered by an NDIS. In contrast, the New South Wales Government advocated a broader approach. They proposed including people with chronic illness, where their condition requires long-term support and care with activities of daily living (sub. 536, p. 62).

The Commission does not favour a blanket 'yes' or 'no' response to the question of whether individuals with chronic health conditions would be covered by the scheme. Rather, the answer should be informed by whether the NDIS is the most appropriate system to meet the person's needs. This is the approach that the Commission has advocated more broadly (for example, in relation to aged care). This is also the approach adopted by the Victorian Government in determining whether individuals with chronic medical conditions are within the target group for disability services in that state (DHS Victoria 2009c, p. 51).

For many people with chronic health conditions, the question is not whether they have significantly reduced functioning in self-care, communication, mobility or self-management. Rather the question is, having received the optimal duration and type of treatment:

- is their condition permanent (or likely to be permanent) and

- do they have significant, long-term support needs in order to participate in the community (whether that be continuous or episodic).

People with support needs that persist, or are likely to persist, for only several years due to chronic illness would generally not appropriately have their needs met by the NDIS. The NDIS is intended to give people certainty of support over a long time horizon, recognise that personal choice and power over support needs are greatest for people who will have to get lifelong and enduring supports, provide significant

risk pooling from a lifetime perspective, and to facilitate lifetime community and employment goals that would not otherwise be attainable to the person.

Being precise about what constitutes 'several years' is difficult and the details should be worked out in the implementation of the NDIS. But a rule of thumb may be five years. It is important to stress that relaxing the criterion for 'permanence' too greatly could threaten the sustainability of the scheme. Notably, one of the reasons for the sudden increase in Disability Support Pension claims in the 1990s was the relaxation of the criterion for entry of 'permanent incapacity' to 'substantially incapacitated' (PC 2005b).

Distinguishing between assessment criteria and estimates of the target population

To avoid misunderstanding, it is critical to distinguish between the Commission's proposed assessment criteria for tier 3 and the estimates of the numbers of people and their support costs in the scheme. In making those estimates, the Commission has had to confront the limitations of the SDAC, which uses six months as its definition of permanence and has small and unreliable sample sizes for some conditions. Given that definition, the Commission has had to adopt a hybrid of a functional limitation and medical diagnostic approach in its estimation strategy. The Commission has assumed that (a) 100 per cent of people with certain chronic health conditions with daily support needs would be covered by the NDIS (when in fact, certain individuals with such conditions would not be eligible), and that (b) no people with other chronic health conditions would be covered (though some would in fact be so).

As much as possible, the choice between these two states has been based on clinical advice about the likely long-term support needs of people with given chronic conditions. But the estimation approach should not be taken to mean that no people in group (b) would be in the scheme or that all people in group (a) would be. To do so would imply a medical rather than a functional approach to disability. The conditions that underpin the Commission's cost estimates are outlined in chapter 16 and appendix H.

Other boundary issues

Boundary issues between the health sector and the NDIS are not limited to coverage of individuals with chronic health conditions. Other issues include which sector should be responsible for research and early intervention.

The Commission proposes that the NDIS agree to a common memorandum of understanding (MOU) with the health sectors in each state. The aim of the MOU would be to ensure:

- the health, care and support needs of individuals with chronic and progressive health conditions were met in an integrated fashion

- adequate incentives existed for investments in research, prevention, early intervention and timely service delivery in cases where:

  - both health and the NDIS would be joint beneficiaries

  - where responsibility for the intervention or service would lie with health but the NDIS would be the main beneficiary

  - where responsibility for the intervention or support would lie with the NDIS but the main beneficiary would be health (such as in the provision of suitable accommodation to facilitate timely hospital discharge).

Given historical arrangements, it is likely that parties to the MOU would employ a diagnostic lens. If this is the case, emphasis should first be given to high cost and/or prevalent conditions.

Intersection with mental health

The Commission sought feedback in its draft report on where the boundaries between the mental health sector and the NDIS should lie. In particular, the Commission requested feedback on which system was best placed to meet the non-clinical support needs of individuals with a significant and enduring psychiatric disability.

The dominant view of participants in this inquiry, consistent with the advice of experts independently consulted by the Commission, was that the NDIS should meet the *disability* support needs of individuals with significant and enduring psychiatric disability (box 3.4). This reflected the similarities in support needs and the broad principles underpinning the community mental health system and disability supports generally.

Same support needs

The Commission has been advised by experts that many people with significant and enduring psychiatric disabilities have the same day-to-day or weekly support needs as people with an intellectual disability or acquired brain injury. These can include assistance with planning, decision making, scheduling, personal hygiene and some

communication tasks (sub. DR1057). Providing daily or regular supports allows such people to live successfully in the community. As with other disabilities, individuals sometimes require supported accommodation, or support to maintain their tenancies.

Box 3.4   Participants' views on the inclusion of mental health

The MHCA and the NMHCCF support eligibility for access to this scheme for disability acquired through a 'health condition' (not just through accident or misadventure), however want to be clear that this also refers to a mental health condition, as physical disability is often what people think of as a 'disability'. (Mental Health Council of Australia (MHCA) and National Mental Health Consumer & Carer Forum (NMHCCF), sub. 357, p. 5)

The inclusion within the proposed NDIS of people experiencing disability related to mental illness is strongly endorsed. That the scheme be proactive in contacting people with mental illness who may be eligible for supports. (Catholic Social Services Victoria, sub. 453, p. 4)

Mind also believes that there are equity issues which should inform the decision about inclusion of people facing serious mental health problems. People with similar levels of disability should receive similar access to public resources and status. (Mind Australia, sub. DR808, p. 11)

… equity should be the key issue driving the distribution of resources under the NDIS and so people with mental illness should able to access the benefits that accrue to others with similar levels of disabling symptoms, injuries and conditions under Tier 3 of the insurance scheme. (Mental Illness Fellowship Victoria, sub. DR1042, p. 3)

Carers Australia considers that it is imperative that the Productivity Commission's final report makes it clear to what extent people with a psychiatric disability will be included in a NDIS. There is a history of this group of people being theoretically included in some programs but not in practice. Examples of this are the Home and Community Care Program and Carer Payment and Allowance for those providing care. In some ways, ambiguity is a worse outcome for people with a psychiatric disability as a group than a clear exclusion as it can preclude future investment from other sources. (Carers Australia, sub. DR981, p. 15)

The Council believes that the support needs of people with psychosocial disability should be included in the NDIS … People with psychosocial disability should be able to access supports under the NDIS such as specialist employment and daily care supports when required. (National People with Disabilities and Carer Council, sub. DR1026, p. 5)

The NDIS is the more appropriate vehicle for managing community supports

The NDIS is underpinned by support and planning that helps people achieve their goals and maximises their participation in the community. Only a small part of the existing mental health system — the community mental health system — shares similar approaches and philosophies to the NDIS. However, this part is placed in a broader mental health system that, given its clinical orientation, has been slow to recognise these approaches, and has given priority to managing and funding the clinical, rather than the community needs, of people. As with the health system generally, the traditional mental health system focuses on clinicians' diagnoses and treatment of people with 'pathologies'.

The view from the literature, consistent with the feedback provided to the Commission, suggests that the medical model underpinning the traditional mental health sector is ill-suited to the community support of people with psychiatric disability:

> New paradigms of care which incorporate concepts of holistic care combining clinical interventions with psychosocial interventions which address the social determinants of health challenge mental health practice systems. International evidence shows that it is particularly difficult to bring the providers of clinical services into whole-of-government approaches. Health services tend to be professionally dominated and focused on the immediate imperatives of meeting the demands for acute clinical care.

> Consideration of broad social determinant issues, such as affordable housing and employment, are therefore seen by most clinicians as outside the scope of care and of influence. (Courage Partners 2011, prepared for the Department of Families, Housing, Community Services and Indigenous Affairs, p. 8)

> We are concerned at any inference that disability supports for the mental health could possibly be better provided through the mental health sector. This is akin to proposing that the disability support needs of people with intellectual disabilities could be met through the primary health care sector rather than through a disability support scheme. (Mental illness Fellowship of Australian Inc, sub. 865, p. 2)

The poor fit of the emerging community mental health system and the traditional clinically oriented mental health system, means that the NDIS is a more appropriate umbrella for the provision of community support. Community mental health services will be strengthened by the extra resources provided through the NDIS.

The NDIS would bring to community support for people with psychiatric disabilities, the advantages of an insurance model, with its certainty, long-tem perspectives, governance and data mining approaches. Personalisation is also an important feature of the NDIS, and would apply to people with psychiatric disabilities. As with others with a disability, this would sometimes include the scope for self-directed funding (chapter 8). However, as recognised in the literature in this

area — this requires appropriate support and needs to address some of the barriers to adoption of individualised approaches for this group (Social Care Institute for Excellence (SCIE) 2009; Alakeson 2008).

Who would be covered?

Consistent with the general criteria outlined for tier 3 supports, those receiving NDIS funded, individualised packages would have significant and enduring disability. These are individuals who, having received the optimal duration and type of treatment:

- had permanent conditions (or conditions that were likely to be permanent) (this would include individuals who were no longer responding to treatment)

- had significant, long-term support needs in order to participate in the community (whether that be continuous or episodic) — for example, individuals whose conditions had resulted in a level of cognitive impairment that required ongoing, non-clinical support to live in the community (akin to the planning and support that the NDIS would provide for people with other cognitive disabilities).

Individuals receiving individualised packages would have been assessed by the mental health sector as being well enough to live safely in the community (for themselves and the community). This is consistent with the principle that those receiving NDIS supports would not have needs that were better met by a parallel system.

This approach was supported by a number of participants:

> For those people who have not been able to recover adequately from Mental Illness, the MHCAA strongly urges that they are included in a national Disability Scheme. (Mental Health Carers Arafmi Australia, sub. DR773, p. 1)

> … eligibility for people with a mental illness should only be considered when a person needed ongoing support to live within their community or to obtain and maintain employment. (Western Australian Association for Mental Health, sub. DR848, p. 2)

Early interventions in mental health typically take a clinical approach and there are established bodies that specialise in the provision of these services (for example, the Early Psychosis Prevention and Intervention Centres). Responsibility for these clinical interventions would remain with the mental health sector. As the Australian Medical Association noted:

> Some may be in a group for which there was 'a reasonable potential for cost-effective early therapeutic intervention'. For example, individuals whose mental illness is acquired during their youth, and without intervention, would progress to a serious and chronic condition. Again, however, the early therapeutic interventions that would be

appropriate to this group are clinical ones, which fall squarely within an appropriately resourced mental health sector. (sub. DR875, p. 2)

However, consistent with the general criteria for tier 3 supports, the NDIS would provide non-clinical interventions (such as assistance with planning and decision making), where the evidence showed long-run returns (chapter 13). For example, evidence may suggest that supports would help a person avoid becoming homeless or requiring hospitalisation. (The NDIS would also include early intervention for autism, as this is already situated within the disability sector even though some classify autism as a psychiatric disability.)

How many individuals does this encompass?

The Commission consulted a range of experts in mental health epidemiology and planning about the appropriate numbers of people with psychiatric disability who would be best served by the NDIS. Their advice underpins the Commission's estimates of how many individuals with a mental health condition have significant and enduring support needs, and the indicative costs of meeting these support needs (chapter 16). Overall, the Commission estimates that the NDIS would provide community supports to around 57 000 people with severe and enduring psychiatric disability (appendix M).

A good interface between the two systems is essential

It would be essential that the (state-based) mental health system work closely with the NDIS. In particular, there would need to be:

- clear lines of responsibility and strong communication between the NDIS and the mental heath system, given the ongoing need for well-coordinated clinical and non-clinical support. To achieve good outcomes, clinical care must also be available when required and be appropriately integrated (a clear responsibility of the mental health system). This is similar to other people with significant disability who have support needs with daily living in the community, but who will also be using medical services.

- As with other types of disability, agreement from state and territory governments that they would provide complementary supports, such as public housing and clinical care, which are essential in achieving better outcomes for these groups.

The need for a better interface and expertise cuts both ways. The NSW Council for Intellectual Disability highlighted the lack of expertise in the mental health sector in

dealing with people with intellectual disability who also had mental illness and the poor access of people with intellectual disabilities to clinical supports:

> The mental health needs of people with intellectual disability are poorly met. Australian research shows:
>
> - Very poor access to mental health services for people with intellectual disability and a mental illness. In a ten year period, only 10% of adults with intellectual disability and a mental disorder had received mental health intervention …. By contrast, Slade & others (2009) found that 34.9% of the overall community with mental disorders had received treatment in a twelve month period.
>
> - Psychiatrists and GPs see themselves as inadequately trained to treat mental disorders in people with intellectual disability. Psychiatrists see people with intellectual disability as receiving a poor standard of care. (sub. 1020, p. 2)

The skill set for workers providing supports for those with psychiatric disability is typically more specialised and requires more training than those providing many forms of attendant care. This reflects the fact that people with mental health problems benefit from social, relational and personal support (as for many others with cognitive impairments), rather than physical and personal care (SCIE 2009). The need for specialist staff and other workforce issues are discussed in chapter 15.

Consideration of the skills required of support staff will form part of a comprehensive needs assessment. The assessment process will draw on the current medical records of the individual, the services currently received as well as the aspirations and reasonable needs of the individual (chapter 7). The nature of supports that will be provided by the NDIS is outlined in chapter 5 and Appendix M. The latter also provides further information about where the mental health and disability systems would need to coordinate their roles.

Intersection with palliative care

Individuals in the final stages of their life traditionally receive palliative, or end of life care. These individuals share some common care needs with those with a disability and both should have their needs met in a sensitive manner. However those with terminal illness might also require:

- care focused on making the individual comfortable, including medications and treatments to control pain and other symptoms

- services for themselves or their families to help deal with the medical, psychological and spiritual issues surrounding dying.

In its draft report, the Commission recommended the following arrangements for individuals with terminal conditions. Where an individual:

- first approached the scheme for individually funded support *after* their terminal condition had become sufficiently advanced, such that they were in the very final stages of their life, they would be referred to the palliative care sector. (The NDIS would have a role in connecting such people to palliative care services. For example, that might involve helping identify the relevant provider in their area and making a warm referral)

- was in receipt of individually funded support and their condition subsequently deteriorated such that they were in the final stages of their life, they would continue to have their care and support needs met by the scheme. The NDIS would source, and the palliative care sector would fund, any specialist services to address their palliative aspect of their care needs. Such an approach would ensure continuity of care in the individual's final stages of life.

Participants were generally supportive of this approach:

> We agree with the Commission's recommendation that for those individuals who are currently receiving funded support when they then required palliative care that the NDIS would source, and the palliative care sector would fund, any specialist services to address the palliative aspect of their care needs. We would endorse the view that such an approach would ensure continuity of care in the individual's final stages of life. (Valued Independent People, sub. DR932, p. 5)

> Further, the exclusion of support needs which are more appropriately met by the health, palliative care or aged care systems, or through mainstream service systems (such as employment, public housing or education) is supported. Failure to exclude these services would likely result in duplicated services which are more expensively provided as 'specialist disability services', in addition to reducing incentives for mainstream service providers to keep their services accessible to people with a disability. (Queensland Government, sub. DR1031, p. 12)

> NDS agrees with the proposal for the intersection of palliative care and the NDIS; it is a workable and sensible solution. (National Disability Services, sub. DR836, p. 10)

However, it was clear from participants that some individuals currently fall between the cracks of the two systems, and when this occurs the impact on the individual, their family and carers can be devastating:

> Definitions of palliative care in Australia (unlike in some other countries) tend to very narrow, focusing on the late stages of terminal diseases, most especially cancer. Patients with chronic life-threatening illnesses other than cancer tend to fall outside of the 'system' as it is currently constituted (this is certainly not meant to infer that families dealing with cancer get all of the help they need). The choice for such patients and their families, at the moment, is stark and dispiriting: they have the option for the disabled family member to be admitted to a totally inappropriate (especially if they are still young) aged-care nursing facility or to struggle on alone at home. (Chris Kynaston, sub. DR949, p. 1)

I am very aware that there are a great many unsupported patients and families in the community who would benefit from a hospice, particularly those with a non-cancer diagnosis with a high level of medical need but unsure prognosis. Many patients with conditions other than cancer suffer as much, if not more, their symptoms in the last few days of life are similar, and due to difficulty assessing when they are entering the palliative phase have no support in adjusting or accepting that end of life is near. Many younger patients only have the option of being at home (where the care for the realative or carer is hard emotionally and physically), going into hospital, which is often inappropriate and expensive, or going into a nursing home, clearly inappropriate for a certain age group ... I feel there are many changes which could be made to raise the profile of palliative care and provide better support, which is why I have included this submission. (Lynne Megginson (palliative care nurse), sub. DR831, p. 1)

Other participants pointed out that palliative care arrangements vary both between and within States:

Palliative Care in NSW currently varies significantly from one area to another. Eligibility varies but overall they require the person to have complex care needs to receive specialist palliative care services. In some areas this includes a multidisciplinary team and in others this may be a palliative care nurse. It is getting more difficult to access a palliative care multidisciplinary team for people with MND in NSW. There is no consistency across the state or between local health networks. Some services do provide excellent service to our members and assist in people having a peaceful death while other areas have no such involvement and people die in distressing situations. Often people need to be at end of life before referrals are accepted by some services and in many areas a person must be referred by a medical practitioner. With MND it is not easy to know when a person is at the end stage of their disease.

In Victoria, people with MND are eligible to access palliative care services from the time of diagnosis or when they first need a service provided by a palliative care service. This "pre eligibility" facilitates earlier access to support and services, and removes waiting lists. (MND Australia, sub. DR783, p. 5)

While the Commission considers that the intersection between the scheme and palliative care sector is workable, care will need to be taken to ensure that some individuals or groups do not find that they fall outside the scope of both. Parties to the MOU should pay particular attention to the treatment of those with progressive neurological diseases and consider establishing care pathways to ensure that individuals receive timely, appropriate and continuous care.

3.7 How many people are likely to receive individualised supports

Estimates of the number of individuals likely to access individualised supports are *indicative only* as the proposed assessment criteria do not map directly to existing data and the data are largely based on self-report. Moreover not all individuals who meet the assessment criteria will elect to take up services. That said, the Commission estimates that the potential population of NDIS-funded, individually tailored service users (based on 2009 population and prevalence data) would be around 411 000. This number is higher than the estimate contained in the Commission's draft report, as people with mental health conditions meeting the criteria described earlier were not fully represented.

The estimated number of individuals likely to access individualised supports under an NDIS would exceed the number of current service users. About 172 000 people used specialist disability services under the National Disability Agreement in 2008-09 (excluding Australian Government employment services) (SCRGSP 2011).[5] Around 200 000 people aged under 65 years used Home and Community Care (HACC) in 2008-09 for services such as nursing care, allied health, and the provision of aids and equipment that were not available under the National Disability Agreement. (Though a significant share used very little HACC services — approximately one hour of care a fortnight.) Current total service users are less than the sum of both National Disability Agreement and HACC users since people often use both services (around 20 per cent of people using National Disability Agreement specialist services — excluding employment services — also access HACC services).

The assessment criteria also lead to coverage that is broader than those associated with criteria employed in other countries. For example, applying the criteria for entry into long term care and support schemes in Sweden and Singapore to the Australian population yields potential populations of about 220 000 and 290 000, respectively.

It is important to emphasise that not all individuals who meet the assessment criteria will elect to take up individually funded services. This is currently the case with state and territory disability and accident-based schemes. As the New South Wales Government observed:

> … a person may be eligible for the system but, due to their capacity to self care or due to strong family support, may not access any services in the immediate future. (sub. 536. p. 63)

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5 As noted in chapter 5, in the main, the NDIS will not provide employment services.

The Commission's assessment criteria identify those who would benefit from support, but it would not indicate the form or value of supports. More detailed objective assessments would identify people's support needs and the appropriate level of supports, after taking account of the roles performed by other publicly-funded services and the reasonable contributions of volunteers, family, friends, employers and the community.

It should also be emphasised that the population of people using individualised supports is not a reliable guide to scheme costs. Many people will use services irregularly (for example, periodically replacing their wheelchair or receiving an hour of counselling every so often to maintain a high level of functioning). The largest costs and the challenge for scheme management will be for the relatively small population of people with very high support needs, particularly those with high attendant care costs (chapter 16).

3.8 Implementation issues

Access to funded services would apply to the entire stock of relevant people with disability, and not just to the flow of new cases ('incidence'), (as happened with the introduction of the New South Wales Lifetime Care and Support Scheme). This approach was supported by a number of participants. Moreover, the alternative would mean the persistence for decades of sub-standard support for hundreds of thousands of people:

> Acknowledgement by the Commission that NDIS once operational, should be available to all eligible individuals irrespective of when they acquired their disability, is considered by our Association to be an equitable response. (Association for Children with a Disability, sub. DR1022, p. 6)

The NIIS will cover all newly acquired catastrophic injuries (chapter 18). Hence, the Commission recommends that the care and support needs of people with existing catastrophic injuries, who are not covered under any of the present no-fault arrangements, would be met through the NDIS (subject to meeting the broader assessment criteria). In some cases, people with a catastrophic injury that occurred before the onset of the NIIS would have received a payout. In which case they could join the NDIS with a contribution from the payout or join later after using their payout to reasonably meet their needs.

Given that the estimated population of the scheme significantly exceeds the number of current National Disability Agreement service users and that traditional service users are captured by the proposed assessment criteria, the overwhelming majority of current users would be likely to access their supports from the NDIS after its

implementation. Indeed, most would get more supports given the expanded funding of the NDIS and an obligation for the system to deliver the supports determined by the independent assessment process. This feature is an essential element of avoiding the chronic underfunding that has beset past allocation systems. To a large degree, this should allay the concerns of people that they might receive no or fewer supports under the NDIS after years of fighting or waiting for adequate services.

While current users of National Disability Agreement services will overwhelmingly receive funded supports under the NDIS, the same is not necessarily true of all HACC users. According to the relevant eligibility criteria, HACC services currently cover a wider range of individuals than are the target of funded supports under the NDIS. But this does not mean that everyone covered by HACC eligibility criteria actually receive HACC services. As the guidelines in one state note:

> Eligibility for a HACC service does not infer entitlement for services. Service providers allocate assistance in accordance with available resources, and the assessed priority of each client. (Department of Health and Human Services Tasmania, p. 1)

There are no available data to test whether all current HACC users would be covered by the scheme. Indeed, very little is known about the characteristics of current HACC users, including about the nature and severity of their disabilities. It is clear that 'high-level' HACC users (those who receive more than one hour of support per day) would be covered by the scheme. What is less clear is whether all 'low-level' HACC users would get the same level of services using the NDIS assessment criteria:

- *Some low-level HACC users might get much more support,* such as people with 'high-level' needs who were only ever able to secure 'low-level' supports. Given the extent of rationing and unmet need (chapter 2), the Commission considers that many individuals might fall into this category.

- *Some low-level HACC users might get more or the same level of supports*, such as some people with intellectual or significant and enduring psychiatric disability. The Commission has included in its costing a number of individuals with cognitive disabilities who require only an hour or two of support a week (chapter 16). While the number of hours of support required per week is only small, the support needs are significant. Absent this support, these individuals would be unable to live independently in the community. Discussions with HACC providers confirm that some low-level HACC users fall into this category.

- *Some low-level HACC users might not be eligible for NDIS services*. The NDIS would not provide individualised supports to those with low-level needs. The Commission considers that on balance, relatively few HACC users would fall into this category, since resources are typically allocated on a priority basis.

While the Commission has received no evidence of current low-level HACC users who might not be covered by an NDIS, it is possible that this is the case. The Commission considers that states and territories would have a small, residual role in meeting the care and support needs of these individuals. States and territories would also have a role in meeting significant, but shorter-term support needs, such as the needs of someone who had two broken legs or someone undergoing treatment for cancer.

No disadvantage tests

The Commission understands the intrinsic appeal to current service users in no-disadvantage tests and that people would seek some undertaking that they be no worse off under new arrangements. As one participant noted:

> However, the Community Educators Group wants to underline that, in the implementation phase of any new system, anxiety levels of potential recipients are going to be high. Regardless of the levels of reassurance given by the administrators, nothing will allay people's fears or remove obstacles to implementation like a 'no-disadvantage' test, and nothing will obstruct the implementation of a new system like fears of disadvantage. If the conversations around this topic within the Community Educators Group are any indication, great efforts to quell concerns of disadvantage will need to be made by the administrators, if a 'no-disadvantage' test is dismissed as an option. (Scope Disability Educators Group, sub. DR1005, p. 3)

However, beyond the much greater funding of the NDIS, a further protection against the risk of losing supports is that the nature, frequency and intensity of a person's support needs would be comprehensively and objectively assessed. The assessment process would be person-centred and forward looking. It would consider the supports that would allow a person to fulfil a range of functions, rather than only respond to what an individual cannot do.

Some participants were supportive of a person's support needs being determined by a person-centred assessment rather than inferred from past use — but only in the context of an entitlements based system in which the supports provided matched people's assessed needs:

> The Report raises the question of whether a so-called 'no-disadvantage' test should therefore apply, but ultimately argues against it in favour of comprehensive and objective assessments of the nature, frequency and intensity of a person's current support needs. It proposes that the assessment process be person-centred and forward looking, and consider the supports that would allow a person to fulfil a range of functions, rather than only respond to what an individual cannot do. FAO and NAPWA are supportive of this approach in principle However, if there is any gap between assessment and receiving the assessed benefit, the individual should be at no disadvantage with the support they receive in the interim. (Australian Federation of HIV-AIDS, sub. DR969, p. 9)

In the context of person-centred, forward looking assessments which determine entitlements, the Commission does not consider that 'no disadvantage' tests would be appropriate. This reflects the practical complexity of such arrangements, the fact that needs change over time anyway and their unfairness — given assessment of needs under the NDIS will be objectively based rather than inferred from past service use.

But the Commission recognises that people will naturally worry about losing hard-fought for supports. The NDIA should work, in conjunction with key disability groups, to ensure that potential users know that they would have clear entitlements to their assessed needs.

RECOMMENDATION 3.1

The National Disability Insurance Scheme (NDIS) should have three main functions. It should:

- *cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, create community awareness of the issues that affect people with disabilities and facilitate community capacity building. These measures should be targeted at all Australians*

- *provide information and referral services, which should be targeted at people with, or affected by, a disability*

- *provide individually tailored, taxpayer-funded support, which should be targeted at people with significant disabilities who are assessed as needing such support (but excluding those people with newly-acquired catastrophic injuries covered by the National Injury Insurance Scheme — recommendation 18.1).*

RECOMMENDATION 3.2

Individuals receiving individually tailored, funded supports through the NDIS:

- *should have a disability that is, or is likely to be, permanent, and*

- *would meet one of the following conditions:*

  - *have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support*

  - *be in an early intervention group, comprising individuals for whom there is good evidence that the intervention is safe, significantly improves outcomes and is cost effective*

In exceptional cases, the scheme should also include people who would receive large identifiable benefits from support that would otherwise not be realised, and that are not covered by the groups above. Guidelines should be developed to inform the scope of this criterion and there should be rigorous monitoring of its effects on scheme costs.

RECOMMENDATION 3.3

The NDIS should cover:

- *all residents of Australia who are also one of the following:*
  - *Australian citizens*
  - *Australian permanent residents*
  - *New Zealand citizens who were Australian residents on 26th February 2001*
- *asylum seekers.*

NDIS entitlements should be available to eligible people only while they are within Australia.

The Australian Government should consider reciprocal arrangements for disability support with other countries, including New Zealand, after the NDIS is rolled out.

RECOMMENDATION 3.4

The NDIS should provide advice to people about those instances where support would be more appropriately provided through non-NDIS services. Support should be provided outside the NDIS for people whose:

- *disability arose from a workplace accident or catastrophic injury covered by the National Injury Insurance Scheme (NIIS)*
- *support needs would be more appropriately met by the health and/or palliative care systems, comprising:*
  - *those who would benefit from largely medically oriented interventions (including less restrictive musculoskeletal and affective disorders, and many chronic conditions)*
  - *many people with terminal illnesses*
- *support needs would be more appropriately met by the aged care system*
- *needs were only in relation to open employment, public housing or educational assistance.*

RECOMMENDATION 3.5

The NDIS should put in place memoranda of understanding with the health, mental health, aged and palliative care sectors to ensure that individuals do not fall 'between the cracks' of the respective schemes, and to have effective protocols for timely and smooth referrals.

RECOMMENDATION 3.6

Upon reaching the Age Pension age (and at any time thereafter), a person formerly receiving an individualised package from the NDIS should be the given the choice of:

- *staying with NDIS service arrangements, where their support arrangements would continue as before, including any arrangements with disability support organisations, their group accommodation, their local area coordinator and their use of self-directed funding*

- *moving to the aged care system, where they would be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches).*

If a person over the Age Pension age requires long-term residential aged care then they should move into the aged care system to receive that support.

The Australian Government funding responsibility for the support of aged people using disability services should be along the lines specified in the National Health and Hospitals Network Agreement.

In implementing this recommendation, a younger age threshold than the Age Pension age should apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

RECOMMENDATION 3.7

Following the transition spelt out in recommendation 19.1, the NDIS should fund all people who meet the criteria for individually tailored supports (as specified in recommendations 3.2 to 3.4), and not just people who acquire a disability after the introduction of the scheme.

RECOMMENDATION 3.8

The supports to which an individual would be entitled should be determined by an independent, forward-looking assessment process by the NDIA, rather than people's current service use.

4 The role of the community and the NDIS

Key points

- The community — particularly, not-for-profit organisations — will play a vital role across all tiers of the NDIS and across a wide range of activities from specialised services provision to activities that promote engagement and employment for people with disabilities.

- The NDIS will create opportunities and challenges for not-for profit organisations.
  - Many will continue to provide specialised services supports for people with disabilities funded by the NDIS (tier 3).
  - There will be greater opportunities for them to improve and extend services.
  - They will be less reliant on the charity dollar for reasonable and necessary services.
  - They will provide supports with a much more individualised approach, freeing up their capacity and potential to act more broadly.

- The NDIS should retain the valuable contribution of not-for-profit organisations in terms of community engagement, common sense and grass roots contact. In particular:
  - they have the ability to harness fundraising, volunteering and community networks to freely provide activities of benefit to people with disabilities
  - their broader activities in the community (tiers 1 and 2 of the NDIS) can reduce the need for more costly individually-funded services and supports.

- The National Disability Insurance Agency (NDIA) should improve engagement of the community with people with disabilities by:
  - forming a 'compact' with not-for profit disability service providers
  - undertaking local initiatives, including improving access to buildings and public spaces, to address disability issues within the community
  - offering modest grants that leverage engagement by community clubs and associations with people with disabilities
  - specifying a role for local area coordinators to connect participants in the NDIS with the local community and to build the capacity of the community for such interaction.

- The NDIA should also consult with relevant not-for-profit organisations and government agencies on the best arrangements for community capacity building or social inclusion initiatives. This is to ensure that any overlap or paper work burden, or displacement of funding, are kept to a minimum.

4.1   Introduction

People with disabilities have many connections with the community — for example, with other individuals, not-for-profit organisations (such as disability service providers, and community-based clubs), local councils, businesses, community health centres, schools, and public libraries. They make a contribution to, and derive benefits from, this broad community.

This chapter considers:

- the importance of promoting community participation and inclusion (including employment) for people with disabilities

- how this objective could be achieved through engaging the community by way of community capacity building and the not-for-profit sector

- issues arising about the role of the community from the NDIS.

Some of the material in this chapter overlaps with existing chapters in the Commission's report — principally, chapter 3 on who is the NDIS for, chapter 5 on what individualised supports will the NDIS provide, and chapter 10 on delivering disability services.

4.2   The importance of community participation and inclusion of people with disabilities

In understanding what is community participation and inclusion, it is helpful to refer to the terms used in the WHO International Classification of Functioning, Disability and Health (ICF). The ICF defines functioning, disability and health as three multi-dimensional concepts relating to: the body functions and structures of people; the activities people do and the life areas in which they participate; and the factors in their environment which affect these experiences. It is the last two of these concepts that are particularly relevant to community participation and inclusion, where:

- 'activities and participation' include:

  - 'interpersonal interactions and relationships' such as basic interpersonal interactions, relating with strangers, and informal social relationships

  - 'major life areas' such as education, work and employment, and economic life

  - 'community, social and civic life' such as community life, recreation and leisure, religion and spirituality, human rights, and political life and citizenship

- 'environmental factors' include:

  - 'products and technology' such as the design, construction and building products and technology of buildings for public and private use

  - 'attitudes' such as individual attitudes of friends and health professionals, societal attitudes, and 'social norms, practices and ideologies'

  - 'services, systems and policies' such as relating to housing, communication, transportation, health, education and training, and labour and employment.

Promoting the participation and inclusion of people with disabilities in the community is an important policy objective for all Australian governments. It is evident in:

- the United Nations Convention on the Rights of Persons with Disabilities, which Australia has ratified, where a guiding principle is 'full and effective participation and inclusion in society' (United Nations 2006, article 3c)

- the Council of Australian Government's (COAG's) National Disability Strategy 2010–2020 — which covers six policy areas including policy area one — inclusive and accessible communities — and policy area four — personal and community support (Australian Government 2011a)

- COAG's National Disability Agreement, which has as its objective that people with disabilities and their carers have an enhanced quality of life and participate as valued members of the community (Australian Government 2009b, paragraph 6)

- Australian, state[1] and territory, and local government's social inclusion policies, which also apply to people with disabilities (box 4.1 in relation to the Australian Government social inclusion agenda and principles)

- the objectives of a raft of individual government initiatives specifically promoting the participation and inclusion of people with disabilities by engaging the broad community (next).

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[1] For example, the:

- Tasmanian Government has a Social Inclusion Strategy 2009, which 'acknowledges the entrenched and seemingly intractable social exclusion' of some groups within the community, including people with disabilities, and a Disability Framework for Action, which sets out the Government's 'vision for Tasmania as an inclusive and caring community' (sub. DR1032, p. 5)

- ACT Government's Future Directions: Toward Challenge 2014 focuses on actions to enhance inclusive practice across business, sports, arts, recreation and community generally (sub. DR1012, p. 1).

Box 4.1   **The Australian Government's social inclusion agenda and principles**

Social inclusion agenda

The Australian Government's social inclusion agenda seeks to make Australian society a more inclusive one as well as to overcome the processes leading to, and the consequences of, social exclusion. The agenda sets out six priorities:

- supporting children at greatest risk of long term disadvantage

- helping jobless families with children

- focusing on the locations of greatest disadvantage

- assisting in the employment of people with disabilities or mental illness

- addressing the incidence of homelessness

- closing the gap for Indigenous Australians.

Social inclusion principles

To guide its social inclusion agenda, the Australian Government has adopted a set of principles developed by the Australian Social Inclusion Board.

Aspirational principles

- reducing disadvantage

- increasing social, civil and economic participation

- developing a greater voice, combined with greater responsibility.

Principles of approach

- building on individual and community strengths

- building partnerships with key stakeholders

- developing tailored services

- giving high priority to early intervention and prevention

- building joined-up services and whole of government solutions

- using evidence and integrated data to inform policy

- using locational approaches

- planning for sustainability.

Sources: DEEWR (2011c,d).

While the policy objective is clear, compelling evidence from large-scale Australian surveys and the *Shut Out* report reveal relatively poor levels of community participation and inclusion of people with disabilities. (Information on the

participation of people with disabilities in employment is given in chapter 6 and appendix K.)

- The ABS General Social Survey 2006 (appendix N, table N.1) indicated that:

  - 84 per cent of people with a core activity restriction aged 18 to 64 years had no face to face daily contact with family or friends outside the household compared with 79 per cent of people with no disability or long-term health condition

  - 64 per cent of people with a core activity restriction had no other forms of daily contact with family or friends outside the household compared with 57 per cent of people with no disability or long-term health condition

  - 12 per cent of people with a core activity restriction could not or often had difficulty getting to the places needed compared with 2 per cent of people with no disability or long-term health condition.

- The ABS Survey of Disability, Ageing and Carers 2009 (appendix N, table N.2) indicated that:

  - 18 per cent of people with a profound core activity limitation aged 15 to 64 years had no social contact in the last three months compared with people with less than 1 per cent of people with no disability[2]

  - 3 per cent of people with a profound core activity limitation did not leave home in the last 12 months for culture or leisure participation compared with 0 per cent of people with no disability

  - 41 per cent of people with a profound core activity limitation did not participate in any culture or leisure activity away from home in the last 12 months compared with 10 per cent of people with no disability

  - 18 per cent of people with a profound core activity limitation did not use any type of communication (for example, phone, SMS, Internet, mail) in the last three months compared with less than 1 per cent of people with no disability.

- The ABS Survey of Disability, Ageing and Carers 2003 (appendix N, table N.3) indicated that 11 per cent of people with a profound core activity limitation aged 15 to 59 years lived in a private dwelling alone compared with 7 per cent of people with no reported disability.

- Drawing on seven waves of the Household, Income and Labour Dynamics in Australia (HILDA) Survey (appendix N, table N.4), Yu (2009) found that young people aged 15 to 24 years with sensory disability, 'other disability', or disability from birth were more likely to have significantly lower levels of contact with a

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[2] Although these people had no disability, they were restricted in schooling or employment.

friend or club membership than those in the reference group (that is, those without the type of disability in question or with no disability).

- Wave 8 of HILDA (appendix N, table N.5) indicated that for 2006-07:

  – 46 per cent of people aged 15 to 64 with a 'restrictive condition'[3] never or rarely chatted with neighbours compared with 30 per cent of people with no restrictive condition

  – 49 per cent of people with a restrictive condition often or very often made telephone, email, or have mail contact with friends or family compared with 68 per cent of people with no restrictive condition

  – 19 per cent of people with a restrictive condition never or rarely encouraged others to get involved with a group that is trying to make a difference in the community compared with 11 per cent of people with no restrictive condition.[4]

- The 2009 *Shut Out* consultation report prepared by the National People with Disabilities and Carer Council (Australian Government 2009a, p. 3) found that a lack of social inclusion and multiple barriers to meaningful participation in the community faced by people with disabilities were the most frequently raised issues in submissions and consultations. More than half the submissions received (56 per cent) discussed the experience of exclusion and the impact of negative social attitudes on the lives of people with disabilities, and their families, friends and carers.

Addressing the relative lower levels of community participation and inclusion of people with disabilities will have important benefits.

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[3] People with a restrictive condition are those with a long term condition, which they indicated limited their ability to work (9 or 10 on a 1 to 10 scale). The age distribution of the restrictive condition group was adjusted to be consistent with the no restrictive condition group.

[4] Despite these indicators, the evidence from HILDA wave 8 on the extent of community participation of people with disabilities is quite mixed. People aged 15 to 64 with a restrictive condition were more likely than people with no restrictive condition to say they:

- often or very often: chatted with neighbours, and made time to keep in touch with friends

- occasionally or sometimes: made telephone, email or mail contact with friends or family; got in touch with a local politician or councillor about issues of concern; made time to attend services at a place of worship; encouraged others to get involved with a group that is trying to make a difference in the community; volunteered spare time to work on boards or organising committees of clubs, community groups or other non-profit organisations; made time to keep in touch with friends; talked about current affairs with friends, family or neighbours; and saw their extended family in person.

- It can lead to improved well-being outcomes of people with disabilities and their carers (in relation to health, employment, education, income, and life satisfaction outcomes).

- It can lessen the longer-term costs of care and support for people with disabilities — indeed, it may prevent people who have modest disability care and support needs from requiring more costly levels of care and support. For example:

    - The provision of public or community transport that are accessible to people with disabilities can reduce the need for them to use taxis and, thus, the associated costs of taxi vouchers.

    - The design of shopping centres that are accessible to public or community transport can enable people with disabilities who can use these transport options to shop for themselves, rather than to have others shop on their behalf.

    - The provision of orientation and mobility services to people with moderate levels of vision impairment can reduce the likelihood of them falling or having accidents that lead to further disability or impairment.

- The community as a whole benefits from inclusive arrangements, not just people with disabilities. In the broadest sense, inclusion can enhance Australia's 'social capital'[5] by engaging more people within the community and, through that, better reflecting the community's diversity.

- To the extent that it creates better networks among people and breaks down stereotypes, it can promote economic (such as employment) as well as social participation.

Addressing societal attitudes and raising awareness about people with disabilities

A factor that is strongly linked with community participation and inclusion of people with disabilities is societal attitudes and awareness. Greater acceptance was a major theme of the *Shut Out* report, noted earlier.

Many participants in this inquiry have stressed that societal attitudes and awareness are a major influence on a person's ability to participate in daily life (box 4.2). Indeed, they noted that, aside from direct support, what people with disabilities require is greater acceptance in society on a day-to-day basis.

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5 Social capital relates to the social norms, networks and trust that facilitate cooperation within or between groups. It can generate benefits to the whole community by reducing transaction costs, promoting cooperative behaviour, diffusing knowledge and innovations, and through enhancements to personal wellbeing and associated spillovers (PC 2003a).

Box 4.2   Participants' views: the importance of addressing societal attitudes and awareness about disability

Australian Human Rights Commission:

There would clearly be roles for institutions administering a NDIS in relation to awareness raising and attitude change pursuant to article 8 comparable to roles of other social insurance agencies such as OHS and motor accident authorities … For example, organisations in the mental health area have described a large scale awareness program comparable with road safety campaigns as a necessary equivalent in providing community inclusion for people affected by mental illness to processes of installing level or ramp access in providing for participation by people with physical disability. (sub. 72, p. 20)

Korey Gunnis and Laurie Strathdee:

Indeed, perhaps educating the public through such avenues as disability advocates raising disability awareness in local communities could be important in reducing stigma, and may help to reduce barriers to participation for people living with disabilities. (sub. 132, p. 4)

Mental Health Coordinating Council:

The social model of disability proposes that barriers, prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognizes that while some people have physical, intellectual, or psychological differences from a statistical mean, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are 'normal'. (sub. 263, p. 2)

Queensland Parents for People with a Disability:

… any new scheme must recognise that the person with disability is not the problem nor "burdensome" but rather that it is the social impacts of living with disability — societal barriers, prejudices and attitudes, as well as lack of supports — which cause burden. (sub. 262, p. 3)

Self Help for Hard of Hearing People Australia:

It is important that all Australians value the NDIS scheme. We propose that any introduction of such a scheme be preceded by a public awareness campaign that highlights the random and unexpected way in which disability can be acquired. The Commission has rightly identified fault to be a poor determinant of need. However, the public awareness campaign needs to go further than criticizing the shortcomings of the current fault-based compensation system. It needs to go further than highlighting the possibility of catastrophic injury. It needs to highlight the random nature of acquisition of disability. (sub. DR728, p. 4)

The Commission recognises that societal attitudes and practices are potentially just as disabling as underlying medical conditions. In this sense, influencing attitudes and practices in society may be one of the most significant roles of the NDIS, outside of its role of directly providing much needed supports. This is considered in the next section on engaging the community.

4.3 Engaging the community

Many participants (for example, Scope, sub. DR841; Prof. Christine Bigby and Dr Chris Fyffe, sub. DR933; Centre for Development Disability Health Victoria, sub. DR901; Victorian Government, sub. DR996; NSW Government, sub. DR922; Karden Disability Support Foundation, sub. DR772; Disabled Surfers Association of Australia, sub. DR1046) stressed the importance of community engagement in respect of people with disabilities.

The remainder of this section considers two broad, but overlapping, routes to community engagement — namely through:

- community capacity building
- not-for profit organisations.

Community capacity building

There are many different views as to what is community capacity building (box 4.3). It is sometimes described as 'community development' or 'community building'. In the context of this report, it is essentially about getting organisations (for example, not-for-profit organisations, local councils and businesses) and individuals within the community to interact more with people with disabilities.

In addition to the broader benefits of community participation and inclusion of people with disabilities noted earlier, participants (for example, Scope, sub. DR841; Prof. Christine Bigby and Dr Chris Fyffe, sub. DR933) identified specific benefits of community capacity building for people with disabilities as including the following.

- Reducing the reliance by people with disabilities on specialised and costly levels of services and support.
- Better leveraging of community resources to support people with disabilities.
- Minimising the risk of people with disabilities trying to access mainstream services and 'bouncing back' to more specialised means of support.

Community capacity building could include the following:

- Improving the community's general awareness and understanding about people with disabilities through public campaigns.
- Creating personal networks that connect people with disabilities to opportunities (such as employment opportunities) they might otherwise miss.

| Box 4.3 | **Participants' views: what is community capacity building** |

National Council on Intellectual Disability said:

> In the context of people with disabilities, community development must be about access and inclusion in all parts of the community from the beginning. This means building the capacity of the community and of people with disabilities and their families, and engaging with the community. In practice this type of work is often carried out by State and Territory Governments and local councils. (sub. DR1000, p. 7)

Scope said that community building and inclusion work 'leverage' community resources to support people with a disability participate in the community. It refers to 'community building activities that works to build communities in order to facilitate the inclusion of people with disability' (sub. DR841). It goes on to describe the following three 'orientations' of 'community building and inclusion':

> *Orientation 1:* individual person-centred work leads to inclusion. Inclusion work and community building happen in direct response to the expressed interests, needs, and aspirations of specific people with a disability.

> *Orientation 2:* opportunities are created in community. Inclusion work and community building require workers to be proactive in identifying, creating and offering opportunities to people with a disability.

> *Orientation 3:* Broad level community change. Inclusion and community building focus on broader structural and attitudinal work. (sub. DR841, p. 7)

The Blue Skies Team considered that research and literature in the area of 'community development' can be drawn upon for the purpose of expanding on 'capacity building (sub. DR947, p. 1).

> … Asset Based Community Development … informs us that three essential qualities must be present for effective community development to occur. It must be:

> 1) Asset Based: focuses on identifying and making visible the assets that can be mobilized and made productive in a community.

> 2) Internally Focused: recognises an inside-out approach to build community as required where the individuals from the community are drivers of the development.

> 3) Relationship Driven: acknowledges interdependence (or connection through relationships) as intrinsic to strengthening individuals and communities and hence relationship building strategies are critical. (sub. DR947, p.1)

- Providing basic training to individuals (for example, paid employees, operators of businesses, or volunteers) to enable them to more effectively relate to, or work with, people with disabilities.

- Providing activities within the community in which people with disabilities can participate.

- Establishing 'circles of support' for people with disabilities and their families consisting of members of the community.

- Providing information to people with disabilities about activities and opportunities (such as employment opportunities) within the community.

- Consulting with, or incorporating the views of, people with disabilities in the provision of community activities and other goods and services.

- Investing in product design, technology, buildings, and public infrastructure and services to enable the inclusion of people with disabilities in the community.

The following real-life examples are by no means exhaustive of what is meant by community capacity building, but illustrate what is involved:

- Talking Taxis is a Victorian Department of Human Services funded project. It was initiated by a MetroAccess worker at the City of Maribyrnong to improve communication between taxi drivers and their passengers. A set of picture boards, personal journey cards and an alphabet board was developed with the assistance of adults with communication difficulties. These sought to improve communication between drivers and passengers, reducing confusion about destinations, payments and routes (Victorian Government, sub. DR996, p. 38).

- The Recharge scheme began in the Victorian Shire of Nillumbik in 2006 to encourage local businesses to provide an accessible power point for recharging electric scooter/wheelchair batteries. It is now implemented by 79 councils and supported by around 1000 businesses and organisations (Nillumbik Shire Council 2010).

- Holiday Explorers is a not-for-profit organisation in South Australia that provides holidays for people with intellectual disability living in that State. The organisation trains volunteers to accompany people with disabilities on the holidays (South Australian Council on Intellectual Disability, trans., pp. 888–9).

- My Place is a not-for-profit organisation in Western Australia that is funded by the Disability Services Commission to provide accommodation support to people with a disability who seek to live in their own community. People with disabilities can receive support to live in their own homes, with a host family, or in their family home (Scope, sub. DR841, attachment, p. 27).

- Sailability is a not-for-profit organisation whose main objective is to encourage and facilitating sailing and boating for people with disabilities. There are around 50 clubs in Australia. Sailability activities range from recreational, therapeutic to competitive activities, from grass-root entry level through to elite world championships and paralympic training. It provides general information about disability, volunteer training, and safety manuals in relation to people with disabilities (Sailability Australia 2011).

- In Tasmania, facilities were built at the Plenty River to provide safe and accessible fishing to anglers with a disability. The facilities were funded by the Australian Government Department of Agriculture, Fisheries and Forestry and

co-managed by the Inland Fisheries Service and Paraquad Tasmania (Inland Fisheries Service 2008).

- Scope's Community Educators Group, consists of a team of people with disabilities that provide training to members of the community to help them understand the complexities of life with disability. The Group joins with several other teams within Scope to provide this training, primarily with the Disability Educators Group, Scope Young Ambassadors, and the Community Inclusion and Development Department (sub. DR1005, p. 1).

- Technical Aid to the Disabled Queensland (TADQ) supports volunteers with technical skills throughout Queensland to make practical aids for people with disability. It has partnered with Foresters Community Finance to purchase two new office units in Brisbane. Investment in these properties through Foresters Community Finance will enable TADQ to increase the support it provides to technically skilled volunteers who created aids for people with disabilities and move TADQ towards stability and financial independence (Foresters Community Finance 2008).

- Campaigns to raise awareness and change attitudes within the community about disability (box 4.4) .

Box 4.4   Campaigns to raise public awareness about disability

- The publicly-funded Don't Dis My Ability campaign promotes awareness and appreciation of people's *abilities* rather than their disabilities. Both confronting and inclusive, it uses real people to challenge misconceptions of helplessness. The campaign uses print and television commercials and arts events, as well as various ambassadors both with and without disability. The face of the campaign — *First Flight Crew* — is a break dance troupe made up of people with various disabilities.

- The Prime Minister's Employer of the Year Awards recognise employers who excel in employing and retaining people with disability. The awards also promote the efforts of employment service providers which are organisations that help people with disability gain and keep a job.

- The Australian Network on Disability (AND) is a non-profit organisation comprised of employers who are committed to greater awareness and inclusion of people with disability. AND is resourced by its diverse membership of over 100 organisations, such as Westpac Group, IBM Australia, Compass Group, the Children's Hospital at Westmead, and the Australian National University. An example of the initiatives by AND members are awareness strategies by McDonald's, where disability awareness training is integrated into corporate policy and all levels of employee education. The awareness covers both the needs of employees and those of customers.

Governments at all levels fund specific community capacity building initiatives. For example, the Australian Government funds several programs:

- An Accessible Communities Program, which includes:
  - the Make Local Communities Accessible for all Australians initiative where grants are provided to local governments with matched funding to make local buildings and public spaces more accessible for people with disabilities so that they can fully participate in the community
  - the Leaders for Tomorrow initiative— this is intended to help people with disabilities become leaders in business, the community and government through mentoring and leadership development
  - funding for providing digital playback devices and improved access to digital content in public libraries around the country
  - funding to establish the RampUp website in partnership with the ABC to provide discussion, news, debate, humour and general information for people in Australia's disability communities
  - the Cinema Access initiative, which seeks to provide new audio description and captioning technology to improve cinema access for people who are deaf, blind, visually or hearing impaired. Funding of the project is shared with cinemas
  - the Liveable Housing Design initiative developed with the residential building and construction industry to promote new voluntary guidelines for housing built to meet the needs of older Australians and people with disabilities.

- A Volunteer Grants Program, which makes specific grants available to not-for-profit organisations to reimburse the transport costs incurred by volunteers with disabilities who are unable to drive.

- Specific programs or initiatives to support employment of people with disabilities or mental illness — identified within the Social Inclusion Agenda — including the:
  - Disability Employment Services Program, which helps job seekers with disabilities, injury or health conditions find work
  - Job Access Program, which provides information and advice to people with disabilities and their employers
  - Developing a Disability Action Plan, which provides guidelines to businesses to help improve access and opportunities.

- Measures as part of the Service Delivery Reform, which are intended to transform Government human services service delivery to enable people to participate more fully in the economy and their community, and to support the design and delivery of better and more comprehensive support for vulnerable and isolated people (Department of Human Services, sub. DR1052, p. 5).

There are also numerous state and territory government as well as local government initiatives. An example of one state government's community capacity building initiative is presented in box 4.5.

Box 4.5   The Victorian Community Building Program

This Program was introduced in 2010 by the Victorian Government to assist the community to include people with a disability and their families and carers by:

- helping people and organisations work together more effectively

- improving community understanding about the needs and aspirations of people with a disability

- developing and implementing responses to community priorities

- ensuring that the needs of people with a disability are the focus of community planning

- supporting service providers to assist people with a disability to live the sort of life they choose

- developing easy ways for people to access the information they need about services, community activities and consultation opportunities.

The program is implemented by 60 RuralAccess, MetroAccess and deafaccess officers across the State, mostly located within local government. They are supported by Victorian Department of Human Services regional staff with specific responsibility for community building.

Initiatives funded under the program include: Active Oceans: Making a splash in south-western Victoria; Gippsland Auslan Interpreting Service; Greater Geelong's Inclusive Events Planning Group: Working to a common goal; Let's Get Connected: Creating Transport solutions in East Gippsland; Mildura Tourism Ambassador project: participation through volunteering; Monash Medical Students Disability Awareness project.

Sources: DHS Victoria (2011b); Victorian Government (sub. DR996).

The Commission envisages that these government initiatives will continue and complement the NDIS.

Not-for-profit organisations

Another, often overlapping, way of engaging the community to become involved with people with disabilities is through the activities of not-for-profit organisations — principally through not-for-profit disability service providers, and community clubs and associations.

Not-for-profit organisations:

- are established for a community purpose
- add value to the community through how their activities are undertaken
- can mobilise voluntary resources more readily than government agencies or businesses
- undertake many activities that would not be undertaken by government agencies or businesses
- may generate benefits that go beyond the recipients of their services and the direct impacts of their outcomes.

They obtain funding from three broad sources — philanthropy (for example, donations from organisations and individuals, sponsorships, other fund-raising), government and self-generated income (for example, membership fees, sales of goods, income from services, investment income).

A particular group of not-for-profit organisations currently has a prominent role in the community as *disability service providers* (box 4.6). Their activities include:

- information, evaluation and research (for example, the Association of Genetic Support of Australasia, Physical Disability Council of Australia, Scope)
- generic or individual advocacy (for example, Darwin Community Legal Services, National Council on Intellectual Disability)
- respite (for example, Holiday Explorers, Wesley Mission)
- accommodation support (for example, Yooralla, Life Without Barriers)
- personal care (for example, Perth Home Care Services, AbleCare Attendant Care Services)
- therapies (for example, Cerebral Palsy League Queensland, Autism Spectrum Australia, Scope)
- community access (for example, YMCA)
- employment support (for example, Australian Disability Enterprises, Endeavour Foundation, Scope)

- referral and assessment (for example, the Tasmanian Gateways Services operated by Baptcare and Mission Australia)

- aids and appliances, including those that are custom-made (for example, TADACT — Technical Aid to the Disabled ACT)

- planning (for example, Mamre Pave the Way)

- family support (for example, Carers Australia)

- fundraising support for individual cases (for example, Lions International Australia, Hartley Lifecare)

- representation on issues affecting industry (for example, the Attendant Care Industry Association, National Disability Services)

- representation on issues affecting people with disabilities and their carers (for example, Alzheimer's Australia, Gippsland Carers Association, Association for Children with a Disability).

Box 4.6   **Some data on not-for-profit providers of social services**

ABS data on not-for-profit organisations involved in 'social services' that include but are not limited to disability services show that:

- there were around 5800 not-for-profit organisations at the end of June 2007 providing 'social services'

- these organisations employed around 220 000 people at the end of June 2007

- around 255 000 people volunteered with these organisations during 2006-07

- these organisations received $11.7 billion in income during 2006-07 with 55 per cent from government funding, 22 per cent from income from services (delivery and provision), 10 per cent from sales of goods, 4 per cent from donations, sponsorships and fundraising, and 9 per cent from all other income (such as investment income; rent, leasing and hiring; and membership fees)

- more than two-thirds of government funding were volume-based (for example, funding based on the volume of services provided such as per bed funding to residential aged care services) with a further third allocated on a non-volume basis (for example, general purpose grants or funding for a specified purpose but not dependent on the volume of services provided).

Source: ABS (2009, *Not-For-Profit Organisations, Australia, 2006-07*, Cat. no. 8106.0).

Some of these not-for-profit organisations undertake more than one activity (for example, Scope, Yooralla, Mission Australia, and Novita Children's Services).

Another group of not-for-profit organisations consists of community clubs and associations. The activities of these 'grass roots' organisations are as diverse as those of disability service providers and include sport, cultural and recreational activities, religious worship, advocacy, and environmental activities. The activities may be available to a broader population or they may target people with disabilities (box 4.7).

Box 4.7   How two grass roots organisations interact with people with disabilities

Little Athletics NSW (and its affiliated centres) offers athletics activities to all school-aged young people. It also provides opportunities for athletes with a disability to become involved in the sport.

- At a local level, athletes with disability can access regular activities (such as the athletics program and coaching) at a little athletics centre. An athlete with a disability may be totally integrated into the existing program without the need for modifications. Sometimes, the centre will adapt activities (rules, equipment and so on) to allow athletes with a disability to participate. The extent of the modifications will depend on the athlete's level of impairment or disability.

- Little Athletics NSW conducts invitations events for athletes with disability at the State's track and field championships. Events are conducted as multi-disability events. Competitors compete against a multi-disability standard time or distance for their disability classification.

DVA Theatre Company has been an established community theatre company for over 20 years based in Banyule, Victoria. It is a company of adult performers with intellectual disability working alongside volunteer facilitators and a professional artistic director. It has 25 participants aged 18 to 60 years and has no selection process based on audition. It resources its activities largely by fundraising through its public performances and through the efforts of volunteers.

There is a range of government initiatives in respect of not-for-profit organisations — some of which have a social inclusion objective. For example, Australian Government initiatives include the following.

- There is a National Compact between the Australian Government and the Third Sector intended to build the capacity of not-for-profit and other non-government community organisations to improve community well being

- A Not-For-Profit Sector Reform Council has been established to drive the Government's plans to reform the sector. It will examine the scope of a national one-stop-shop regulator, provide advice on streamlining tendering and contracting processes for Government funded not-for-profits, consider

harmonisation of federal, state and territory laws on fundraising and support the implementation of the National Compact mentioned earlier.

- The Volunteer Grants Program provides grants of between $1000 and $5000 to not-for profit community organisations to assist their volunteers and encourage volunteering. The Program has $16 million available for disbursement in 2011.

- A National Volunteering Strategy is being developed and expected to be completed in 2011. It is intended to articulate the Government's 'vision and commitment to volunteering in Australia and highlight the key issues and emerging trends in volunteering over coming years'.

4.4   NDIS issues

Many participants expressed concerns or comments about the role of the community with respect to the NDIS. These focused on the following.

- The impacts of the NDIS on the current role of not-for-profit disability service providers, particularly in relation to: their philanthropic, fundraising and volunteering activities (Anglicare Sydney , sub. DR799, pp. 21–2; Blind Citizens Australia, sub. DR758, p. 11; Endeavour Foundation, trans., pp. 517–8; Royal Guide Dogs Tasmania, trans., p. 10; Inclusion Melbourne, sub. DR668, p. 1); their economic and social contribution (Lifestart, sub. DR1037, p. 2); their ability to undertake tier 2 activities (Vision Australia, sub. DR793, p. 4); nd existing government funding of some of their activities such as for advocacy, information and referral services (Tasmanian Government, sub. DR1032, p. 15).

- The impacts of the NDIS on existing government initiatives to encourage community engagement with people with disabilities (for example, Queensland Government, sub. DR1031, p. 10; ACT Government, sub. DR1012, p. 1; Bolshy Divas, sub. DR1003, p. 9).

- The need for NDIS funding of initiatives that encourage community engagement with people with disabilities (Housing Resource and Support Service, sub. DR930, p. 10; National Council on Intellectual Disability, sub. DR1000, p. 8; Bolshy Divas, sub. DR1003, p. 4; Scope, sub. DR841, p. 6) or that encourage the community participation and inclusion of people with disabilities (Vision Australia, sub. DR793, p. 5).

- The need for an evidence-base on the efficacy, effectiveness or cost-effectiveness of different forms of community engagement (for example, Scope, sub. DR841, p. 8).

The community — particularly, not-for-profit organisations — will play a vital role across all tiers of the NDIS, and across a wide range of activities from specialised disability service provision to community participation and inclusion. The NDIS will create new opportunities for not-for-profit organisations, but it will also present particular challenges to those who are disability service providers.

Many not-for-profit disability service providers will continue to provide specialised services and supports for people with disabilities funded by the NDIS (tier 3). Providing these services and supports is their mission. They are well-positioned to provide these services and supports (they have a strong client base, capital investments, a skilled workforce, and expertise). However, with the shift away from block-funding to largely consumer-driven funding of tier 3 services and supports, there will be pressure on these organisations to become more attuned and responsive to the needs of participants in the NDIS and to use their resources more effectively.

- Consumers will increasingly be interested in the price of the services and supports available, the choices available to them and variations in quality.

- Some not-for-profit organisations might attract people with disabilities for tier 3 funded services and supports by using their capacity to engage the community or mobilising their volunteers to provide 'free' supports that promote economic and social participation.

Although many not-for-profit disability service providers will remain in their current areas of activity, some will change their activities largely in response to improved funding for tier 3 services and supports that would become available under the NDIS.

- They might reorient some of their activities from tier 3 to tiers 1 and 2. For example, they might divert more of their resources, fundraising and volunteering activities to:

  - providing (conventional) supports to people not eligible for the NDIS (tier 2), or to providing (the few) supports not covered by the NDIS under tier 3 (such as a special wheelchair for athletes)

  - raising community awareness about reducing barriers to employment or social inclusion in tier 1, or to increasing their activities for people with disabilities in tier 2 (family supports and community access).

- They might become disability support organisations — that is, they might now focus on providing intermediary services to tier 3 participants such as personal planning, assembling packages of support from specialist and mainstream providers, undertaking administrative tasks for people using self-directed

funding, or providing connections to the activities of community clubs and associations in which NDIS participants can participate.

- They might move into other areas of community need like addressing homelessness, child poverty, education and unemployment. For example, 60 years ago, the Endeavour Foundation established its first school for children with disabilities who were overlooked by the Queensland school system. In 1986, when it was operating 25 schools across Queensland, the State Government took over the administration and funding responsibility of the schools. Endeavour Foundation subsequently moved into other activities such as providing education programs to young adults with an intellectual disability, employment to people with disabilities, and accommodation services (www.endeavour.com.au, accessed 16 June 2011). With increased funding for individualised services under the NDIS, Endeavour may embark on new services for participants in the NDIS.

- Some not-for-profit disability service providers will face additional demands by people with disabilities in tier 2 for information and referral to mainstream providers of health and other services. However, resources, fundraising and volunteering efforts that are freed-up from providing tier 3 services and supports could be redirected to providing more tier 2 (or indeed tier 1) services.

The Commission recognises the importance of retaining the valuable contribution of not-for-profit organisations, and others in the community, in terms of community engagement, common sense and grass roots contact (box 4.8):

- Not-for-profit organisations have the ability to harness philanthropic fund-raising, the efforts and creativity of volunteers, and community networks and connections to 'freely' provide activities of benefit to people with disabilities.

- By involving volunteers and others in the community in the provision of activities for people with disabilities, not-for-profit organisations can help generate greater understanding and acceptance of people with disabilities.

- A strategy aimed at greater social and economic involvement of people with disabilities needs to include more than current providers of specialist disability supports. Many organisations (for example, community clubs and associations, local councils and businesses) are engaged in a diverse range of activities involving the community — from sport and recreation, politics, religious worship to art and craft. These activities can benefit people with disabilities in terms of their economic (such as employment) and social participation. The organisations offering these activities will themselves benefit from the involvement of people with disabilities.

Box 4.8   Community solutions

Grass roots and other community organisations can harness the creativity and spirit of the community to find solutions to problems in ways that governments find hard to do. For example, they can harness:

- people's sense of humour — Movember

- the competitive streak of people — Tidy Town contests

- people's creative talents and skills — community folk festivals.

The following examples illustrate how community organisations can find solutions that provide significant benefits for people with disabilities or who are disadvantaged.

Fundraising

The 24 Hour Mega Swim was a fundraising idea conceived in 2001, by Carol Cook who was diagnosed with multiple sclerosis in 1998. The Mega Swim is promoted as a fun team event comprising no more than 15 swimmers. Each team must have a swimmer in the water for the entire 24 hours. Swimmers raise money through sponsorship. The first Mega Swim, held at the City of Yarra's Fitzroy Pool with 10 competing teams raised $22 000. In 2011, there were many more teams with over 20 Mega Swims held Australia-wide, which raised more than $1.1 million. Funds raised are directed to the Go for Gold Foundation that provides scholarships to people living with multiple sclerosis to 'aspire and achieve' to the best of their ability as well as to financial assistance programs that provide direct support for people living with multiple sclerosis.

Creating employment opportunities

Through a chance meeting, a future employment relations manager of a social enterprise called Nexus got to know a Canberra supermarket owner. In 2010, they discussed having people with mental illness work at the supermarket. Now, half of the supermarket's employees are Nexus' clients who have mental illness. According to Nexus, this has helped their clients regain their confidence and self-esteem.

Social inclusion

The Choir of Hard Knocks consists of homeless or disadvantaged people. It formed in Melbourne with its first rehearsal in 2006. Singing teacher and choir master, Jonathon Welch, was inspired by an article in an old Reader's Digest magazine about a choir for homeless people that had been set up in Montreal. Welch approached RecLink, a charity that organises sport and recreation events for homeless or disadvantaged people. RecLink agreed to support the choir and recruitment began through flyers on the streets, meeting with agencies, visits to crisis accommodation centres and hostels. At its first rehearsal, more than 20 people turned up. The choir busked to raise money to make a CD and then used the profits to put on a concert at Melbourne Town Hall before 1600 people. The choir now has 50 regular participants. It continues to make public performances and CDs.

Sources: ABC (2011); Canberra Times (2011); Multiple Sclerosis Limited (2010).

To this end, the Commission considers that the relatively small proportion of NDIS funding allocated for tier 1 and 2 functions could be applied in the following ways:

- Following consultations, the establishment of a general 'compact' or 'understanding' between the NDIA and the not-for-profit sector currently involved in providing supports for people with disabilities that would:
  - use the voluntary and philanthropic resources freed up by the creation of a properly funded NDIS for activities that promote community engagement and employment for people with disabilities
  - clarify their new role in the scheme.
- The undertaking of low cost but effective local initiatives by community groups and businesses to address disability issues within the community — such as the social isolation of people with disabilities evident from large scale surveys and the *Shut Out* report noted earlier. These initiatives could include:
  - improving access to buildings and public spaces
  - better signage
  - a campaign to increase the number of people with disabilities volunteering or participating in the activities of clubs and associations
  - community fairs that catered for people with disabilities
  - local community recognition for businesses that provided employment opportunities for people with disabilities.
- The creation of incentives and support by the NDIA for community groups and others in the community to undertake particular activities of benefit to people with disabilities. These incentives could include:
  - one-off grants or block funding for not-for-profit organisations that act as disability support organisations to provide more tier 1 and tier 2 activities — for example, in developing connections between people with disabilities and the wider community
  - a flat fee for providing referral services for people with disabilities in tier 2 where the organisation can prove it has had a net additional call on its services as a result of the NDIS
  - seed or even block funding to establish new tier 3 activities such as providing emergency attendant care services, or providing connections and networks between NDIS participants and community-based activities to leverage funds from not-for-profit organisations
  - one-off grants to enable organisations to reposition themselves with respect to the NDIS through new business plans and strategies

– small grants to grass roots organisations that leverage their voluntary involvement with people with disabilities. This could include grants to assist in: capital investments (for example, to partly fund boat modifications that make it easy for a sailing club to involve people with disabilities); training and information for volunteers on how to relate to people with disabilities; volunteer mentoring; and taking out public liability insurance to cover people with disabilities.

- The NDIA could also assign an explicit role to local area coordinators to help tier 3 participants to identify existing activities within the community, such as sailing, bushwalking, volunteering in soup kitchens, scrapbooking, community gardening, and land-care, and in the use of mainstream for-profit services (gyms, cinemas), where a light touch may overcome social and physical obstacles to interaction with people with disabilities. This role might include the provision of information to NDIS participants about activities, or actively connecting or referring NDIS participants to the organisations responsible for the activities, or actively contacting organisations themselves.

In considering which actions it should take, the NDIA must be mindful of the myriad of Australian, state and territory, and local government 'community capacity building' and 'social inclusion' initiatives (as well as a broader range of HACC services) in order to avoid unnecessary overlap and adding to the paper work burden of not-for-profit organisations, and to avoid displacing funding. Accordingly, an important first step would be for the NDIA to consult with not-for-profit organisations and relevant government agencies and, if necessary, negotiate with them a memorandum of understanding.

There will be a need for the NDIA to ensure rigorous performance monitoring and evaluation of any funding decisions. The Australian Government (Treasury) could initiate an independent evaluation of these decisions after such time when sufficient information of their effects emerges.

Not-for-profit organisations that have participated in this inquiry have overwhelmingly supported increased funding and greater consumer choice. Change for not-for-profit organisations is not without risks and some challenges. Given the level of unmet need and the remarkable adaptability of not-for-profit organisations, the Commission is confident of their continuing vital role in relation to people with disabilities.

RECOMMENDATION 4.1

The NDIA should improve engagement of the general community and people with disabilities by:

- *forming a 'compact' with not-for-profit disability service providers that would:*
  - *use the voluntary and philanthropic resources freed up by the creation of a properly funded NDIS for activities that promote community engagement and employment for people with disabilities*
  - *clarify their new roles in the system*
- *undertaking local initiatives, including improving access to buildings and public spaces, to address disability issues within the community*
- *offering modest grants that leverage engagement by community clubs and associations with people with disabilities and that would be likely to yield social or economic benefits consistent with the size of the grant. The effectiveness of such financial incentives should be independently evaluated after a reasonable period*
- *specifying roles for local area coordinators and disability support organisations to connect NDIS participants with the local community and to build the capacity of the community for such interaction.*

RECOMMENDATION 4.2

Prior to implementing recommendation 4.1, the NDIA should consult with not-for-profit organisations and relevant government agencies on the best arrangements for 'community capacity building' or 'social inclusion' initiatives to ensure that any overlap or paperwork burden, or displacement of funding, is kept to a minimum.

5 What individualised supports will the NDIS fund?

Key points

- The NDIS will fund a broad range of individually tailored supports. Key supports will include aids and appliances, personal care, domestic assistance, respite, home and vehicle modifications and community access.

- More flexible funding arrangements, including the option for self-directed funding, will allow NDIS provided supports to be better tailored to individuals' needs.

- The NDIS will provide and fund specialist disability supports on a 'reasonable and necessary' basis.

- There should be no income or asset tests for obtaining funded NDIS services and no requirement for a front-end deductible. However, a front-end deductible should be considered if, after the implementation of the NDIS, small claims clog up the NDIS assessment process.

- The scheme would fully fund the number of services (primarily therapies) that were appropriate to the person and were in keeping with current clinical practice, evidence based practice and/or clinical guidelines, with people choosing further episodes meeting their full costs.

- The provision of health, education, employment, housing, transport and income support will remain a mainstream concern. The NDIS would however, have a role in promoting the development of, connecting people to, and where needed, supporting the activity of people in mainstream services.

- The NDIS should not respond to problems or shortfalls in mainstream services by providing its own substitute services. To do so would undermine the sustainability of the scheme and the capacity of people with disability to access mainstream services.

5.1 Introduction

Supports and assistance aim to increase opportunities for people with disability by tackling such things as inadequate housing, the need for personal care, and assistance in getting about and participating in the community. Sometimes, just

simple things — a wheelchair, an hour or two of planning help every so often — can allow a person to live a full life in the community. In other cases, more intensive supports are required. The first part of this chapter considers the supports and assistance of relevance to people with disability. These include:

- specialist disability supports, such as attendant care, community access and home and vehicle modifications (section 5.2)

- generic or 'mainstream' services and assistance available to the whole population, including health, housing, transport, education and employment services (section 5.3)

- income support, including the Disability Support Pension and Carer Payment (section 5.4).

The second part of this chapter looks at how the NDIS would provide specialist supports tailored to a person's individual needs, including:

- what constitutes 'reasonable and necessary' (section 5.5)

- what role, if any, means testing, front-end deductibles or co-contributions should play (section 5.6).

Information and referral services target a much broader group of individuals. The role of the scheme in providing these services is outlined in chapter 3.

5.2   Specialist disability supports

This section deals with the proposed *scope* of specialist disability supports to be funded by the NDIS. As noted by the AIHW, these are supports that 'enable people with disabilities to participate in society by meeting their disability-related needs' (2007a, p. 95). Specialist disability supports will be oriented to people with support needs that would otherwise not be reasonably met without NDIS funding, or that are not more appropriately met by other systems (chapter 3).

The broader issue of self-directed funding and which supports would form part of an individual budget is explored in greater detail in chapter 8. But anticipating that chapter, the Commission considers that there is a strong rationale for people with disability to have more power over the way support services are delivered to them and their type. Self-directed funding — the capacity (but not the obligation) for people to make choices about how to spend their individualised budget — will be key in giving people with disability greater autonomy.

The NDIS would provide the full range of specialist disability supports currently provided under the National Disability Agreement (NDA) (box 5.1).

Box 5.1   Specialist disability supports provided by the NDIS

Aids and appliances — a range of products to improve functioning, enable a person to live at home and in the community, and enhance independence. These would range from low to high-tech aids and encompass toilet supports or hand-held showers, continence aids, wheelchairs, hearing aids, mechanical lifters, electronic communication devices, equipment to support the use of Braille, and artificial limbs.

Home modifications — modifications to the structure, layout or fittings of a home to enable an individual to utilise the home's standard fittings or facilities.

Vehicle modifications — modifications which allow individuals to access, travel as a passenger or drive a motor vehicle.

Personal care — supports that enable an individual to take care of themselves in their home and community. These include help with showering, bathing, dressing, grooming, personal hygiene (including bowel and bladder care/toileting), assistance with eating and/or drinking, mobility and transfers, health maintenance (such as oral hygiene, medication use or regular and routine exercises and stretches). This would also include nursing care when this was an inextricable element of the care of the individual (for example, when meeting the care and support needs of a ventilated quadriplegic).

Community access — supports to provide opportunities for people to enjoy their full potential for social independence — the intention is to allow people a lot of choice and innovation in this area. Supports would focus on learning and life skills development, including continuing education to develop skills and independence in a variety of life areas (for example, self-help, social skills and literacy and numeracy). Supports would also focus on enjoyment, leisure and social interaction. The supports would:

- include facility and home-based activities, or those offered to the whole community

- include supervision and physical care

- range from long-term day support to time-limited supports.

Respite — to provide a short-term and time-limited break for people with disabilities, families and other voluntary carers of people with a disability. These services are designed to assist in supporting and maintaining the primary care giving relationship, while providing a positive experience for the person with a disability and include:

- respite care provided in the individual's own home

- respite care provided in a community setting similar to a small 'group home' structure

- host family respite that provides a network of 'host families' matched to the age, interests and background of the individual and their carer

- 'recreation/holiday programs' where the primary purpose is respite.

(Continued next page)

Box 5.1 **(continued)**

Specialist accommodation support — such as group homes and alternative family placement encompassing support for clients to carry out essential activities of daily living (net of the standard contribution from a person's income for rent). The NDIS would not necessarily *own* the 'bricks and mortar' but the funding it provided would cover the cost of capital.

Domestic assistance — to enable individuals to live in the community and live on their own, such as meal preparation and other domestic tasks; banking and shopping; assistance with selecting and planning activities and attending appointments.

Transport assistance — provision or coordination of individual or group transport services, including taxi subsidies.

Orientation and mobility training — to increase the independence of individuals to move safely around their environment and build confidence in using public transport or crossing roads.

Supported employment services and specialist transition to work programs that prepare people for jobs.

Therapies — such as occupational, speech and physiotherapy, counselling, and specialist behavioural interventions.

Local area coordination and development, which are broad services, including individual or family-focused case management and brokerage (disability support organisations), as well as coordination and development activity within a specified geographical area. They aim to maximise people's independence and participation in the community. Crisis/emergency support — following, say, the death of a family member or carer, including emergency accommodation and respite services.

Guide dogs and assistance dogs — including the reasonable costs of being assessed for the dog, the dog, user training and veterinary costs.

Whole-of-life personal planning — for those who need more wide ranging or intensive assistance with planning in order to achieve more personal aspects of well-being such as with relationships, aspirations and achievements, employment, financial security as well as succession planning.

Since the Commission favours a significant capacity for someone to tailor their supports, box 5.1 focuses on the *intent* of the proposed supports, rather than their precise form. Self-directed funding would open up opportunities for more innovative and imaginative approaches to service delivery. For example, community access for individuals with an intellectual disability may take the form of going to the movies rather than more traditional, costly and often less effective day programs. (See chapter 8 for a real life example.)

Given the capital-intensive nature of supported accommodation services and the current deficit of places, this particular issue warrants further discussion. The

provision of prostheses and the incremental costs of running specialist disability equipment are also discussed in more detail — both were raised as issues by participants.

Supported accommodation

Individuals with disability have diverse housing needs, so it makes sense for the NDIS to employ a range of options to address those needs (table 5.1). In some cases, mainstream housing services will be the most appropriate solution, and where people need assistance, the role of the scheme would be to refer people to public housing or to act as their advocate in dealings with public housing authorities. (Mainstream housing is discussed further in section 5.3.) Some people (irrespective of whether they live in public housing or in their own homes), may require modifications to make their homes more accessible. The need for housing modifications would form part of a broader assessment of need for people receiving individually tailored supports.

Table 5.1 **Responding to diverse housing needs**

Affected individuals	*Range of possible NDIS supports*
People seeking independent living arrangements	• Referral to appropriate housing options
Public housing tenants	• Home modifications (subject to a person occupying the house for a reasonable period of time)
People residing in their own home	• Home modifications (subject to a person occupying the house for a reasonable period of time)
People residing in private rentals	• Home modifications (subject to agreement with the landlord and the person occupying the house for a reasonable period of time and this being reflected in a tenancy agreement)
People who require specialist disability accommodation	• NDIS-funded specialist housing (supported accommodation) which would enable people to move out of home in line with community norms
Homeless people	• Outreach services

For another, smaller group of people, supported accommodation will be the most appropriate response. This includes, but is not limited to so called 'group homes' which encompass accommodation and support for activities of daily living. Currently, supported accommodation is in short supply.

This gives rise to a number of serious problems. It is common for people to remain in their parents' homes for longer than is appropriate. Some people (typically those with a newly acquired disability) remain in hospital due to a lack suitable alternatives. In other cases, people are placed in respite on an ongoing basis. Not only is this an inappropriate outcome from the individual's perspective, it

effectively 'blocks beds', such that many other families can no longer use respite services. In more critical cases, parents who can no longer cope, relinquish care of their children. A number of participants highlighted the significant problems arising from shortages in this area:

> Clinicians in Queensland have identified that the lack of ABI [Acquired Brain Injury] beds and slow stream brain injury rehabilitation beds is causing significant "bed block" in the acute sector. (Brain Injury Australia, sub. 371, p. 22)

> Two weeks ago I made a decision that for the sake of my personal health and my family's wellbeing I could no longer care for my almost 11 (big boy) year old son due to his ongoing unpredictable aggression, epilepsy and autism due to Tuberous Sclerosis Complex. Naively I thought there would be a group home somewhere for him to have a controlled and structured environment with all of the emotional attachment. Now he is in a respite centre blocking a bed. (Gippsland Carers Association Inc, sub. 133, p. 12)

The NDIS would provide supported accommodation, including for those with significant and enduring psychiatric disability, subject to an assessment of need. This would include group home type arrangements but there would also be flexibility to employ innovative responses (such as the Melbourne-based Haven project which provides long-term housing for people living with mental illness). However, it would not extend to clinically staffed homes in the area of mental health. (Examples of clinical and non-clinical based accommodation arrangements are provided in appendix M.) The scheme would not necessarily own the 'bricks and mortar', but the funding it provided would cover the cost of capital.

Given the shortfall in specialist housing, and the consequent impact on families, the Commission has explored some more innovative housing options.

An innovative approach to supported accommodation

The choice of housing for any individual involves a series of tradeoffs — people make choices, constrained by their budgets, about location, amenity and whether they live alone or with others. For example, a person might choose to live closer to town but be prepared to share the expense of doing so by living with others. Alternatively, one might value living alone and so elect to live further out. For others, being close to family or friends or proximity to public transport might be paramount. However, for many people with disability — particularly those that require supported accommodation — their choices are constrained. This is partly due to scarcity, but also reflects the inability of the current systems to take account of individuals' preferences.

The Commission considers that there are strong grounds for individuals to have the capacity to cash out specialist disability housing (where the NDIS has assessed

individuals as needing this form of accommodation). This would involve estimating the value of rent (priced at the market rate, not the subsidised rate) for a given person using supported accommodation, which then could be cashed out for accommodation services. This process would allow the person to make more flexible decisions about accommodation.

For example, people could make choices about who they lived with. Alternatively, they (or their family) might add some funding to pay a higher rent for a private dwelling in a more convenient location or with features better suited to the person. Similar arrangements apply in other countries such as the United States, though they do not specifically target people with disability (US Department of Housing and Urban Development 2011).

The Commission notes that this approach could potentially extend to the purchase of housing.[1] Extending the 'cashing out' model to the purchase of housing is more complicated. To be workable, there would need to be clear guidance on matters such as who would be responsible for undertaking repairs and whether a party's equity stake would change if they undertook capital improvements. The NDIA should first gain experience in delivering services under the simpler, rental-based model as part of the national roll-out before exploring this option.

The separation of 'bricks and mortar' from supports

Typically, the provision of supports is tied to a particular residence — the 'bricks and mortar'. But tying support to accommodation unnecessarily restricts the choices people with a disability have. One of the advantages of the model outlined above, is that it could effectively unbundle the support from the accommodation. A number of participants called for the separation of care and support from the bricks and mortar. For example, Yooralla recommended:

> That the scheme fund supported accommodation in a way that enables the level of supports a person receives to be changed without requiring the person to move house. That this funding model breaks the connection between funding for housing and funding for support. (sub. 433, p. 7)

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[1] This would involve estimating the present value of the expected stream of rents over a much longer period of time, say for example 40 years. Individuals would have access to an amount of that value, to use to purchase a dwelling (though they would be expected to pay an amount in interest equivalent to the cost of capital to the NDIS, based on the long-term bond rate). The scheme would have an equity stake in the dwelling, which would decline over time and be extinguished after a given number of years had elapsed (40 years in this example).

The same approach was advocated by the National People with Disabilities and Carer Council and the Disability Investment Group:

> Appropriate housing is vital to people with disability. It increases their choices and opportunities to live in the home and location of their choice. Equally important is the fundamental right of people with disability to be able to choose with whom they live, just like any other Australian. Finally, investment in personalised support is critical to people with disability being able to maintain dignity, independence and participate in and feel part of their local communities.
>
> The Council supports the inclusion of accommodation in the NDIS but believes that to maximize opportunities for people with disability, support and accommodation needs should be separated. (sub. 1026, p. 3)
>
> An alternative approach is to provide more choice, by separating the care and support from the physical infrastructure or dwelling. This recognises that preferred suppliers of accommodation and care and support to people with disability may not be the same organisation. In this alternative framework, providing housing should form part of an affordable housing strategy because disability is just one among many possible causes of poverty. However, the housing must be accessible. (DIG 2009a, p .41)

The Commission sees merit in this approach and considers that the NDIA should encourage the development of an accommodation model that gives people the capacity to unbundle the provision of the 'bricks and mortar' and the provision of services. This would allow people to choose to live in a dwelling owned by one provider and to purchase supports from another. This could encompass a wide range of living arrangements. For example, people could separate out their housing support and pool their funds with others to form a group home, or request that a DSO organise other potential co-occupants.

Inevitably, the NDIS will not be able to meet *all* of an individual's housing preferences. But the provisions outlined above would allow individuals to decide which preferences they valued most highly and which preferences they were prepared to trade off.

The issue of age-appropriate transitions to independent living affects a broad group of people with disability (not just those requiring supported accommodation) and is discussed further in section 5.5. But anticipating that section, the Commission considers that the NDIS should facilitate the transition of young adults, into public or private housing or supported accommodation, if they wished to do so, in line with community norms.

Homeless outreach

At present, people with disability are over-represented among the homeless. As UnitingCare Australia observed:

> We now know that people with a mild intellectual disability and or mental illness are over represented in the criminal justice system, in licensed boarding houses and among the homeless. (sub. 291, p. 17)

Similarly, Brain Injury Australia noted:

> A number of local surveys have attempted to estimate the number of people with an ABI who are homeless. A 1998 "Down and Out in Sydney" project found that 10% of people using inner city Sydney hostels and refuges had cognitive impairment as a result of alcohol-related brain injury or TBI [Traumatic Brain Injury].[2] (sub. 371, p. 6)

Traditionally, these individuals do not access disability services. Some jurisdictions currently provide outreach services, in an effort to improve the access of homeless people to mainstream and disability supports. The primary purpose of outreach services is to connect people to support, and educate people about the services available within their community.

While an important goal of the NDIS will be to assist people with disability to access suitable and secure housing, outreach services will still be required. The Commission considers that the NDIS should provide homeless outreach services and work collaboratively with not-for-profits (such as Matthew Talbot Homeless Services) and other government agencies, including Centrelink, to connect people to a broader range of services.

Prostheses

The Commission received clear and consistent feedback from participants in response to proposed NDIS coverage of prostheses. Participants called upon the Commission to include prostheses in the scope of services and supports provided by the scheme. According to the Australian Orthotics Prosthetics Association (AOPA), a prosthesis (or prosthetic device) is:

> 'an externally applied device used to replace wholly, or in part, an absent or deficient limb segment' (International Organisation for Standards, 1989). It is not intended to describe dental implant prostheses, joint replacement prostheses, or cochlear implants. (AOPA sub. DR971, p. 7)

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2 TBI refers to an injury which is the result of force applied to the head from a motor vehicle accident, a fall or an assault.

Prostheses are used by individuals of all ages, though many tend to be older. The Australian Orthotic Prosthetic Association (2010) note that there are more than 20 000 amputees in Australia, three quarters of whom are over 60 years of age. Of the 2500 new amputees each year, 75 per cent occur as a result of vascular disease. The remaining 25 per cent of amputations result from injuries, tumours or congenital conditions. This is consistent with data from the Artificial Limb Scheme which reveals that people over 60 account for over half of prosthesis recipients.

Prostheses in Australia are currently subject to many of the same problems facing the disability system generally. Namely, that the provision of prosthetics is reported to be insufficient and grossly underfunded, as well as being subject to delays (sub. 301). For instance, waiting times in the public health system are reported to be a *minimum* of three months (subs. 241 and 301). As one participant observed:

> Amputees also indicate that current waiting times are between three and 12 months within the public system, causing lengthy periods without mobility or independence. (Ms Noonan, Limbs 4 Life, trans., p. 862)

Participants also noted the inequity of support across jurisdictional boundaries, between people who had acquired their amputation from different causes, as well as those who were eligible for compensation or private insurance and those relying on the public system (for example, subs. 237, 241 and 301). A number of participants also remarked that the quality of prosthetic limbs available from publicly funded schemes is also very limited. They note, in the case of prosthetic feet, for example, many schemes limit this quality to a basic rigid (SACHS) foot, which was designed in the 1950's (sub. 301).

Prostheses in the NDIS

As noted in the Commission's draft report, there are sound reasons why an NDIS would have a role in funding prostheses for those individuals who were covered by tier 3 of the scheme:

- Prosthetics, particularly for limbs, have the same functional purpose as wheelchairs and other mobility aids that would be covered by the NDIS.

- Like many other aids and appliances, prosthetics used for mobility would generally be on a long-term basis, and require maintenance and replacement. In this way, the ongoing costs would be similar to those for aids and equipment.

- There may also be some scope for consolidation of current delivery methods. Limbs 4 Life note that there are over ten different funding programs for prosthetics (sub. 301).

In its draft report, the Commission sought feedback on what aspects of prosthetics provision should fall under the NDIS. Limbs 4 life argued that NDIS coverage should be comprehensive:

> In response to the question pertaining to 'which items should be included', all items, products and services which support an amputee's rehabilitation and ability to regain mobility and independence should be included. They include maintenance and repairs of artificial limbs, supporting suspension liner products, stump socks, creams and lotions (where applicable to promote good hygiene and skin care) and the treatment/support required from a prosthetist, physiotherapist, occupational therapist, orthotist, and where necessary social workers. (sub. DR980, pp. 3–4)

However, the provision of prosthetics spans many stages. As the South Australian Government points out, the earlier stage includes the fitting of an interim prosthesis, and is related to the rehabilitation process carried out in hospitals:

> … rigid removable dressings, interim prostheses and stump shrinkers in the acute phases post amputation are normally undertaken as part of acute care and early rehabilitation programs in health. Definitive prostheses are then provided by the community care model …

> Hospital based or day rehabilitation health services provide interim prosthetic care to maximise ambulation ability and re-integration to home and community life. The client is usually ready for discharged from the health service once they can manage their prosthesis and ambulatory aid (stick, frame or crutches) safely.

> This is the point where the client would be ready to access the NDIS. This would include the provision of definitive prosthesis. Liaison between the health service and the NDIS would be critical at this point. (South Australian Government sub. DR861, p. 12)

The NDIS should provide permanent prostheses as part of its tier 3 supports. Prostheses supplied should meet the standard reasonable and necessary test as in other aids and appliances. The NDIS should allow co-contributions from amputees who wish to upgrade their prostheses, subject to an agreement about the costs of, and responsibilities for, repair. The Commission considers that the fitting of interim prostheses and the related rehabilitation process should remain the responsibility of the health system.

Additional costs of everyday living

Aside from the costs of supports and aids and appliances, several participants pointed to the additional costs of everyday living they face. Examples include higher electricity costs, which may be due to the use of medical equipment or to provide temperature control, and higher water costs for washing clothes.

> Many disabilities have difficulty stabilising body temperature and require air-conditioning to assist sleeping, comfort and prevent seizures. Incontinence results in washing machines going regularly. (Alison Bennett-Roberts, sub. 319, p. 3)

The NDIS may have a role in providing supports around some of the *additional* costs of living related directly to disability. However, this would need to be consistent with the NDIS' role as a funder of specialist disability supports, as opposed to a funder of all general costs of living (such as regular groceries). In general, participants have already made such a distinction, focusing on the additional costs related to disability (subs. 184, 376, DR783 and DR868).

Enteral or PEG feeding

One area where living costs are higher for people with disability is in regard to medically necessary diets (subs. 569, 376). In particular, enteral or Percutaneous Endoscopic Gastrostomy (PEG) feeding is likely to lead to higher food costs than would otherwise be necessary. Northcott Disability Services argued that:

> … the scheme should not fund general lifestyle needs (eg food) but should fund these needs if they would not have existed in the absence of a disability (eg. specialised food /formula required for a person who is PEG fed). (sub. 376, p. 17)

The Commission considers that the NDIS should cover the additional costs associated with PEG feeding, and had noted this in its draft report. This was generally welcomed by participants (subs. DR868 and DR783).

Electricity and other utilities

Many participants have also noted that people with disability have greater needs for electricity or heating (subs. DR862, DR702 and DR780). Two particular examples were of increased heating needs for people with Multiple Sclerosis (sub. 184) or for amputees (sub. DR692). Reflecting this, a number of state governments have implemented electricity rebate schemes which provide concessions under certain circumstances for people with disabilities (box 5.2).

It is not clear the extent to which these schemes sufficiently cover the additional costs of electricity arising from the disabilities concerned, particularly when energy costs differ between regions. Nor is it clear whether the eligibility criteria are sufficiently broad for people with disabilities to benefit from these concessions — some of the current schemes appear narrow in their focus, with some employing diagnostic-based eligibility criteria.

The Commission considers that a consistent national approach would be preferable to current state-based arrangements. Individualised supports, under tier 3 of the scheme, should therefore include some coverage of the *additional* costs of utilities directly related to disability. The extent of coverage would be based on an assessment of an individuals' reasonable needs. Among other things, the assessment should take account of whether individuals are in receipt of the Pension Supplement which is available to some DSP recipients (currently $58.40 per fortnight), given that it incorporates allowances to partly cover the costs of the GST, utilities and telephone bills.

Ideally, the Australian Government would obtain some offsets from state and territory governments for its greater responsibility in this area.

Box 5.2   **Examples of current concessions for utilities**

Under the medical cooling concession, Victoria provides a 17.5 per cent discount off electricity costs over a six month period from 1 November to 30 April for concession cardholders with multiple sclerosis and other qualifying medical conditions such as Parkinson's, motor neurone disease, scleroderma and lupus.

The Queensland Government provides financial assistance to low-income Queenslanders with a medical condition which requires the use of electricity for cooling or heating. Assistance of $216 per year is provided for two years, at which time eligibility is reviewed. The concession is provided to assist individuals with increased electricity costs incurred by frequent operation of an air-conditioning unit in order to regulate body temperature.

Similarly, in New South Wales, the Medical Energy Rebate is for eligible customers who have a medically diagnosed inability to self-regulate body temperature when exposed to extremes (hot or cold) of environmental temperatures. Generally associated with certain medical conditions such as Parkinson's disease and multiple sclerosis, the rebate provides $161 a year for eligible customers.

The Western Australian Government provides a subsidy of $502 per annum to help offset energy costs for financially disadvantaged persons or their dependents with thermoregulatory dysfunction. The subsidy is aimed at people who hold means-tested concession cards (or the dependants of such people), who require heating and/or cooling to control the temperature in their homes under specialist medical advice.

5.3   The role of 'mainstream' services

Mainstream services are those that people generally use. They may include government-funded services (education, health care, public housing and transport,

and employment services) and services provided by the private sector (a swimming pool, gym, the theatre and holidays). People with disabilities use these services like anyone else. It is generally accepted that disability services should not replace mainstream or other specialist services available to the broader population, or be expected to meet all the needs of people with disability. Indeed, a key policy goal is to move away from primary reliance on specialist disability services to the use of mainstream services or at least to a mix of the two (KPMG 2009). The former often isolates people with disability and reduces their power and choice. Strengthening access to mainstream services for people with disability is one focus of the current intergovernmental agreement on disability services.

But, as KPMG observed, achieving change requires a new way of thinking:

> These reform directions require a shift from seeing the disability service system as the source of all support for a person with a disability, to seeing the disability service system as one part of a broader service response that complements other informal and formal supports (including health, education, housing, employment and income support). This shift towards more inclusive mainstream services and a greater emphasis on informal supports is in line with progressive thinking that is at an early stage internationally (2009, p. 2).

Access to generic services, such as health and housing, can affect demand for NDIS-funded services, and vice versa. It will be important for the scheme not to respond to problems or shortfalls in mainstream services by providing its own substitute services. To do so would weaken the incentives by governments to properly fund mainstream services for people with a disability, shifting the cost to another part of government (such as from a state government to the NDIS, or from one budget 'silo' to another). This 'pass the parcel' approach would undermine the sustainability of the scheme and the capacity of people with a disability to access mainstream services. If governments and departments thought that the NDIS would address both specialist and mainstream service needs, people with a disability may well be seen as a lesser priority for the generic services provided by government.

The risk of mainstream service providers adopting a 'pass the parcel' approach was recognised by participants, as were the difficulties of establishing clear boundaries:

> The Commission's recognition of the importance of the connectedness between the disability service system and other mainstream service systems such as education, health and housing is well received by Lifestart. The intent of the NDIS to focus on meeting 'disability related needs' reinforces the need for strong relationships between the NDIS and other service systems. This requires a clear enunciation of supports which will be available under the scheme so that the community is clear about entitlements and other service systems and governments do not renege on appropriate provision for mainstream or generic services, resulting in cost shifting and a diminution

of disability services. The intersection of the NDIS with the National Disability Strategy must reflect these safeguards. (Lifestart, sub. DR1037, p. 2)

We note that cooperation and collaboration between the NDIS and other mainstream and existing disability services may offer the best way to meet the needs of persons with a disability. However, we note the difficulty involved with coordinating many different departments and organisations. It is also a valid point that many "mainstream" services are provided by State governments. A further complication arises given that the exact boundaries between the roles of mainstream services and specialist disability services is often unclear. (KPMG, sub. DR973, pp. 7-8)

Even where boundaries are clear, they may not be consistent between states. As the Queensland Government observed, 'States and territories may include different service types in their mainstream service delivery' (sub. DR1031, p. 12).

The Commission proposes that the NDIS seek memoranda of understanding (MOU) with the relevant mainstream service sectors. The MOUs shoud detail the separation between specialist disability and mainstream services and the process for making referrals between the two.

The remainder of this section considers each of the key mainstream services. The Commission considers that such services should mainly remain outside the scope of the NDIS. That said, the NDIS should have a role in connecting people to them and, where needed, supporting the activity of people in mainstream services. Several participants recommended this approach, including the South Australian Government:

People with disabilities need a multitude of services, some of which would be the responsibility of other areas of government (housing, health and aged care, also public transport, education etc.). While a new disability care and support system is unlikely to be able to provide and finance all of these services, the system should link with other service providers to ensure that people with disability have equal access to the community. Existing disability services have tended to assume a 'whole of life' responsibility, including care and support as well as education, accommodation and employment. This has limited the capacity of the disability system to adequately meet demand. It also denies people with disabilities the same access to mainstream services as all other members of the community. There is significant room for increased mainstreaming of services. (sub. 496, p. 11)

Employment

Any disability policy should strongly encourage employment, since it is a major route to financial and social independence, as well as a general contributor to the community as a whole. Given that, access to employment services should be freely available to all people with disability, not just those in the scheme.

Australia's employment outcomes for people with disabilities are significantly lower than the OECD average (chapter 6). One explanation could be the damaging effects of the Disability Support Pension on people's incentives to work, rather than the disability employment services themselves. The Australian Government has taken some steps to address these disincentives by making it easier for people on DSP to get help to find work. But more reform is warranted, including providing greater support to employers to encourage employment of people with disabilities (chapter 6).

The Department of Education, Employment and Workplace Relations provides open employment services through Job Services Australia. This covers disability employment services (which are uncapped and include specific supports for people with disabilities) and generic employment services (which offer standard employment assistance to job searchers regardless of disability). The number of people with disabilities covered by Job Services Australia would be much greater than those eligible for NDIS-funded supports. Given that, and the significant benefits from having a single coherent system for open employment services, these services should lie outside the NDIS.

The Commission considers that employment services should remain a mainstream concern. However, a clear exception would be 'job readiness' programs (targeted support) currently provided by the disability services sector. These intensive post-school programs last around two years, and help people in the transition to the workforce. The 'Transition to Work' program in NSW is a good example.

Another clear exception would be supported employment. Supported employment is designed to assist those 'people with disability whose employment opportunities would be very limited or non-existent if they were to compete for a job in the open labour market' (Australian Government 2010d, p. 10). Some 70 per cent (13 166) of supported employees have an intellectual disability. One quarter (4530) of supported employees were living in residential facilities and group homes (Australian Government 2010d).

Supported employment is provided by Australian Disability Enterprises (ADEs). These enterprises provide a broad range of supports in the workplace:

> Australian Disability Enterprises manage a complex range of factors associated with their unique role. These include building their commercial business around their supported employee workforce and providing a wide range of support services that far exceeds the general obligations of an employer. (Australian Government 2010d)

The importance of NDIS coverage of supported employment was underscored by participants:

> ADE's provide a very important employment option for some people with disability. In some cases they are the only employment type which provides the level of support necessary for a person to stay in employment; in other cases they offer a great entry level and pathway to open employment.

> … allowing the purchase of these services via an NDIS package effectively uncaps the program. The current capping has been one of the greatest criticisms and drawbacks of the ADE service. Studies show that governments spend roughly twice as much to keep a person with disability in day programs, as it does to fund them in an ADE place. In addition, the DSP is reduced when a person is earning a wage in an ADE – hence the public, as well as the personal, economic benefits are much greater through increased access to ADE employment options. (Yooralla, sub. DR755, p. 2)

The NDIS would have a strong employment focus. Hence, access to supported employment would be governed by what was 'reasonable and necessary', rather than by a predetermined number of places.

Housing is critical

As noted by Carers Australia, 'Lack of access to suitable, stable and affordable housing consistently ranks as one of the biggest challenges for people with a disability' (sub. DR981, p. 35).

People with disability are key users of mainstream housing assistance provided by the Australian and State and Territory Governments. Assistance takes a variety of forms, including public and community housing, home purchase and home ownership assistance, Indigenous housing, state and territory private rental assistance and Australian Government rent assistance. Of these, two are of particular relevance — Commonwealth Rent Assistance and public housing.

While the exact number of people with disability receiving Commonwealth Rent Assistance (CRA) is unknown, around one in five (220 000) recipients also receive the disability support pension. The Australian Government provided $2.9 billion for CRA in 2009-10, and the average payment across Australia was around $2500 per year (SCRGSP 2011).

Public housing

Public housing is an important source of affordable, stable accommodation for people with disability. At 30 June 2008, 31 per cent of public housing households contained a household member with disability (SCRGSP 2010). Across Australia,

the average annual cost (including of capital) per public housing dwelling was $27 345 (SCRGSP 2011)[3].

Three aspects of public housing are particularly relevant to people with disability — the general availability of dwellings, the appropriate location of the dwellings and the suitability of the dwelling for the person. Some have expressed concerns about the adequacies of all three aspects:

> … the stock of public housing in Australia has fallen … much of this stock is seen to be physically inappropriate for persons with a disability because of the design of the dwelling, distance from public transport, poor quality maintenance etc. (Beer and Faulkner 2008, p. 49-50)

The availability of public housing has decreased over recent years, with the number of dwellings falling from 343 000 in 2005 to 333 000 in 2010 (SCRGSP 2011). By comparison, there are around 200 000 applicants on the waiting list for public housing (table 5.2).

However, the share of special needs households — including those with a household member with disability — is increasing as a proportion of all new households allocated public rental housing.[4] Nationally, new public housing tenancies allocated to households with special needs was 65 per cent in 2009-10 (table 5.2). Moreover, surveys suggest that the vast majority of public housing tenants for whom location was important, reported that their needs were met.[5]

Problems regarding the availability and location of dwellings are common to all prospective clients of public housing. For that reason, decisions about where to locate public housing and how much to invest, should remain a mainstream policy concern. Nevertheless, there is scope to trial innovative models of service delivery that are more consistent with self-determination for people with disability. These include 'cashing out' (for accommodation purposes only) the value of public housing and allowing people more flexible accommodation choices.

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[3] This figure is the cost of providing assistance (including the cost of capital) per dwelling (excluding payroll tax) expressed in 2009-10 dollars. For more detail refer to table 16A.4 in SCRGSP 2011.

[4] Other households defined as having special needs are those with a principal tenant aged 24 years or under, or 75 years and over, or has one or more Indigenous members.

[5] As part of a national survey, tenants were asked whether particular aspects of the amenity and location of their dwellings were important to them and, if so, whether they felt their needs were being met. 86 per cent of survey participants, who identified location as being important, reported that their needs were met.

Table 5.2	**Public housing shortages by jurisdiction**			
	Total number of public rental dwellings at June 30, 2010	Applicants on waiting list at June 30, 2010	New allocated households 2009-10	New allocated households for people with special needs[a] 2009-10
	no.	no.	no.	no.
NSW	115 686	60 444	5 861	3 766
Victoria	65 064	50 716	3 799	2 298
Queensland	51 705	30 593	3 886	2 813
South Australia	42 010	25 302	2 249	1 575
Western Australia	31 501	23 723	2 400	1 490
Tasmania	11 460	3 675	921	605
Northern Territory	5 099	3 163	455	304
ACT	10 858	2 479	557	287
Australia	333 383	200 095	20 128	13 138

a Special needs includes any household meeting one of the following criteria: is an Indigenous household; has a household member with disability; the principal tenant is aged 24 years or under; the principal tenant is aged 75 years or over.

Source: AIHW (2011c).

The exact mechanism for doing this in relation to specialist disability accommodation, which was examined earlier, could also apply to public housing generally. And there are strong grounds for doing so. The availability of public housing is often a precondition for independent living. This model would require co-operation with state and territory governments, few of whom responded to the Commission's proposal. The Queensland Government offered the following cautious response:

> In Queensland, people with a disability comprise 47 percent of tenancies in government-managed housing. In the 12 months to 28 February 2011, nearly 60 percent of tenancies allocated to Government-managed social rental housing were to households where at least one person had a disability.

> Potentially, cashing out housing subsidies, if fully funded, could increase the availability of social housing. However further consideration of the complexities around cashing out is needed, including how it would be funded, how entitlements would be determined, and the differences between an expected market rent model and the current social housing income-based concession or rebate amount.

> Given the viability and funding challenges facing the ongoing provision of social housing assistance across Australia, any cashing out scheme would need to be very carefully considered within the broader housing reform agenda and framework under which the Australian Government provides funding for housing support to states and territories. (Queensland Government, sub. DR1031, p. 19)

The cashing out model is one of many options that could potentially improve housing outcomes. Carers Australia highlighted the work done by the Henry Review of Australia's Future Tax System. That review outlines ways in which governments could provide appropriate, affordable and secure housing options to people who are unable to access suitable housing. These proposals are equally relevant for other stakeholder groups, such as the homeless, elderly, indigenous people and young single parents. While outside the scope of this inquiry, they are worth noting and include:

- a high-need housing payment paid to social housing providers for their tenants who have high or special housing needs or who may face discrimination in the private market

- better targeting of, and an increase in the maximum rate of, Commonwealth Rent Assistance so that renters can afford an adequate standard of dwelling.

Other options include harnessing private capital, as occurs in the area of defence housing. (Under the defence housing model, houses are provisioned through construction or acquisition, the majority of which are sold and then leased back.)

Even if access to public housing were improved, there is still the issue of dwelling suitability. All new public housing dwellings should meet any minimum standards for disability access and suitability. Nevertheless, that would still leave a legacy stock that may not meet even those standards, and even new dwellings may not meet the needs of a particular person. Nationally, around one quarter of public housing tenants for whom 'modifications for special needs' were important, reported their needs were not met (AIHW 2011c). As noted earlier, the NDIS would fund home modifications on a reasonable and necessary basis for people in both public and private housing.

Education

People with a disability are more likely to experience poorer socio-economic outcomes. As the New South Wales Government observed, 'education has an important role to play in addressing this issue and preparing young people to participate in a rapidly changing and increasingly complex world' (2010b, p. 5).

Over the last two decades, there have been significant changes in the approach to educating students with a disability. A driving force has been the assertion of the rights of students with a disability to be educated on the same footing within regular or 'mainstream' classrooms rather than in segregated settings. These changes have also been motivated by greater recognition that:

- children and young people with a disability need opportunities to learn and socialise with a broad range of other students if they are to maximise opportunities to participate in the workforce and community life

- mainstream participation of students with disabilities can reinforce positive attitudes to diversity, leading to social inclusion in the community. When children with and without disability interact together on a daily basis, there is potential for long-term acceptance and mutual support

- disability labels can be stigmatising and can lead to lower educational expectations. (NSW Government 2010b)

A significant and growing number of students with disability have enrolled in mainstream education over recent years. For example, in NSW, just under half of students with disability attend mainstream classes in mainstream schools. A further 40 per cent of students attend supported classes in mainstream schools (New South Wales Government 2010b, p. 14).

This transition has been facilitated by several measures, including the Commonwealth Disability Discrimination Act and the Disability Standards for Education. These seek to overcome discrimination based on stereotyped beliefs about the abilities and choices of students with disability. The standards cover enrolment, participation, curriculum development, accreditation and service delivery and student support services (box 5.3). The standards apply to government and non-government education providers. Under section 32 of the Act, it is unlawful for a person to contravene a disability standard and a complaint can be made to the Human Rights Commission.

The Disability Standards for Education require providers to make 'reasonable adjustments' to accommodate a student with disability. That might involve structural modifications for buildings to ensure better accessibility, aids and appliances to increase educational opportunity, teacher aides, development of new curriculum materials, and teacher training. Many of these expenditures are hard to attribute to a specific individual, since they often meet the needs of many students with disability.

Box 5.3   **Disability standards for education**

The *Disability Standards for Education 2005* aim to clarify the obligations of education and training service providers, and the rights of people with disability, under the *Disability Discrimination Act 1992* (DDA).

The Standards give students and prospective students with disability the right to education and training opportunities on the same basis as students without disability. This includes the right to comparable access, services and facilities, and the right to participate in education and training without discrimination. Education providers have a positive obligation to make changes to reasonably accommodate the needs of a student with a disability. The Standards apply to the provision of education and training to persons with disability by 'education providers', including the Commonwealth, states and territories and their public authorities, as well as private sector organisations.

An education provider must make 'reasonable adjustments' to accommodate a student with a disability. An adjustment is a measure or action taken to assist a student with a disability to participate in education and training on the same basis as other students. An adjustment is reasonable if it does this while taking into account the student's learning needs and balancing the interests of all parties affected, including those of the student with the disability, the education provider, staff and other students.

In determining whether an adjustment is reasonable, an education provider should take into account information about:

- the nature of the student's disability
- his or her preferred adjustment
- any adjustments that have been provided previously
- any recommended or alternative adjustments.

The provider may consider all likely costs and benefits, both direct and indirect, for the provider, the student and any associates of the student, and any other persons in the learning or wider community, including:

- costs associated with additional staffing, providing special resources or modifying the curriculum
- costs resulting from the student's participation in the learning environment, including any adverse impact on learning and social outcomes for the student, other students and teachers
- benefits of the student's participation in the learning environment, including positive learning and social outcomes for the student, other students and teachers, and
- any financial incentives, such as subsidies or grants, available to the provider if the student participates.

The DDA and the Education Standards do not require changes to be made if this would impose unjustifiable hardship to a person or organisation.

Source: Attorney-General's Department.

Despite these measures, there remains considerable scope to improve education services and outcomes for people with disability. For example, a NSW Legislative Council Inquiry into the provision of education for students with a disability or special needs found that:

> The overwhelming view among inquiry participants is that there are significant inadequacies in the NSW education system for students with disabilities and special needs. The Committee believes that the NSW Government needs to take immediate action to address these inadequacies if it is to meet its legal obligations to ensure equal access to the education system for all children.
>
> Inquiry participants argued that one of the major barriers to the effective inclusion of students with disabilities and special needs in the education system is the lack of appropriate funding in both the government and non-government sectors. (New South Wales Government 2010b, p xii)

Participants in this inquiry have also highlighted a number of significant problems:

> Neither mainstream or specialist settings have fully inclusive education programs that are leading to measurable developmental learning outcomes for students with disabilities. The current system focuses on disability diagnosis rather than functional capacity to learn, and invests almost exclusively in support services rather than specific educational programs.
>
> Education systems have invested in these 'integration programs' for some years, however they are exclusive and heavily rationed programs. Many children with genuine needs for additional assistance cannot access this funding due to quirks of eligibility filters or lack of overall funding, meaning that their schools are not properly resourced to provide an effective educational program. This is an unacceptable situation for schools, teachers and students, however it can be addressed through reform of the funding system. (National People with Disabilities and Carer Council, Submission to the Review of Funding for Schooling, attachment A to sub. no. DR1026, p. 9)
>
> For the personnel in a school, it is essential that the added responsibilities and time necessary to coordinate a program for a student is given the necessary funding. The responsibility for the education of students with additional needs should not be seen as an 'extra' to be carried out voluntarily on a 'good will' basis. Inadequate appreciation of the additional tasks (and the time it takes to perform them) which accompany students with additional needs, leads to resentment, fatigue and becomes detrimental to the successful carrying out of the role of the teacher. The productivity of an individual staff member affects the productivity of the school.
>
> Essentially, what needs to be acknowledged and planned for, is that for a school to contribute successfully to the full development of the child, the additional tasks that impact on the school's productivity need to be addressed. (Learning Support Team, Armidale High School, sub. no. 67, p. 1)
>
> In autism the situation is dire. Education authorities are not responsive to the needs and perspectives of children and parents. The waste and poor delivery are legend … (Greg Mahony, sub. DR825, p. 1)

The education sector should not have to meet all of the needs of students with a disability. At the same time, shared responsibilities needs to work effectively and not result in unreasonable loads on the individual or their carers. For example, Queensland Parents for People with a Disability highlighted the example of a child with disability attending a mainstream school where the parent was required to attend the school up to three times per day to toilet their child (trans., p. 598).

Rather, partnerships are essential for achieving positive outcomes for students with a disability. These include partnerships between families, communities and schools that are effective in identifying and responding to the needs of individual students as well as inter-agency approaches through collaborative planning and delivery of services.

In this context, the NDIS would have a role in meeting some of the needs of students. This would typically be centred on the provision of goods and services that would be needed regardless of whether a person was attending school or not (personal attendant care, a hearing aid, or a wheelchair).

Collaboration between the NDIS and education departments should be based on agreed frameworks and boundaries. It would be odd if children receiving supports through the NDIS were subject to vastly different criteria for school-based supports. The need for clear boundaries was highlighted by a number of participants, some of whom were concerned that education departments might withdraw funding:

> It is widely accepted that educational outcomes for people with disability is linked to their economic participation. The Council understands the need to establish boundaries between mainstream services and the NDIS. The Council therefore, supports the exclusion of education from the scheme. However, given the need for significant reform in this area the Council believes that the NDIA should take a lead role in advocating for the needs of people with disability in the education system. (National People with Disabilities and Carer Council, sub. no. DR1026, p. 5)

> Given that a NDIS will see an increase in disability funding and support across the nation, Northcott is also concerned that the introduction of a NDIS may be a way in which mainstream services and systems could minimise their responsibilities to children with a disability, believing that the NDIS is providing all the necessary supports. Currently, education systems are not necessarily able to meet their existing responsibilities to support and ensure full and equal participation for students with a disability. Often citing insufficient resources to be able to make the necessary adjustments to support the full participation of a child with a disability, the introduction of a NDIS could see education systems further claiming inadequate resourcing as an issue in meeting the needs of students with a disability. Therefore, Northcott is concerned that mainstream systems may see the NDIS as a way of shifting their responsibilities in this manner, and further be a barrier to full participation and equal rights for children with a disability in these mainstream settings. (Northcott Disability Services, sub. no. DR883, p. 3)

The Commission considers that the NDIA should also have a role raising awareness of the needs of people with disability in the education system and advocating on their behalf.

Health

Primary care and hospital (in-patient and outpatient) based services and medical and pharmaceutical products should remain a mainstream concern. As is the case with the community more generally, people with disability will continue to access the existing health care system as the need arises. Exceptions to this would be when an individual needs care that a familiar personal support worker is best placed to provide or where nursing care is an integral part of the care of the individual (for example, when meeting the care and support needs of a ventilated quadriplegic).

However, people with disability, and in particular intellectual disability, encounter a number of barriers to good health care. As Lennox et al. (1997) and the Centre for Developmental Disability Health Victoria observed:

- communication difficulties between patient and doctor may lead to difficulty in the reporting of symptoms and past history

- carers may not know, or be able to provide, an accurate and reliable history of the person's symptoms or previous medical care

- difficulties using transport can make it hard to independently access medical services and/or independently follow recommendations

- they may experience difficulties understanding the importance and long-term implications of healthy diet, lifestyle choices, and disease screening

- limited literacy may mean they miss out on health information in magazines, books and public health campaigns.

In these instances, the NDIS would have a role in reducing disability-specific barriers. The need for such arrangements was highlighted by a number of participants:

> NDS is pleased that the Commission recognises that the NDIS could have a role in reducing disability-specific barriers to receiving good health care. An important example of this is when some people with disability are hospitalised (particularly those with communication difficulties and/or cognitive impairment). While hospital staff need to be adequately trained in disability issues to minimise the distress these people experience, there is often a need for people to receive additional support from disability support workers they know. The NDIS may be able to make this service available. (National Disability Services, DR 836)

Transport

Access to transport is often a necessity for employment, social participation and access to other services such as health and education. As noted in the National Disability Strategy Consultation Report *Shut Out* (Australian Government 2009a):

> Few things are more fundamental than the ability to get where one needs to go. Without access to transport, participation in such critical activities as education, employment and health care is difficult, if not impossible. Yet this is the situation many people with disabilities find themselves in. (pp. 44-5)

Access to transport is often poor for people with a disability, and many participants have noted the difficulty this causes regarding access to other services (box 5.4).

Improving access to transport for people with disability is an important policy goal. This can be achieved through better access to mainstream public transport (for example, wheelchair accessibility) and private transport (such as by modifying vehicles), and through specific subsidies or provision of taxis and community buses. In some cases, this can be targeted directly by the NDIS. In many other cases, these goals will have to be pursued in the course of wider transport policy by state and territory governments.

Public transport

Many people with disability are physically able to use public transport, either with or without assistance. In 2009, around 73 per cent of people with severe or profound core activity limitations indicated that they could use public transport of some form, while around 21 per cent could not use any (ABS 2010d). Barriers to the use of public transport take several forms. Among the latter group, 37 per cent cited physical accessibility of public transport and associated buildings and infrastructure.

A significant proportion of the public transport network is not accessible to some people with disability. A five year review by Allen Consulting Group (2007) noted that the introduction of the Disability Standards for Accessible Public Transport in 2002 had led to a focused and systematic approach to improving accessibility. That said, the review also highlighted the lack of comparable data to properly gauge the impact of the Standards.

Improvements in accessibility generally relate to the replacement of legacy vehicles. As such, the improvement of accessibility to public transport mainly depends on state and territory governments' ongoing upgrades of public transport. The long timeline for reform was noted in the Shut Out report:

As many noted, the Disability Standards for Accessible Public Transport (2002) has a 30-year timetable. These same standards stipulate that only 50 per cent of buses have to be accessible by 2012. (Australian Government 2009a, p. 45)

Box 5.4   The importance of public transport

Several parties raised concerns about the availability of accessible and affordable transport:

> A priority is the need to ensure people have access to affordable transport. The public transport system is generally hard to navigate in the Perth metropolitan area, and taxis are expensive — even when subsidised with a taxi voucher. (Headwest Brain Injury Association of WA, sub. 448, p. 12)

> Restricted access for people with disabilities to mainstream public transport, and transport funded under other programs such as HACC, places pressure on the CSTDA and/or on people with disabilities themselves to locate and pay for appropriate transport services. There have been anecdotal reports of CSTDA flexible respite funding being used to pay for transport assistance (AIHW 2007).

Many noted that this lack of transport was a barrier to day-to-day access of the community and supports

> The lack of cheap and accessible transport continues to be a barrier for community access, employment, social and recreation options even attending health & medical appointments. Transport options for people with disabilities needs to be a major consideration, if community inclusion and participation are to be achieved. (City of Port Adelaide, sub. 64, p. 2)

> The lack of timely public transport only makes access to current respite beds even worse. The inconvenient and unrealistic travel times make it inequitable to get to services in other municipalities. For example, a carer living in South Morang who obtained respite at the Special Kids facility would take 2 hours and 10 minutes using 5 different individual trips on public transport for a Friday night drop off just to access the service. Then there is the return trip afterwards. (Respite Alliance Whittlesea, sub. DR1006, p. 6)

> Transport is a major problem, particularly for people with physical disabilities. In South Australia, the Public Transport services fail to meet even the basic needs of people with disabilities. The Access Taxi service, because of the small number available, also fails to meet those needs. And yet, as the Productivity Commission reports, being able to attend community venues and to go to one's workplace greatly improves a person's quality of life. (Physical Disability Council of South Australia, sub. DR857, p. 5)

In addition to accessibility, the *availability* of public transport is also an issue for people with disability (subs. 163 and DR869). But a lack of public transport services, particularly in regional areas, is an issue for the wider community. The Commission considers that the provision of public transport, including the planning of public transport routes, is and should remain a mainstream concern. However, an NDIS may be well placed to contribute to future discussions of national accessibility standards, provide useful data, as well as help identify barriers and failures in public transport.

Australian disability parking scheme

Under the Australian Disability Parking Scheme, a single permit allows the same minimum parking rights within and across states. The distribution of disability parking permits continues to be a function of state, territory and local government authorities.

The NDIS would not be well placed to take over the assessment for *all* parking permits, simply because the population accessing permits is likely to be broader than those receiving NDIS assessments (including those with temporary injuries). As such, state and territory road authorities should continue to oversee access to such permits. However, the scheme could act as an assessment agent (on behalf of state and territory road authorities) for NDIS clients who require disability parking permits and, with the agreement of states, issue these permits. The Commission has explored a number of options to help minimise duplicative assessments (chapter 7).

Accessible taxis

Taxis are an important mode of transport for people with disability, particularly for those for whom public transport is not accessible. Currently, all states and territories have taxi fare subsidy schemes for people with disabilities. Each subsidy scheme differs in terms of the subsidy size and eligibility criteria. Moreover, taxi fares differ greatly between jurisdictions — reflecting different booking fees, flagfalls and per kilometre and per minute charges.

Many people continue to experience great personal expense when reliant on this form of transport. For example, one participant noted that it cost around $120 per week to travel 11km by taxi to work — this is after accounting for a 50 per cent taxi subsidy discount and weekly mobility allowance (sub. 197). The out of pocket expense is likely to deter many people from travelling by taxi.

The NDIS may be able to provide a more efficient taxi subsidy to those receiving individualised supports. The limits placed on current taxi subsidies (either as maximum percentages or dollar amounts) are relatively 'blunt' tools which try to distinguish between necessary and discretionary travel. Individualised assessment would allow the NDIS to take account of:

- where a person lives in relation to their service provider(s)
- the availability of appropriate public transport in their area
- the availability of appropriate transport from informal carers
- the true cost of travel in the area, given the taxi tariff rates.

Hence, the NDIS could more heavily subsidise high priority travel, and provide less subsidy for further discretionary trips. On a per person basis, this is likely to result in greater 'mileage'.

These efficiency gains, however, do not mitigate the potentially large costs associated with taxi travel generally. The potential for controlling the costs of taxi subsidies, as well as providing reasonable transport entitlements, will lie in alternative modes of transport. This is likely to include a significant increase in the use of community transports, as well as other innovative programs. To the extent that the NDIS can make alternatives more accessible or affordable, the need for subsidised taxi fares can be decreased. The details of the taxi subsidy levels would need to be decided by the NDIA.

Encouraging savings

Private funds have been seen as a partial remedy to the chronic rationing of disability services. The Australian Government introduced Special Disability Trusts in Australia in 2006 to help people privately finance essential supports for people with disability. Disability trusts have some advantages over other trusts.[6] To address possible risks of being misused, disability trusts are subject to strict criteria covering the trust's purpose, beneficiary, and size.

Users of trusts underscore their importance (subs. 66, DR654 and DR993). But Special Disability Trusts have historically had low take-up rates and several commentators have questioned whether they are practical for the majority of people with disability, noting the large costs involved, and hence the emphasis on larger, rather than smaller asset pools. Moreover, Disability Trusts have been characterised as a way of transferring assets rather than a way of promoting savings:

> … because SDTs are individual trusts they are expensive to establish and maintain as they need auditing, and they are likely to pay retail rather than low-cost wholesale fund management fees. (DIG 2009, p. 34)

> … Nor is the Special Disability Trust viable for small amounts of capital that are still of a size to affect the pension entitlements. The message for parents is make no provision for your family member unless you have the capacity to provide considerably. (sub. 43, p. 2)

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6 For example, Special Disability Trusts offer concessions on means and assets tests for social security payments. These concessions apply to payments for both the beneficiary and the contributors of the trust. By forming a disability trust, a parent caring for a child with disability may transfer assets to the trust, and thereby not have these assets counted towards the means test of a social security payment.

More recent changes to Special Disability Trusts have sought to encourage their take-up. These changes have been welcomed by some participants (see, for example, sub. DR993). But, as noted by the Senate Community Affairs Reference Committee, take up rates remain low despite the new measures:

> the committee is still concerned by evidence suggesting that the take-up rate remains relatively low. Departmental officers informed the committee that as at 30 September 2010, there were only 119 SDTs in operation. (2011, p. 35)

Special Disability Trusts appear to be of limited use for most people with disability, bearing in mind that many families experiencing disability have lower assets and income. Further, with a fully functional NDIS, there would be much less need for such measures. The Commission considers that the role of Special Disability Trusts should be reviewed once the NDIS is up and running. They should be considered against a range of options that might be more efficient in leveraging private assets for the provision of accommodation for people with disability. (Social Impact Bonds may be one alternative or additional option.)

Improving access to mainstream services

As noted earlier in this chapter (and in chapter 3), the Commission considers that the NDIS should have a role in connecting people to mainstream services. Where people approach the scheme for supports that would be more appropriately addressed by a mainstream provider (public or private), the scheme should endeavour to 'connect' people to the relevant provider. That might be as simple as giving them a contact name or number. In other cases, that might involve making an introductory call on their behalf. These 'warm referral' services might be important for particular groups (for example, those with intellectual disability), or in particular circumstances (such as in more urgent or serious matters). In other cases, it might be appropriate for the NDIS to act as an advocate for individuals when dealing with mainstream providers.

While NDIS initiated referrals and advocacy will go some way to improving access to mainstream services, broader-based change is required. As Uniting Care Australia commented:

> there is a need for significant skills development and culture change in many of these services to become inclusive, supportive environments and effective service providers, able to adequately support people living with disability and other complex personal and social issues. (Uniting Care, sub. DR1041, p. 5)

The Commission considers that the NDIS should have a public reporting role. This would involve reporting annually on the progress made by governments, in the areas of education, housing and transport, to improve services to people with

disability. In doing so, the scheme could draw attention to both good and bad examples. Highlighting and disseminating examples of inclusive practices, should help bring about broader-based change.

5.4 Income support

The Australian Government is responsible for the provision of income support targeted to the needs of people with disability, their families and carers (box 5.5). As well as the Disability Support Pension, income support payments and allowances include Carer Payment, Carer Allowance, Sickness Allowance, Mobility Allowance and Child Disability Assistance Payment.

Box 5.5   Australian Government income support payments and allowances

Under the National Disability Agreement, provision of income support for people with disability, their families and carers is a key responsibility of the Australian Government. Outlays on income support payments and allowances to people with disability and their carers in 2009-10 (on an accrual basis) amounted to $11.6 billion for the Disability Support Pension, $2.3 billion for the Carer Payment, $1.5 billion for the Carer Allowance, $83.7 million for the Sickness Allowance, $124.0 million for the Mobility Allowance and $152.3 million for the Child Disability Assistance Payment. The Carer Supplement was not paid in 2009-10.[7]

At 30 June 2010, there were around 792 600 recipients of the Disability Support Pension, 168 900 recipients of the Carer Payment, 508 600 recipients of the Carer Allowance, 57 300 recipients of the Mobility Allowance, 6700 recipients of the Sickness Allowance and 152 400 recipients of the Child Disability Assistance Payment.

Source: SCRGSP (2011, box 14.3, p. 14.8).

Income support for mobility

Mobility Allowance is a two-tiered payment that assists people with disabilities who are involved in qualifying activities and cannot use public transport without substantial assistance. Qualifying activities for the standard rate of payment (of $83 per fortnight) are: looking for work; participation in a Disability Employment Services-Disability Management Service program; or any combination of paid

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7   The first payments of Carer Supplement were made in June 2009. Future payments of Carer Supplement will be paid to those who are receiving Carer Payment and/or Carer Allowance on 1 July each year, starting from 1 July 2010.

employment, voluntary work, vocational training and independent living or life skills training of at least 32 hours every 4 weeks on a continuing basis. A higher rate (of $116 per fortnight) is paid for people working or searching for a job for at least 15 hours a week (plus some other conditions). In June 2009, there were around 56 000 people receiving the allowance at a cost to the Australian Government of around $120 million.

Some people outside the proposed NDIS would be likely to receive Mobility Allowances, and the Australian Government should preserve those arrangements. However, the two flat rates of Mobility Allowance are inconsistent with the individualised approach of the NDIS, in which some people will be assessed as needing very significant support for mobility, and others much less so. In that context, those eligible for funded support should have their assessed mobility needs met by the NDIS, rather than by social security (but they would retain their health care card were they to meet the Mobility Allowance eligibility criteria). For people with significant mobility restrictions, the benefits would often exceed the $2160‑$3020 annual entitlements under the current arrangements. In all cases, individuals would be assessed for what was 'reasonable and necessary' and there would be monitoring to ensure scheme sustainability.

Income support for carers

Other payments, such as Carer Payment, Carer Supplement, Carer Allowance and the Child Disability Assistance Payment encourage the provision of informal care. These payments apply to a broader population than that covered by the NDIS (particularly care for the aged). In theory, these payments could be transferred to the NDIS and directed more flexibly to people's support needs, while reducing the poverty traps that sometimes apply to carers from such payments. However, the issue is complex. The gains may be small relative to the disruption created by the change, especially if carers viewed the change as undermining or diminishing recognition of their critical role. In these circumstances, it could inadvertently impose higher costs on the NDIS.

There may be better options for addressing the work disincentives posed by the Carer Payment (such as by changing the work and education tests in the payment). The Australian Government should investigate these options. Either way, the NDIS should share information about carer payments with Centrelink and take into account the receipt of such payments when assessing people's needs.

The Disability Support Pension

The Commission considers that the Disability Support Pension should be outside the NDIS. It is an income support payment, like unemployment benefits, and covers a broad group of people with disabilities. The DSP is the principal source of income for around 800 000 people with disabilities, of those, around one in five would be eligible for the NDIS. DSP recipients include people whose incapacity for work is due to illness or injury and people without a lifelong disability, who do not need the individualised supports that the NDIS would provide.

There are strong grounds for (further) reform of the Disability Support Pension, given that its design can significantly undermine the NDIS's goals of better economic, employment and independence outcomes for people with a disability. Some people have disabilities so severe that they could not realistically ever work — and the Disability Support Pension would continue to be the major source of long-term income support for them. However, some people using the Disability Support Pension have the potential for employment — with the associated gains of higher income, social connectedness, health benefits and the contribution they could make to the Australian community (and the evidence for such benefits is strong). The Commission has proposed a number of options for reforming the Disability Support Pension, these are outlined in detail in the following chapter.

5.5 The basis for providing specialist disability supports

A key point of distinction between existing arrangements and those proposed under an NDIS would be the obligation for the scheme to deliver the package determined by the independent assessment of need, rather than the present arbitrarily rationed amount. This feature is an essential element of avoiding the chronic underfunding that has beset the current disability system. However, that does not mean that the provision of supports will be unconstrained. Indeed, in other, better resourced schemes — such as no-fault accident insurance schemes that provide lifetime care and support for catastrophic injuries — service provision is 'bounded' by the concept of reasonable and necessary.

For example, in NSW, the Lifetime Care and Support Authority stated:

> we will pay your reasonable and necessary treatment, rehabilitation and care services … This is decided on a case by case basis, and means you will get what you need — not things that are simply nice to have … (LTCSA NSW 2011).

In its draft report, the Commission recommended that the NDIS fund 'reasonable and necessary' supports, and there was support among some participants for this approach (see, for example, DR832). But as the Tasmanian Government observed, what constitutes reasonable and necessary (and the distinction between needs and wants) will 'be critical to the final model' (sub. DR1032, p. 13). So it is not surprising that many participants sought greater clarity and certainty about what 'reasonable and necessary' might mean in practice:

> At present the proposal is that 'assessments would concentrate on the reasonable and necessary supports that people require'. This principle requires further careful development and operationalisation … An important task for the Commission is to consider the living standard level to be achieved by 'reasonable and necessary' support since this will be defined differently by different people and reflect individual preferences. (Dr Michele Foster, Ms Ros Harrington and Dr Paul Henman, sub. DR940, p. 3)

> … the report uses the terms 'reasonable and necessary' in the assessment of supports eligible for funding under the scheme. There is little explanation as to how these will be assessed and by whom. SACOSS believes it is relevant to give greater definition to these terms. (South Australian Council of Social Services, sub. DR794, p. 2)

But this is not an unchartered area. As noted in the Commission's draft report, both the LTCSA NSW and the Transport Accident Commission (TAC) in Victoria have refined the concept of 'reasonable and necessary' in general terms, as well as for the provision of specific services, such as home modifications (box 5.6).

The Commission considers that these guidelines provide a useful template that could be adapted by the NDIS. As is the case with the LTCSA NSW and the TAC, 'reasonable and necessary' guidelines will need to change over time, to take account, among other things, of changes in technology and community norms.

'Reasonable and necessary' criteria

The NSW Lifetime Care and Support scheme has particularly well developed general guidelines for determining whether a support or service is reasonable and necessary. Guidelines are based on a number of considerations, many of which would be equally relevant for a NDIS. Guidelines would inform resource allocation decisions. (Where an individual elects to have self-directed funding, they would have greater flexibility to decide how best to use that budget to meet their needs.) The Commission recommends the following guidelines, adapted from the NSW Lifetime Care and Support scheme:

- the benefit to the participant

- there are goals, expected outcomes and an expected duration for the requested support or service

- there is evidence to show the requested support or service will benefit the participant. For example, the outcome will progress or maintain the participant's functionality

- appropriateness of the support or service request

  - the service is in keeping with current clinical practice, evidence-based practice and/or clinical guidelines

  - other services or supports will not provide an improved or equal outcome

  - the requested service or support is consistent with the participant's other supports and relates to their goals as outlined in their individual support plan

  - the support request would meet the community's perception of what is appropriate, given that the NDIS reflects the pooled contributions from all Australians

- appropriateness of the provider

  - the provider is appropriately experienced to provide the support service (and *where appropriate* qualified and/or registered)

  - the provider does not have conflicts of interest that may result in over-servicing or direction of people to less effective supports or services

  - the provider is appropriate considering the participant's age, ethnicity and any cultural and linguistic factors

- cost effectiveness considerations

  - consideration has been given to the long-term compared to the short-term benefits of the service, based on evidence-based practice, clinical experience or consensus

  - the long-term and short-term benefits, including social benefits, and expected outcomes of the proposed support or service have been considered and are likely to outweigh the costs

  - the cost of the proposed support or service is comparable to those charged by providers in the same geographical or clinical area

  - the support or service represents the most cost-effective option of those available. For example, where equipment or modifications are required, factors relating to lease or rental have been carefully considered and compared to the cost of purchase.

The NSW Lifetime Care and Support Authority takes account of a range of factors when deciding if a home modification is 'reasonable and necessary'. These include:

- the anticipated length of time that the participant will need home modifications and whether this need is likely to change
- structural constraints, for example, size, surrounding terrain and the condition of the home
- ownership of the property
- permission of the owner or body corporate to temporarily or permanently undertake modification to the home
- local planning regulations and building permits
- length of lease of a rental property
- anticipated period of occupancy of the home to be modified
- the scale and cost of the proposed modifications relative to other residential options.

Source: LTCSA NSW (2010a).

The Commission proposes a further criterion, that being:

- the support or service would be most appropriately provided through the NDIS

    - the support or service would not be more appropriately delivered by a mainstream government service (like the health system)

    - taking account of community norms, the support or service would not be addressed better at an individual, familial or informal support network level. For example, community norms suggest that parents would provide sleepover care for a young child who was a passive sleeper.

An important implication of this last criterion relates to the transition to independent living. Under current arrangements individuals with disability, particularly intellectual disability, remain in the family home for considerably longer than is the community norm (figure 5.1).

The scheme would facilitate the transition of young adults into independent living or supported accommodation, if they wished to do so, in line with community norms.

A number of participants supported this objective:

All young adults with a physical and/or intellectual disability have the right to move out of home, be settled and live their own lives and, in a compassionate society, parents should be able to see their child successfully settled in their own home, with a working and appropriate support system in place, long before death! I want to see my daughter

in her 'own' home long, long before I am no longer able to look after her myself. I don't want to be carted off to the Nursing Home or Crematorium, while my daughter stands bewildered at the front door of the only home she has ever known, while a stranger packs her suitcase (personal response).

I am the mother of a 13 year old with Rett Syndrome. My daughter does not speak or walk, is incontinent and has uncontrolled epilepsy. She needs me or another carer to look after her every need.

I love having her at home while she is school age but I do not want to be taking care of her in our home for the rest of my life. I would like to have my daughter set up in a home with one or a few other children like her by the time she is 21. (name withheld, sub. 391, p. 1)

I am the same as any parent. I love both my sons, I want them to live with me for about 20 years and I want them to be happy and safe for their whole lives. (name withheld, sub. 74, p. 17)

Figure 5.1   **Indicative housing careers**a
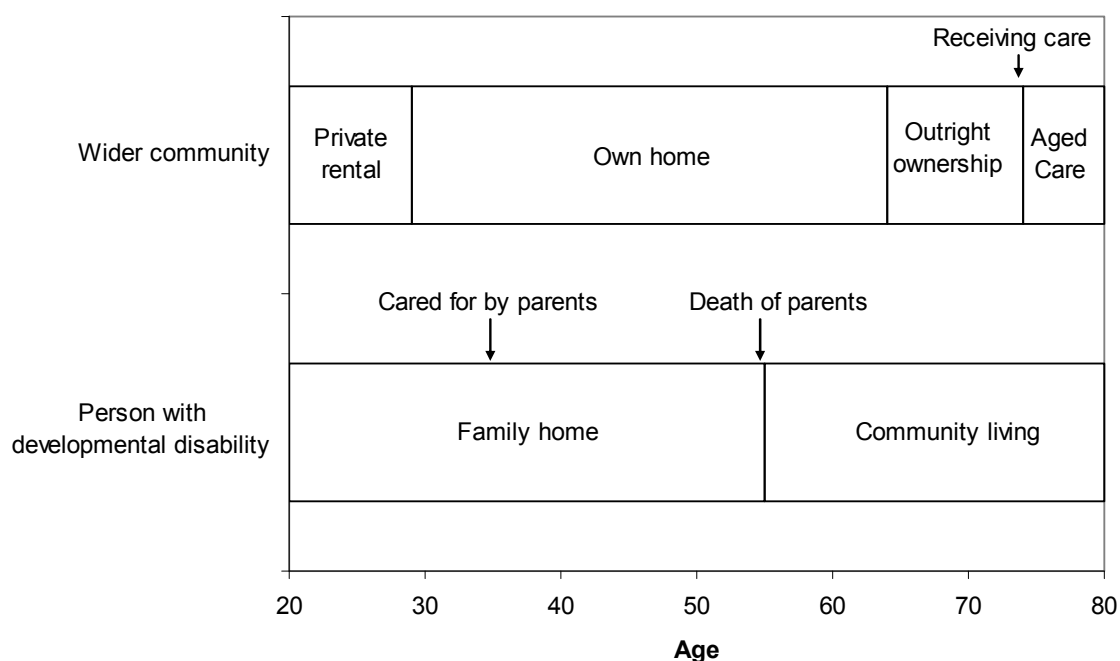
a Housing careers are indicative of trends in large groups, and will not apply in many individual situations.

Data source: Adapted from Beer and Faulkner (2008, figures 2.2 and 2.5).

5.6 Means testing, front-end deductibles and co-payments

Means testing is a common feature of long-term care and support schemes internationally, particularly in those schemes that target the aged.

Income and assets are relevant to an NDIS in two ways.

- In theory, some people could be unable to access individually-tailored, NDIS-funded services *altogether* because their income or assets exceeded a threshold level. (This is a common feature of income support payments from the Australian Government). However, it does not apply to Medicare, with people eligible for subsidised services regardless of income.

- People could pay a greater co-contribution if they had sufficient means (as in the Pharmaceutical Benefits Scheme (PBS)).

So long as the disability is sufficiently severe, there are weak grounds for removing access to services based on a person's income and assets. In effect, a tax-funded NDIS amounts to the compulsion for people to insure themselves for the costs of support associated with a disability.

Under the Commission's proposed funding arrangements, the well-off would pay a much larger contribution towards the NDIS than medium and low income earners.[8] It would be both inequitable and inefficient to exclude people from NDIS supports solely on the basis of income. It would be inefficient because high-income people still value insurance for catastrophic events, and would not be able to participate in the most efficient way of providing that insurance (or in some instances to access any insurance at all, such as when there might be a family history of certain conditions). It would be inequitable in that high-income people would have to contribute to the costs of a scheme that they could not actually draw on, even when facing a catastrophic disability.

Moreover, such arrangements are likely to dampen incentives to work and/or save, by acting as a high effective marginal tax rate. A number of participants commented on the adverse incentives embodied in such arrangements:

> The scheme must not be means-tested. The disincentives to workforce participation inherent in a means-tested scheme would far outweigh any savings to be made. (Maree Ireland, sub. 233, p. 2)

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[8] The Commission's preferred funding option is for the Australian Government to direct payments from consolidated revenue into a National Disability Insurance Premium Fund. Since Australia's tax system is progressive, the well-off would make a higher contribution.

> I strongly believe that a long-term disability support system must be needs based and not income based … To do otherwise provides a huge disincentive to people with disabilities seeking employment, and the improvements in socio-economic circumstances that brings. (Name withheld)

> A related issue is whether benefits should be means tested. Apart from the difficulties of determining an applicable level of income or wealth, it may discourage people to seek work, or encourage people to restructure their financial assets, to allow them to access the scheme. Also it may alienate whole sections of the community who have to contribute to the scheme but are not eligible for assistance because of their income or wealth. (Tasmanian Government, sub. 600, p. 3)

The Commission proposes that the NDIS would *not* include any income or assets test.

A second, related question is whether individuals should face:

- a requirement to pay a fixed upfront contribution to the NDIS, with free access to services after that point (so-called 'excesses' or 'front-end deductibles'). In effect, a front-end deductible is a dollar amount below which an insurer, in this case the NDIS, would not share in the costs of care

- a contribution to the costs of services as they are used (such as in PBS prescriptions).

Excesses

Excesses ('front-end deductibles') are a fixed amount that a person must pay when making an insurance claim, with the remaining portion paid by the insurer. Front-end deductibles routinely feature in insurance products, including motor vehicle and health insurance. They are seen as desirable by insurance providers since:

- the administrative costs of dealing with small claims offset some of the benefits of insurance and so make full coverage undesirable

- when insurance covers the costs of a service, people will request more services than they would without insurance, and these incremental services will be valued by the individual less than they cost the insurance pool (often referred to as 'moral hazard')

- deductibles enable providers to charge lower premiums for a given budget

- they are an upfront fixed cost and so beyond the initial threshold, do not affect individuals' decisions around whether to engage additional services (as distinct from co-payments).

In its draft report the Commission considered that there were grounds for employing front-end deductibles in the NDIS, but also acknowledged that there would be many people who already face an 'invisible' front-end deductible. Those people who rely on natural supports to meet many of their care and support needs already contribute significantly towards the costs of their care. The Commission went on to note that:

> It would be inappropriate for these individuals to be effectively subject to a second payment. The Commission considers that needs assessments should take account of the extent of natural supports, and that the NDIS should waive the front-end deductible where the value of this support exceeds some government determined level. (p. 4.32)

However, a number of participants expressed concern about the proposal for a front end deductible:

> We take the view that a modest fixed upfront contribution to the NDIS would be unlikely to be effective or necessary because: The fee would usually be waived for people who are primarily cared for by their families because their contribution would always be significant. The fee would usually be waived for people who are not primarily cared for by their families because their capacity to pay would be limited. There are so few in a third group, not cared for by their families and with capacity to pay, as to be unlikely to warrant the cost of collecting the upfront contribution. (Uniting Care Queensland, sub. DR776, p. 13)

> A profoundly disabled person who is already contributing to the rent and house-keeping of their supported accommodation would experience financial stress if they also had to contribute an annual up-front payment to access the NDIS services. (Valued Independent People, sub. DR932, p. 8)

On balance, the Commission considers that the high needs basis for initial assessment, the rigorous nature of the assessment process itself and the fact that high needs will dominate NDIS costs means that there would be little need for a front-end deductible, or real scope for such an excess to materially reduce costs. Without specifying a dollar amount, the criteria for entry to the scheme would already have established a threshold level of need to warrant public insurance.

However, there would be grounds for introducing some upfront charge if following the implementation of the NDIS it was revealed that many unnecessary or small claims were clogging up the assessment process (noting that the administrative costs associated with processing small claims may outweigh their benefit).

These upfront charges could take several forms, such as a small minimum threshold for funding by the NDIS, or the imposition of a small excess (say $500) that would be progressively waived as people's total support costs rose (so that, for example, it would be zero for people needing more than $3000 a year). Decisions about any excesses should be deferred until after the initial rollout of the NDIS.

Co-payments

As with front-end deductibles, co-payments are intended to address problems of moral hazard. The premise is that, when individuals have to contribute (even if only partly) to their ongoing care costs, they use only *essential* care and support services. Waste is eliminated and costs are reduced with no effect on outcomes.

While true on an individual level, difficulties arise when applying uniform co-payments to a broad set of services or users. This is because interventions differ in their therapeutic effects and the value of a specific intervention varies across users. In these circumstances, across-the-board uniform co-payments can discourage the use of even high-value supports. Indeed, studies suggest that more efficient resource allocation occurs when co-payments are a function of the value of a specific service to a targeted group of individuals (box 5.7).

Consistent with international best practice, the Commission considers that the NDIS should fully fund the number of episodes of therapy that that were appropriate to the person and were in keeping with current clinical practice, evidence based practice and/or clinical guidelines. People choosing further episodes would meet their full costs. This would stem over-servicing, which was a problem in the New Zealand scheme. A number of participants were supportive of this proposal:

> The APA supports arrangements for co-payment or payment of the full costs of services (primarily therapies) for which clinical evidence of benefits is insufficient or inconclusive. These services should be determined or informed by a representative expert reference or advisory panel, who can also determine an appropriate number of episodes that should be funded by the NDIS, following which co-contribution will be necessary. (Australian Physiotherapy Association, sub. DR878, p. 12)

> We support Draft Recommendation 4.4 which has the premise that co-payments are a function of the value of a specific service to a targeted group of individuals. People should pay the full costs of services (primarily therapies) for which clinical evidence of benefits are insufficient or inconclusive if they wish to consume those services. (Valued Independent People, sub. DR932, p. 8)

In contrast, other participants wanted the NDIS to fund all forms of therapy regardless of whether they were supported by an evidence base. Some parents, for example, were keen for their children to trial non-evidence based alternative therapies and suggested they be able to cash-out any funding allocated to therapies and use the funds at their discretion.

Some other participants, were worried that evidence was not always readily available:

> Evidence is not always available for all interventions; many are provided based on insufficient research simply because insufficient research funding has been invested in

the area. We suggest an approach that only excludes interventions known to cause harm and those that make extraordinary claims for cure and prevention when this is known not to be possible. (Cerebral Palsy Alliance, sub. DR682, p. 3)

For this reason, the Commission has proposed that the NDIA have a role in building an effective evidence base for early interventions (chapter 13). This would help guide the development of clinical protocols governing the optimal intensity and duration of therapies.

The Commission maintains its view that the NDIS should fully fund the number of services (primarily therapies) that were appropriate to the person and were in keeping with current clinical practice, evidence based practice and/or clinical guidelines. People choosing further episodes would meet their full costs. An effective evidence base is essential for several reasons. The NDIA needs to know what is safe, what works, for whom, when and how. It needs need to know whether the benefits of given services and interventions are worth the costs. The reasons for an effective evidence base under the NDIS is discussed further in chapter 12.

Box 5.7   The evolution of co-payments in health services

The impact of co-payments on service use and outcomes in the area of health has been a source of academic, government and general interest. Research has provided a number of valuable insights, which are also relevant in the area of disability support.

It is widely accepted, based on considerable evidence accumulated over decades of study, that higher cost sharing will lead to reduced healthcare expenditures. However, the impact of cost sharing on health status has been much more controversial.

The RAND Health Insurance Experiment was consistent with other research, in that it found that patients reduced utilisation of services deemed clinically appropriate by the same amount as they reduced the use of services deemed clinically inappropriate.

Ideally, co-payments should be structured in a way that does not dampen incentives to use high-value services. And as clinical research advances, more sophisticated cost-sharing strategies are possible. Rather than apply across the board co-payments, 'benefit-based' co-payments are now finding favour. The co-payment for a given service is based on its expected clinical benefits to a certain patient population, as determined by evidence-based medicine. The greater the expected clinical benefit, the lower the co-payment.

In contrast, low-value or unproven services are subject to higher co-payments (up to 100 per cent of the cost). In this context, low value goes beyond waste and inappropriate care to include interventions that deliver positive but limited benefits relative to their costs.

Source: Chernew and Newhouse (2008), Fendrick and Chernew (2006) and Fendrick et al (2009).

Contributions post pension age

As discussed in the previous chapter, individuals could elect to remain in the NDIS after reaching pension age. Where that is the case, they would contribute to the costs of their care and support, as if they were in the aged care system. However, to provide an additional impetus for workforce participation, it may be appropriate for there to be a lower co-contribution for people acquiring disability early in their life (chapter 3).

RECOMMENDATION 5.1

The NDIS should cover the current full range of disability supports. The supports would need to be 'reasonable and necessary'. The NDIS should also support the development by the market of innovative support measures (using the approaches set out in recommendation 10.3).

RECOMMENDATION 5.2

The delivery of prosthetics should be reformed by:

- *establishing proper funding for prostheses and attachments, including timely replacements and reasonable repairs*
- *improving the level of prostheses available to a reasonable and necessary standard, as determined by the NDIA on the advice of a clinical board.*

The NDIS should fund permanent functional prosthetic limbs for those eligible for individualised funded supports. The health system should continue to fund and provide interim prostheses provided in hospitals.

The NIIS should fund functional prosthetic limbs for amputations arising from future catastrophic injury.

The NDIS should allow co-contributions from amputees who wish to upgrade their prostheses, subject to an agreement about the costs of, and responsibilities for, repair.

RECOMMENDATION 5.3

There should be no income or asset tests for obtaining funded NDIS services and no general requirement for a front-end deductible. A front-end deductible should only be considered if, after the implementation of the NDIS, small claims clog up the NDIS assessment process.

RECOMMENDATION 5.4

People should pay the full costs of services (primarily therapies) for which clinical evidence of benefits are insufficient or inconclusive if they wish to consume those services.

RECOMMENDATION 5.5

Services that meet the needs of much wider populations, including people with disabilities not covered by the NDIS, should lie outside the scheme:

- *health, public housing, public transport, education and open employment services should remain outside the NDIS, with the NDIS providing referrals to them*
  - *but Australian Disability Enterprises, disability-specific school to work programs, some taxi subsidies, and specialised accommodation services should be funded and overseen by the NDIS.*

RECOMMENDATION 5.6

The Australian Government should not pay the Mobility Allowance to people eligible for individually funded packages in the NDIS. The NDIS should assess people's individual mobility needs and fund these on a reasonable and necessary basis. People not eligible for funded support by the NDIS should continue to get the Mobility Allowance if they meet the eligibility requirements for that Allowance.

RECOMMENDATION 5.7

The NDIS should seek memoranda of understanding (MOUs), with relevant mainstream services, including housing, education, transport and employment. The MOUs should detail the separation between specialist disability and mainstream services and the process for making referrals between the two.

6 Aligning the Disability Support Pension with the goals of the NDIS

Key points

The Disability Support Pension (DSP), which provides a basic income support safety net for people with disabilities, should stay outside the NDIS. It serves a much bigger group and its function is different.

However, the current design of the DSP arrangements, and the way people perceive them, discourage the social and economic engagement of people with disabilities, and is inconsistent with one of the central goals of the NDIS.

A package of reforms, including all tiers of the NDIS, re-vamped employment services and changes to the DSP should improve employment outcomes, and increase the income and wellbeing of people with disabilities.

DSP reforms should aim to:

- encourage the view that the norm should not be lifelong use of the DSP, among people with non-permanent conditions and people with permanent conditions who could have much higher hopes for employment participation

- redefine the DSP as a transitional disability benefit for those with some employment prospects, while retaining the pension for those with low employment prospects

- reduce the disincentives to work while on the benefit by reducing benefit taper rates, relaxing the work test for people already receiving the DSP, and trialing 'sign-on' bonuses for those on DSP who gain paid work

- provide greater support to employers to encourage employment of people with disabilities, including greater wage subsidies

- tap private innovative arrangements for greater economic and social participation of people on the DSP through social impact bonds and other measures. Social impact bonds involve financial intermediaries who take funds from investors, invest them in projects with a potential return to government, with government providing a share of that return if the interventions work

- improving data collection and analysis for monitoring outcomes for people on the DSP and the interventions that produce the largest impacts.

All people with disabilities should face the same eligibility test for the DSP. Accordingly, the automatic qualification of blind people should no longer apply, except for blind people who qualified for the DSP in the past.

The Australian Government should establish a public inquiry into the DSP to develop the best path to implementation of the above options where they cannot be put in place quickly, and to assess how the DSP could be further re-designed to be compatible with the social and economic participation goals of the NDIS.

The DSP is the principal source of income for many people with disabilities. It provides a basic income safety net for around 800 000 people with disabilities. Its projected costs to taxpayers are around $14 billion for 2011-12, making it the largest income support payment for Australians of working age (appendix K).

There are strong grounds for the DSP to remain outside the NDIS.[1] The DSP:

- covers a much larger population than people receiving funded supports under the NDIS[2]

- has a function that is intrinsically different from other supports. It is not an individualised support, nor one that involves life planning. It provides only basic income support to avoid the incentives of higher payments. Full coverage of income loss due to disability would have problematic outcomes, which would include an excessively expensive and unsustainable scheme, and one in which there was a constant pressure by people to be included in the scheme to get larger benefits. The 'in-kind' nature of benefits in the NDIS does not present this problem

- has its own eligibility, assessment and review processes

- is one of a group of income support payments for people of working age that are linked to employment services (mainly also outside the NDIS) that assist people obtain employment. For example, Disability Employment Services provide support for people with disabilities to get and keep jobs, and draws its clients from many sources other than the DSP (such as Newstart).

However, the design of the pension arrangements and the way people perceive them, discourage the social and economic engagement of people with disabilities, and is accordingly inconsistent with one of the central goals of the NDIS. As the NSW Government pointed out:

> The lack of cohesion between the income support program and the employment support programs means that the DSP can act to provide economic disincentives for people with a disability to work. (sub. DR922, p. 16)

The tension is also contrary to contemporary government and community expectations about the greater social and economic potential for people with

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[1] This view was supported by many participants, such as Blind Citizens Australia (sub. DR758, p. 22), Erin McKenzie-Christensen and Jeff Christensen (sub. DR754, p. 5), the Disability Advocacy Network Australia (sub. DR1010, p. 30) and the Physical Disability Council of NSW, sub. DR832, p. 11), among others.

[2] While it may be subject to some under-enumeration it is estimated from the SDAC that around 50 per cent of people of *working age* receiving funded support from the NDIS would be on the DSP, and that overall, they would account for around one in five DSP beneficiaries altogether.

disabilities, which have shifted over the past few decades. The UN rights framework emphasises the goal of participation. In that context, a major objective should be for people with disabilities to obtain paid employment (or a voluntary job), even if they continue to receive partial income support from the Australian Government.

Several factors underpin this shift in attitudes to the employment of people with disabilities, and are relevant to the role and design of the DSP.

First, the social model of disability emphasises people's potential and the desirability of breaking down social barriers to economic and social participation. In contrast, the previously dominant medical model depicted people with a disability as having a condition that prevented them from participation. As Leonard (1985, p. 1) put it:

> The crux of the matter is that disability is not simply a medically defined condition, but depends rather on an array of surrounding psychological, sociological and economic factors. A person who perceives himself as disabled may thereby disable himself. A person who is perceived by others as disabled may thereby be disabled. And a person who finds greater economic returns to disability than to work may not struggle so hard to work. This need not be a question of fraud or dissembling, but merely of adapting to the given incentives.

Moreover, there is an increasing awareness that work and social participation has many wellbeing benefits for people beyond those associated with a better standard of living. Work also provides people with social interactions and purpose, and it breaks down stereotypes of disability. Measuring the nature and size of these benefits is difficult because it can be difficult to unravel the extent to which joblessness is an outcome of health impairments or the determinant of them. Nevertheless, studies have attempted to disentangle these effects (as summarised in Lattimore 2007), and find that mental health especially appears to degrade if people do not have jobs. Other recent studies appear to support this contention. An OECD study (2010, pp. 46–47), which covered Australia and some other countries, found high mental distress among people leaving employment, especially among those with disabilities, and improved mental health if people found jobs. A study by the Royal Australian College of Physicians and the Australasian Faculty of Occupational and Environmental Medicine (2001) drew on extensive literature on the links between work and wellbeing, and concluded that work is good for people's health and wellbeing. A meta study undertaken by Waddell and Burton (2006) found good evidence that work had positive impacts on people's health and wellbeing, and of particular relevance to the DSP, that people's wellbeing rose after moving off social security benefits. A possible exception to this is if the job quality is poor. There is some evidence that jobs with poor psychosocial attributes are no

better, and may have even more adverse effects on mental health, than unemployment (Butterworth et al. 2011). On that other hand, the latter finding may not hold if there is adequate in-job support.

On the budgetary front, the various Treasury Intergenerational reports and the Commission's own research (PC 2005a) show that population ageing will create significant fiscal pressures and lower economy-wide labour participation rates, with impacts on economic growth. Accordingly, governments are looking for expenditure savings and measures that encourage people to enter or stay in the workforce. Increasingly, people with disabilities are seen as a resource rather than a 'cost centre'. The Henry Tax Review observed:

> Structural ageing of the Australian population makes it particularly important that people in the community who wish to and have some capacity to work should not be discouraged from doing so by the personal tax and transfer system (2010, p. 487).

Australia's relatively low international ranking for employment outcomes for people with disabilities also reinforces the potential for gains in this area. In raw terms, Australia had the 21st lowest employment rate of 29 countries for people with disabilities (appendix K), well below countries like the United Kingdom and Canada. In fact, the situation is worse than this because it is important to correct for some of the factors that can bias measures of employment performance. Once these corrections are made, Australia was ranked 24th in terms of its performance, with the data suggesting that Australia could improve its employment rate for people with a disability by more than 5 percentage points if it were to perform at the average of OECD countries (figure 6.1 and appendix K).

The Commission estimates that less than 30 per cent of working age people eligible for funded support from the NDIS have any kind of employment (figure 6.2), with part-time employment more common than full time employment.

Altogether, this suggests that the Australian Government should align income support arrangements with the participation goals of the NDIS and with contemporary disability policy. It would be paradoxical for the NDIS and other policies to encourage people with disabilities to think about what they can do, and to have an income support system whose orientation encourages people to think about what they cannot do.

Moreover, regardless of any changes to the DSP itself, the greater emphasis of the NDIS on social and economic engagement should reduce the extent to which people with disabilities need to rely on the DSP, producing *some* offsets to the budgetary costs of the NDIS (chapter 20).

6.1   Reform strategies

Australian Governments have undertaken various DSP reforms over the last decade, and further changes have been announced for implementation in 2012 (appendix K). These reforms have included improved assessment arrangements, a tougher test of work capacity, better referral processes for skill development and work readiness, and attempts to address the uncertainty of requalification for the DSP after a period of employment.

The impacts of these measures are unclear as many are yet to be implemented. International and historical Australian experiences suggest that successful reform in this area is challenging. In Australia, the largest falls in the DSP intake have occurred when economic circumstances have improved, although this has had little impact on the outflows, resulting in persistently high numbers of people on benefits.

Figure 6.1   Australia lags behind in employment outcomes for people with disabilities^a
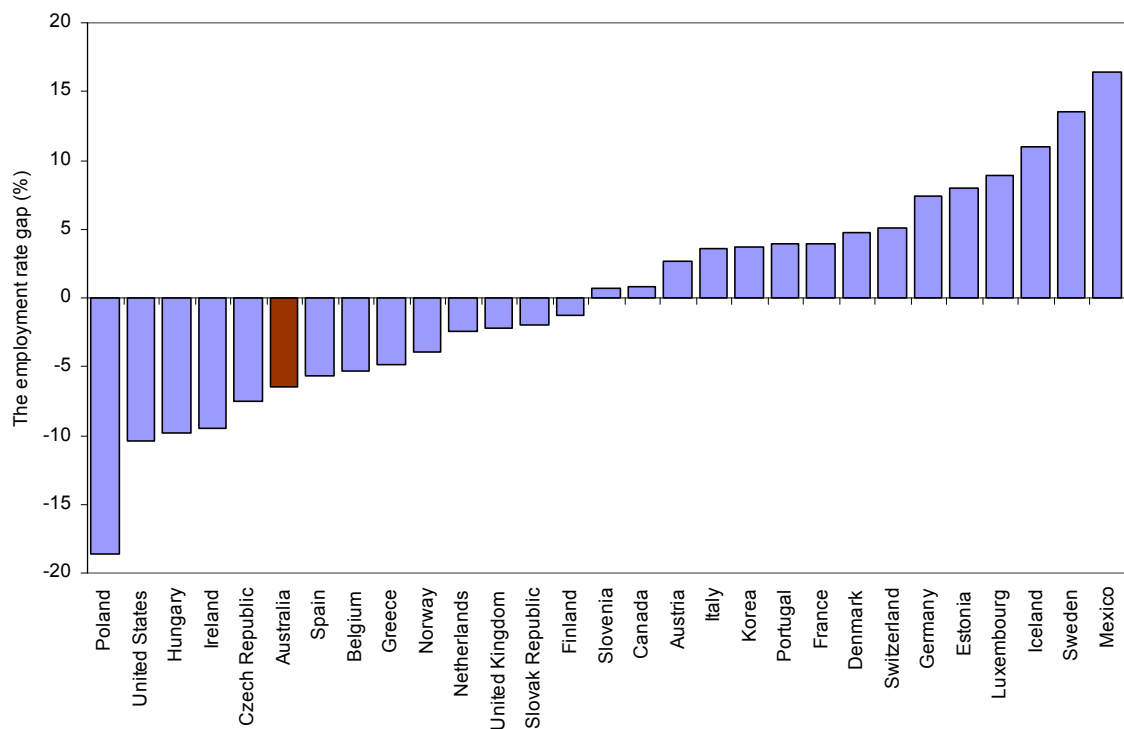
a The data corrects for the overall employment rate in an economy, which would also have a bearing on the achievable employment rate by people with disabilities. Appendix K describes the methodology.

Data source: OECD 2010, *Sickness, Disability and Work: Breaking the Barriers - A Synthesis of Findings across OECD Countries.*

Figure 6.2

Labour engagement is low for people eligible for funded NDIS supports and for people with disabilities generally 2009[a]

Legend:
- NDIS funded support
- Profound, severe, moderate and mild disability
- No disability

Y-axis: Share of relevant population (%)

Category	NDIS funded support	Profound, severe, moderate and mild disability	No disability
Unemployment rate %	11.7	8.8	5.1
Participation rate %	32.5	46.0	82.8
Employment rate (%)	28.7	42.0	78.6
Not in the labour force rate (%)	67.5	54.0	17.2
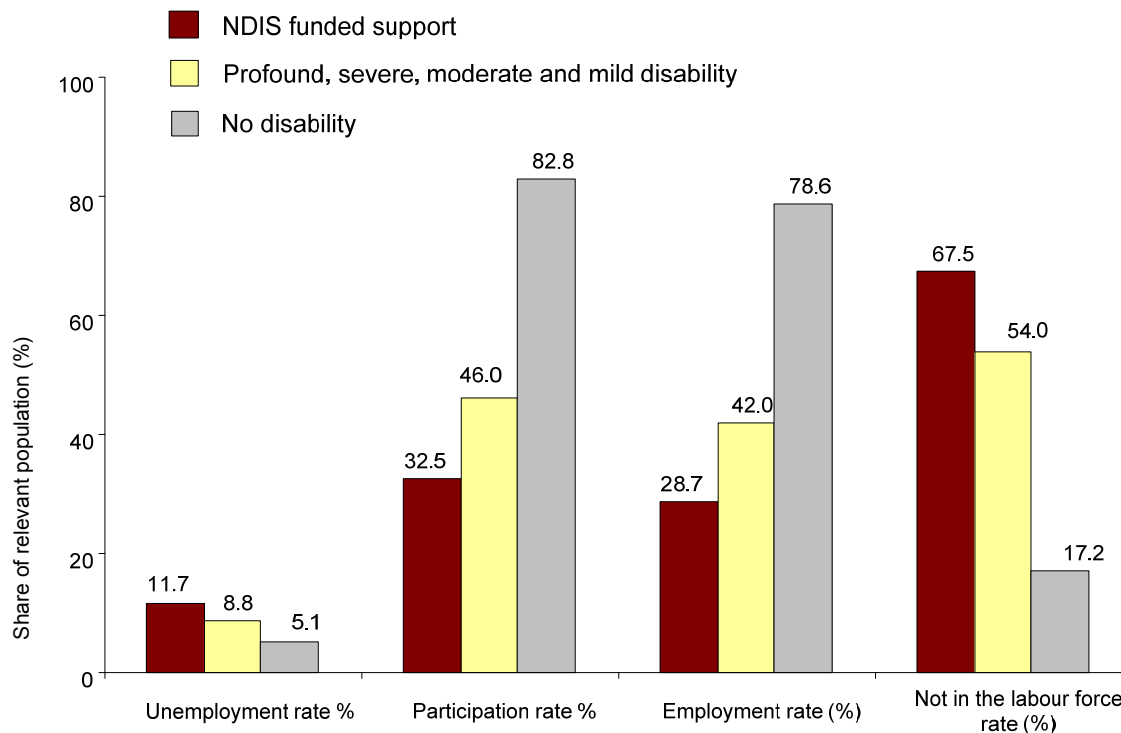
a The data relate to people aged 15-64 years only. The NDIS population has been estimated using the approach underlying the costings in this inquiry. The unemployment rate is the share of people *in the labour force* who are jobless. The employment rate is the share of the *population* who are employed. Note that the employment and unemployment rates do not add to 100 per cent because they use different denominators. The participation rate is the share of the population who are in the labour force (that is who are either employed or unemployed). The 'not in the labour rate' is one minus the participation rate.

Data source: Estimated from SDAC 2009.

While it is important not to oversell the potential for change, some countries, such as the Netherlands and Italy, have achieved significant change through bold reforms (OECD 2010). Drawing on Australian and international experiences and evidence about the deficiencies in current arrangements, there are several additional strategies and policy changes that could be considered, broadly depicted in figure 6.3.

Subsequent sections of this chapter explore some of the specific options for reform.

Figure 6.3   **The purpose of DSP reform and the policy options**

Purposes of reforms	Policy options

Engagement in jobs, training and the community

Outcomes:
- Higher income
- Better health and wellbeing
- Changed attitudes to people with disabilities
- Contributions to the community and the economy
- Integration into the community

Fiscal benefits

Outcomes:
- Lower tax rates and greater efficiency
- Shifts in spending to other areas (eg disability support)

Public trust in the DSP income support system

Outcomes:
- Payments targeted at those most in need
- Social trust
- Reduced stigma for people using DSP

Measures targeted at the person

- Skill development, motivation and behavioural change
- Incentives and supports to commence work, train and participate in the community
- Incentives and supports to stay in a job
- Higher expectations about working
- Information about opportunities
- Reducing uncertainty about the return to DSP
- Rehabilitation and health interventions
- Supports provided by the NDIS, employment services, education and housing
- Case management
- Multi-tiered system based on employment potential and participation
- Non-permanent duration of benefits for some recipients
- Encouragement of short-hours work

Employer initiatives

- Change in employer attitudes
- Wage subsidies for employers and job brokers
- Support for employers
- Innovative job creation

Community initiatives

- Awareness of disability potential
- Encouragement of volunteering by people with disabilities
- Mentoring
- Inclusion in mainstream social activities

Assessment for DSP entry and review

- Reliable and valid assessment
- Referral to other supports (including the NDIS)
- More frequent reviews for changing medical conditions
- Assessments lead to continuum of supports, expectations and participation obligations

6.2   Altering expectations

People on DSP are allowed to have a job without relinquishing their DSP (subject to some hours and income limits). However, only a few are employed and a very small share search for jobs using the available support services. Overall around 3 per cent of DSP beneficiaries use the Australian Government's Disability Employment

Services, with particularly low usage rates for the two dominant conditions affecting DSP recipients (physical and psychiatric disabilities) (figure 6.4). This underlines the highly passive nature of the DSP.

Figure 6.4   **Few people on the DSP use disability employment services**
June 2006 to December 2010[a]
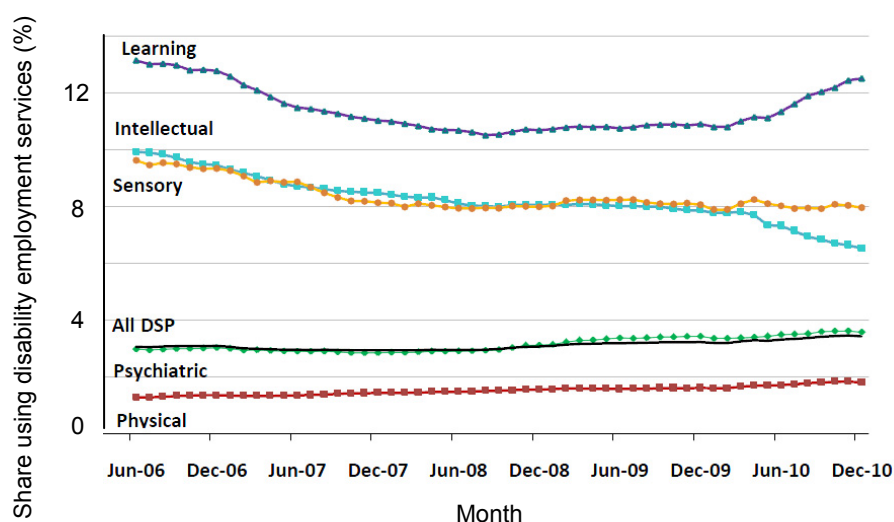
a Percentage of DSP recipients in given disability sub-populations who are using disability employment services. Disability employment services relates to the various forms of open services for people with disabilities over this period.

Data source: DEEWR (2011b, p. 26).

The emerging view is that, contrary to many people's beliefs, there is better scope for employment of people with disabilities. Several participants in the inquiry considered that a greater effort should be made to get better employment outcomes for people with non-permanent or less severe disabilities. For example, one noted:

> At the moment we have people on Disability Pensions that don't necessarily need to be. For example shoulder and back injuries acquired at some point in the past doesn't mean the person should be on a disability pension for ever. In addition, if someone has a "crook" back, this doesn't necessarily prevent them from doing other meaningful work. The Assessment process needs to be more rigorous and look at a number of employment opportunities rather than assume that person can't work again. (Economic Security for Women, sub. DR753, p. 5)

Another participant pointed out that the aspirations for employment should aim high and not just apply to people with lower levels of disability:

> In talking about the DSP, AMIDA would argue that most people should be included in the vision for a future not dependent on the DSP. A narrow view of those who might be 'considered to have higher hopes for employment participation' excludes many people

who we consider have potential to work more than is the case at the moment. (Action for More Independence & Dignity in Accommodation, sub. DR1027, p. 3)

It appears from survey evidence that around half of the people on DSP would like to work, and that the most common benefits they see from doing so are greater income, improvement in wellbeing, and greater social contact (Nucleus 2004). Qualitative research strongly reinforces these results (for example, Morris and Abelló 2005).

In this inquiry, submissions also pointed to the desire by DSP recipients to work and be active:

> There seems to be a widespread conception amongst politicians that people benefiting from the DSP are sitting at home quite happy to accept the money. My experience is that people want work but find it extraordinarily difficult to obtain it. (Quote from a person in Blind Citizens Australia, sub. DR758)

> The reality is that many people with a disability, even significant disability, would LOVE to work. They just can't get it! (DisAbility Connections Victoria, sub. DR702, p. 5)

> For too long a DSP has been associated with 'unable to do' rather than a recognition that they can do differently. (Val Stone, sub. 228, p. 8)

Moreover, there is evidence that many people on the DSP have less severe disabilities, and that factors outside disability may have a particularly strong impact on their economic and social participation. Around 60 per cent of people on the DSP have moderate or lesser levels of disabilities.[3] People with mild, moderate or severe disabilities who are on the DSP have no greater an employment likelihood than people with profound disabilities — the rate is about one in ten in all groups (table 6.1).[4] These results point to the powerful effect of incentives, job opportunities and attitudes, rather than just disability, as a major factor in job outcomes. This is supported by the fact that DSP rates have risen over the long run, while disability prevalence rates do not appear to have done so (figure 6.5). As shown in appendix K, a major factor behind high DSP rates is that labour markets have become more 'hostile' to people with disabilities, rather than disability per se.

In that context, DSP arrangements could place more emphasis on the goal of long-term participation rather than long-term disengagement. This recognises that many people with disabilities have the desire and capacity to work.

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[3] Surprisingly, around one in twenty on the DSP say that they have no disability at all, though this may be a statistical anomaly.

[4] However, people with lesser disabilities (such as a non-core disability) do have a better than average likelihood of employment while on the DSP.

For instance, many people with an intellectual disability could contribute through work (for example, in a family business or in businesses that have learned how to employ them productively, and that have provided the right support to the person). Indeed, of people with disabilities enrolled in the Australian Government's (open) Disability Employment Services, people with intellectual disabilities have generally the highest job placement rates, and tend also to keep their jobs (figure 6.6).

Equally, given the right support (and the increasing sophistication of enabling technologies), the expectation should be that people with sensory impairments should acquire a good education and get a job.

Table 6.1   **Who works on the DSP by severity of disability?**

Disability Status	Share of people on DSP who are employed	Share of people on DSP by severity of disability	Likelihood of being on DSP by severity of disability	Share of working age population by severity of disability
	%	%	%	%
Profound core limitation	10.3	17.7	71.2	1.1
Severe core limitation	13.2	22.3	43.5	2.3
Moderate core limitation	10.7	18.0	30.5	2.6
Mild core limitation	11.7	21.6	22.0	4.3
Disability and restricted in schooling or employment	21.0	6.8	14.4	2.1
Non-core disability (and no schooling or employment restriction)	21.2	1.0	1.8	2.3
Long term health condition only	21.3	8.1	1.6	22.5
No disability or long term health condition	14.7	4.5	0.3	62.8
Total	13.2	100.0	4.4	100.0

a Data relate to people aged 15–64 years not in institutions. The administrative records for the DSP show that under 10 per cent of DSP recipients had some employment, somewhat less than the estimate of just over 13 per cent given here. This will reflect several factors. First, the SDAC is a sample survey with sampling and other errors. Second, the numbers above will partly reflect perturbation by the ABS of the confidentialised unit record file (CURF). Finally, the administrative data relate to a specific two week period, which will not match the period on which the SDAC estimates are based.

Source: ABS (2010d).

Figure 6.5   **DSP prevalence rates have risen, despite static disability prevalence rates**

20 to 29 year olds, 1988 to 2009
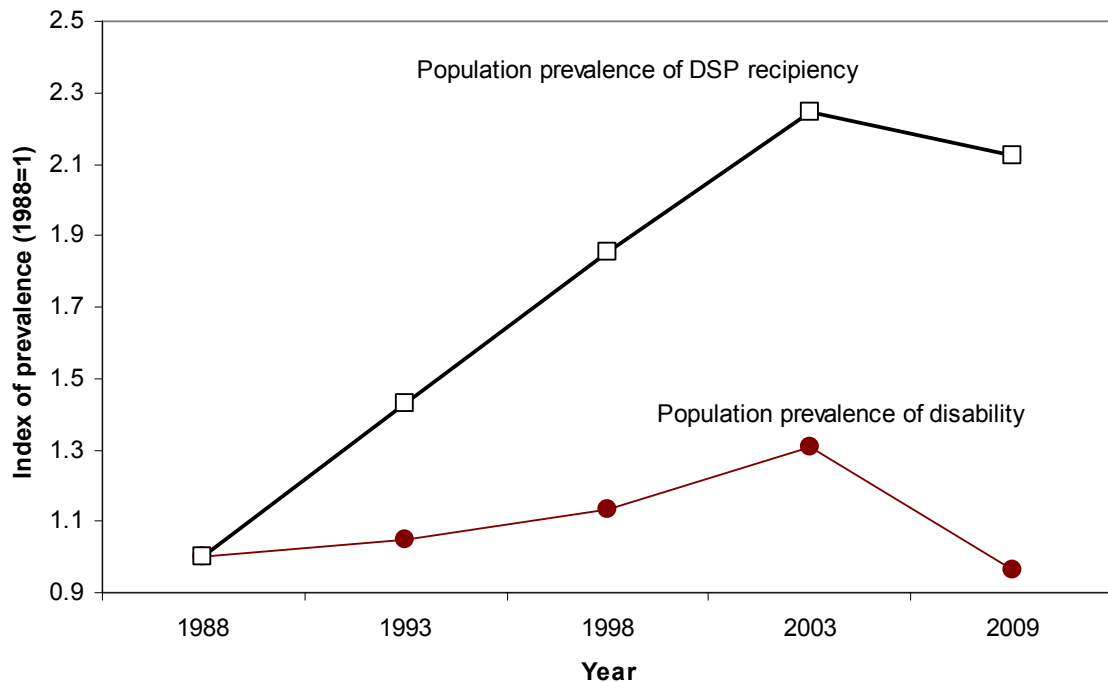
a The chart relates only to 20-29 year olds, though complete data are shown in appendix K. The DSP prevalence rate is the number of people aged 20-29 on the DSP as a share of all people aged 20-29 years old. To aid comparison, the prevalence rates have been converted into indexes, with 1988 values set to unity. The data shows that the disability prevalence rate for 20-29 year olds did not change (once account is taken of sampling errors) over the twenty year period, but that it more than doubled for DSP rates.

Data source: ABS (2004, 2010d); Davis et al. (2001); FaHCSIA (various issues), *Characteristics Of Disability Support Pension Recipients* and ABS, *Australian Demographic Statistics*, Cat. No. 3101.0.

Similarly, people with musculoskeletal conditions may not be able to undertake physical work, but they will often be able to talk with people or provide them with information. Many jobs involve just that skill. For instance, a tradesman with a bad back may be able to give customers in a hardware store advice about products or act as call centre workers. (However, the actual record of entry into disability employment services and the job outcome rates are quite low for this group — figures 6.4 and 6.6).

Figure 6.6   **People's capacity for getting and sustaining jobs varies considerably**[a]

Outcomes after commencement in Disability Employment Services
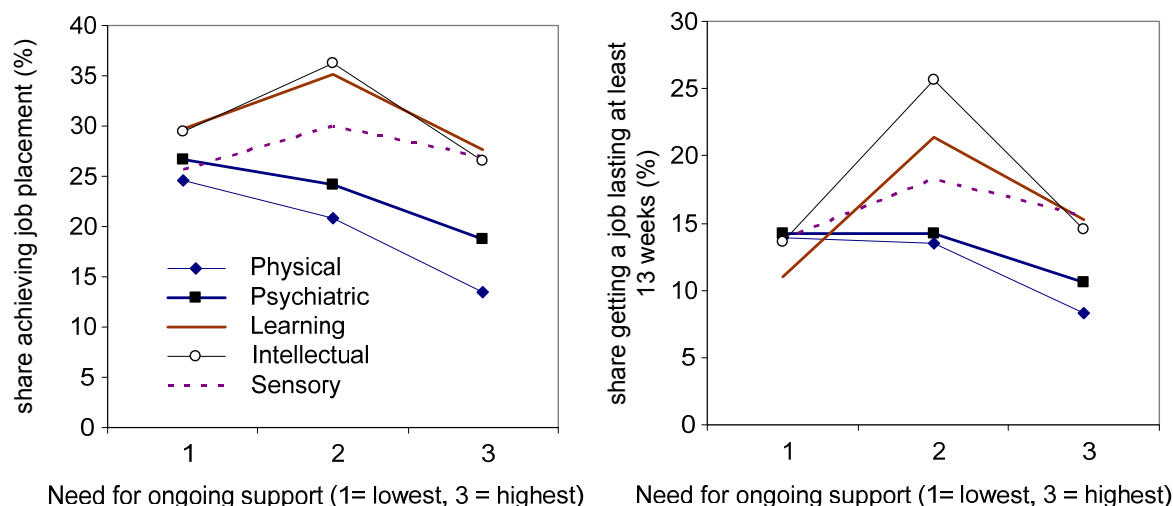
a The results are based on participants who commenced in DES between 1 March and 30 June 2010, counting outcomes achieved by 31 December 2010. The graphs show the share of commencing participants who get a job placement (the left hand chart) and the share of commencements who secure a job lasting at least 13 weeks (the right hand). For example, around 15 per cent of people with less severe psychiatric disabilities entering the DES between 1 March and 30 June 2010 had secured a job lasting at least 13 weeks by 31 December 2010. The results are shown for people by type of and severity of disability. The Level 1 group comprises people who do not require long-term support in the workplace, while levels 2 and 3 are people with ongoing employment support needs, (with the two levels distinguished by the funding levels per participant).

Data source: DEEWR (2011b).

The challenges are greater for people with disability arising from mental health problems. The evidence suggests that people with mental health disabilities have low probabilities of exiting the DSP, and the least success in sustaining such exits when they do make them (Cai et al. 2007). This picture is reinforced by the low take up of tailored job search services and by relatively poor job outcomes for those who do enrol in these services (figures 6.4 and 6.5).

This is disturbing since the share of DSP recipients with a disability due to psychological/psychiatric conditions has grown strongly, especially among male recipients. In 2001, 21 per cent of the stock of male DSP recipients had psychological/psychiatric conditions underlying their disability. By June 2010, this had risen to 29 per cent. It is now the single most important source of disability for males in the DSP and a close second for women. Altogether, there were around 230 000 people on the DSP whose primary medical condition was psychological or psychiatric.[5] Moreover, new entrants to the DSP with mental health conditions tend

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5   FaHCSIA 2011, Characteristics of Disability Support Pension Recipients, June 2010.

to be younger than most new entrants with musculoskeletal and circulatory conditions (figure 6.7). The combination of low exit rates for people with mental health conditions, the increased tendency towards entry into the DSP by such people, and their younger age at entry, suggests that the average durations on DSP may grow, a point also made by Brown (2010).

Figure 6.7 **Many new grants for DSP are for younger people with cognitive impairments**

Distribution of age for new grants by medical condition, June 2010[a]
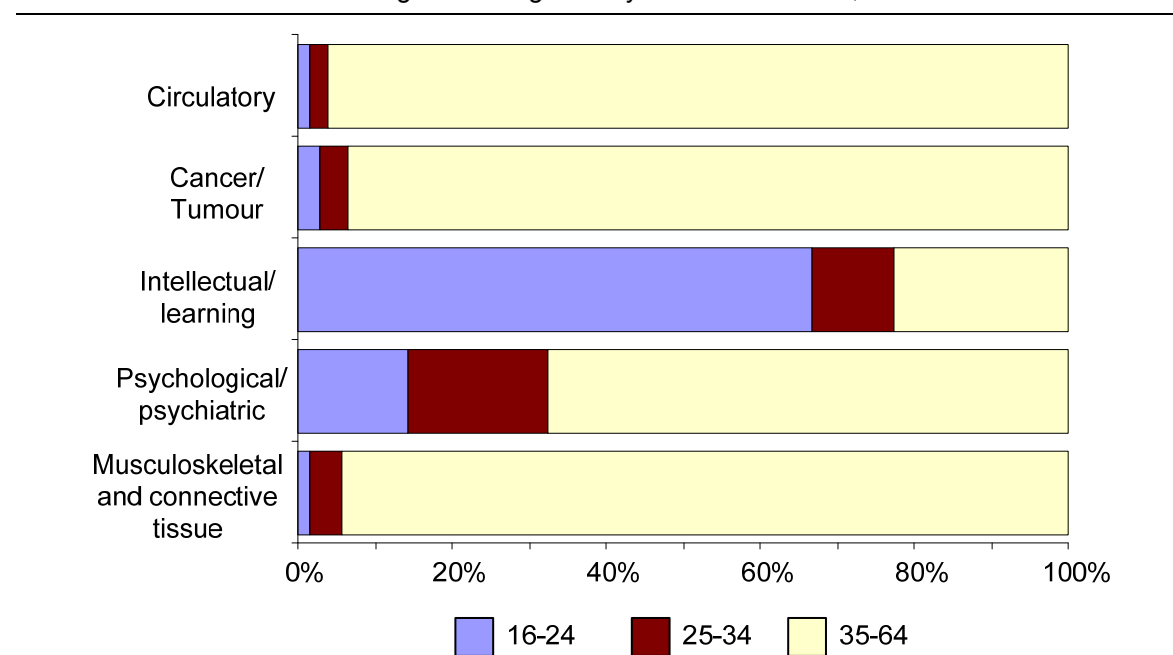
a The graph shows the age distribution of grants for any given condition. For example, nearly 80 per cent of new grants for people with intellectual and learning disability conditions were aged less than 35 years old.

Data source: FaHCSIA, *Characteristics of Disability Support Pension Recipients*, June 2011.

On the other hand, many mental health conditions are not permanent and can be managed through early intervention. Better mental health and disability supports that are coordinated with incentives to gain and keep employment, and job designs that take account of the episodic nature of some mental health disabilities, may work well for many people with psychiatric disabilities.

Tiered arrangements may raise expectations of employment

The new arrangements announced in the Australian Government's 2011-12 budget encourage greater participation by those able to work at least eight hours, but the DSP is still framed as a permanent payment. It may be preferable to construct

several layers of disability income support arrangements[6] which, with greater in-work support and more rewards from working, may achieve better job outcomes:

(a) As is currently the case, some people with less significant disability and health-related barriers to work (with a partial capacity to work of less than 30 hours a week[7]) would get access to a pensioner concession card, as well as Newstart (or a similar allowance) and employment supports through Job Services Australia, with the expectation of work, rather than graduation to the DSP.

(b) Second, a 'transitional disability benefit' could be available for people who currently go onto the DSP, but who have a reasonable work capacity or where their work capacity was hard to assess. This would be consistent with the new eight hour rule announced in the 2011-12 federal budget, but build on that concept. (It would be a matter for government whether the transitional benefit was at the same payment level as the DSP.) It could also apply to people whose underlying source of disability was less likely to be truly permanent. People would need to re-apply periodically for the benefit to assess whether they needed different kinds of support and to test the degree of ongoing impairment. The expectation would be that people would not be on the DSP for life. The relevant period for re-application might depend on the severity and likely persistence of the disability (which over time could be explicitly modelled by considering the probability of exits by the characteristics of the individual).[8]

The new disability payment category would explicitly avoid the 'pension' terminology. It would be combined with employment supports under Job Services Australia. In many instances, people accessing a transitional allowance would not be in the NDIS, but some would, and these would benefit from the school to work training, motivational supports, and personal planning offered by the NDIS. The exit work test for this group could be at least partly relaxed (see later). The focus would be on employment.

It is sometimes suggested that people on such a transitional payment would have monetary incentives to 'game' the system so that they could move onto a permanent and more generous DSP payment. However, many people do not behave in this

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[6] A point made by Valerie Johnstone (sub. 228, p. 8).

[7] Section 16B of the *Social Security Act 1991* (version as registered on 6 June 2011).

[8] The existing two year definition of permanence may be a poor guide to the likelihood of highly persistent disability. While some disabilities, such as intellectual disability, major spinal cord damage, degenerative diseases, and chronic, severe and complex psychiatric disorders are lifelong disabilities, the most common sources of disability in the DSP (musculoskeletal and many other psychiatric conditions) may eventually resolve themselves in time, or become amenable to rehabilitation at a later date.

strategic way and genuinely want a job. In any case, moving people who make up the transitional group straight on to DSP hardly addresses any such gaming — it merely guarantees such a transition.

(c) The third layer could be the current disability support pension for people whose:

- condition is unambiguous (such as genetically-based cognitive impairments) *and* with functional limitations that are sufficiently severe that they would be unlikely to get a job in open employment (for example, very severe impairments); or

- people who were on transitional benefits for a sufficient period, *and* where the evidence emerges that they are highly unlikely to secure a job.

These beneficiaries would only rarely face reviews (or never in cases where the severity and permanence of the disability was obvious). While effective marginal tax rates would probably not act as the limiting factor in getting a job for such people, there are arguments that the DSP for this group could be paid regardless of labour income or that, as a minimum, any taper rates should be very low and there be no hours restrictions after entry to the scheme (appendix K). This would ensure that most people in this group would keep any dollar earned from work.

These features recognise the importance of still trying to achieve economic and social participation outcomes for people with severe disabilities. Passivity and low expectations should not be the default. The Commission has seen examples of arrangements that have led to employment for people with significant disabilities. For example, in one case a parent set up a microbusiness, JACKmail, around the skills and preferences of her son, Jackson (who has a profound intellectual disability), which she used to buy 24 hours of weekly support a week (Sally Richards, sub. 26). In another instance, a man spent a long time in what was then a sheltered workshop, when in fact he was quite suited to mainstream employment. He now works full-time as a windscreen fitter (Judy Huett, Hobart, trans, p. 16).

Especially for the first two groups above (a & b), tiers 1 and 2 of the NDIS could significantly reinforce people's capacity to obtain jobs by creating networks, building confidence and skills, breaking down stereotypes about the capacities of people with disabilities to contribute and by shifting people's perspectives about what is achievable. In some instances, multiple generations of families may have had little connection to work, and such systemic disadvantage may apply to many in specific geographic areas. For example, in 2009, around one in five adults aged 15 to 64 years in the Peterborough statistical local area (in South Australia) were on the DSP and altogether around 45 per cent of working age people were on income

support benefits.[9] Involving people in a broader community can alter people's views about what they see as normal labour market prospects.

6.3 The incentives to work are often blunted by current arrangements

Many things affect people's decisions about whether and how much to work, but one factor is whether they can improve their economic wellbeing from work. Earnings, income taxes and the capacity to get social security benefits and concession cards interact with each other to determine the extent to which people financially gain from working.

Australia has a very complex tax and welfare system, with benefits that depend on family income and assets; age of the potential beneficiary; the number and age of any children; the couple or single status of the person; the receipt of other benefits; and when a person first entered the system (reflecting the many grandfathering features of the system or 'time of year' effects). The extent to which people have incentives to work depends on the exact mix of their characteristics. The calculations shown in appendix K on the effects of the DSP on work incentives are based on the most simple scenario: a single person subject to the current rules (rather than grandfathered arrangements) and with no children. Even then, the calculations must take account of the income tax system, the low income tax offset, the Pensioner Concession Card, Medicare levy concessions, rent assistance benefits and the complex taper and hour restrictions that affect eligibility for, and benefits from, the DSP.

Appendix K shows that for realistic assumptions, people on the DSP have few incentives to work anything other than a few hours. In many plausible circumstances, working just one more hour can *reduce* people's take-home income by thousands of dollars (that is, implicit tax rates on additional wages that are well in excess of 100 per cent). Since the calculations do not factor in the fixed costs of working (see later), the incentives for working even short hours while on the DSP are low. One participant pointed out the complex 'magic' of high effective tax rates in frustrating the employment of people with disabilities:

> I don't think that people with disabilities are lazy just because they are on the DSP. There are so many disincentives, like if you do too much work (like more than 15 hrs) or if you have a partner who earns too much money, plus the money you earn while working then the DSP drops … At present, by the magic of effective marginal tax rates

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9 Based on the ABS National Regional Profile for 2009 (Ausstats). The Parliamentary Library (Daniels 2011) cites high and low figures for various other local areas.

(EMTRs), I lose half of every dollar I earn over my normal salary – 30% to increased income tax and 20% to a reduction in the DSP. If Erin got a job of over 15 hours per week, she would lose the DSP and all its other benefits – and she would need far more than an entry-level job to justify that. Even if she got a job working less than 15 hours per week, we would lose at least 40% of every dollar she earned, even without taking her income tax into consideration – 20% reduction in DSP and 20% off my dependent spouse tax offset. (Erin McKenzie-Christensen and Jeff Christensen, sub. DR754, p. 6)

Our son has a mild intellectual disability, autism and medicated ADHD, and first entered the disability sector at the age of 4. … Our son is entitled to DSP, and is encouraged by his family to 'work' — in fact this translates to 2 days per week volunteering as an assistant gardener, one day at a service provider to the disability and aged care sector, and one day at a supported employment gardening service. The latter may lead to limited paid work, which may, perversely, result in a net reduction in his overall 'income' from the DSP/income combination. (Elizabeth Coe, sub. DR697, p. 1)

While the high implicit taxes in the DSP are only one obstacle to working, and probably not the most important, it is relatively easy to reduce them.

There are several major contributing factors to the high implicit taxes on working while on the DSP.

People can only work a little before their pension is reduced

The income level at which people's benefits begin to be withdrawn is $146 a fortnight (equivalent to less than five hours of work a week at the minimum wage). Currently, unlike the pension itself, the threshold is not indexed. Accordingly, the Australian Government has to make a decision each year about the appropriate level of the threshold. In 2011, the threshold did not change from the previous year. There would be grounds for indexation and for examination of whether the income cut-off is appropriate.

Withdrawal ('taper') rates are high

When income exceeds $146 a fortnight, DSP benefits are withdrawn at 50 cents in every additional dollar earned (a 'taper' rate of 50 per cent). Such an implicit tax is higher than the maximum rate applied to a high income tax earner (45 per cent). Moreover, as income rises, other benefits and offsets are eroded, increasing the implicit tax rate on additional income by even greater amounts (appendix K).

A lower taper rate would improve incentives to work, but would also be likely to have some initial negative fiscal impacts. This is because the government would have to make greater DSP payments than otherwise for those whose working hours

did not increase at all or did not do so by much (noting that for many there would be no income tax offsets for this group given the tax-free threshold and the low income tax offset).

On the other hand, currently only around ten per cent of people on DSP work, so these fiscal impacts are not likely to be large. Moreover, there would be some savings in DSP and gains in tax revenue for those who ultimately ramped up their labour market activity. The latter group is likely to be smaller than the former. Even so, the living standards of people with disabilities would rise and they would participate more in the community and the economy. Like other supply-side gains, this would be an economic benefit for Australia. There would be some slight GST revenue offsets.

Restrictions on hours worked

The current design of pension arrangements also include restrictions on the number of hours a person may work while retaining the pension (the 'exit' work test). In many instances, this threshold is more important for the incentives to work than taper rates. The current restriction on hours worked while on the DSP is less than 15 hours. This matches the *entry* work test to the DSP, which requires that people cannot get the DSP if they could work 15 hours or more. On the face of it, consistency between the entry and exit work tests appears appropriate.

However, an exit test based on such low hours strongly reduces working incentives for people already on the DSP. Under the current exit test, a person working for just under 15 hours a week at the minimum wage would earn around $32 000 annually, after accounting for their earned income, income support benefits and taxes. Working a few minutes more per week would reduce their annual income to around $12 000 or $20 000 less — representing a huge implicit tax rate.

In the 2011-12 federal budget, the Australian Government announced that, by 2012, people on the DSP would be able to maintain eligibility for the DSP (subject to the income test) if they worked up to 30 hours a fortnight up to two years, thus creating a gap between the entry and exit work tests.[10] This policy should stimulate working to some extent (though see appendix K and below).

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[10] Making it a 30 hour limit results in a $14 000 reduction in benefits at the 30 hour limit, but many people on DSP are unlikely to work above these hours.

The issue of future uncertainty about reviews and re-qualification for the DSP

People undertaking work (or even volunteering) while on the DSP are often concerned about the impacts of their economic and social participation on ongoing eligibility for the DSP. This arises for two reasons.

First, people going off the DSP because they have obtained a job, are often concerned about their uncertain capacity to subsequently re-qualify for the DSP.[11] Depending on the exact design of the new arrangements announced by the Australian Government in the 2011-12 Budget (the details of which are not fully finalised), the presence of such uncertainty may undermine the goals of the temporary higher exit work test discussed above and lead to other perverse outcomes:

- A 30-hour threshold may not have its intended effects if people working 15 hours or more for up to two years are concerned that if they go back on to the DSP they may fail a subsequent review (which uses the 15-hour entry test and takes account of past work history). Appendix K gives some illustrative impacts on *expected* earnings from working longer, taking into account the likelihood of future DSP review failure associated with varying choices about hours and job duration in the two-year grace period noted above. For that reason, people may not increase their weekly work to 15 hours or more, or may only do so for short durations.

- The two-year grace period means that people who do have a work capacity of 15 hours have incentives to oscillate between working 15 or more hours and working less than 15 hours, with the frequency of change based on the qualifying period to re-commence the two year grace period.

A second source of uncertainty concerns the outcome of any future review, even if someone works (or volunteers) *below* the 15 hours work test limit. Participation of this kind suggests some capacity for work. Some people worry that any form of participation increases the risk of a review and the removal of the DSP. As one person put it:

> Currently, the disabled person is only "not living in fear" if they do nothing. Government decision is: they are not to be capable of doing more than 15hrs/wk, even voluntarily. (name withheld, sub. DR623, p. 1)

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[11] Previous changes to the DSP arrangements partly addressed this uncertainty by initially suspending, rather than cancelling, the DSP if a person worked between 15 and 30 hours. People were given a guarantee for automatic re-qualification for the DSP so long as their hours dropped back to meet the 15 hour threshold within two years of working above the 15 hour limit.

Both sources of uncertainty would largely be addressed by retaining a 15 hour work capacity test *on entry*, and then relaxing that to 30 hours, or to no work test, permanently after that (but with retention of the medical review and the usual fraud controls). As a result, someone on the DSP who is working or volunteering would be re-assured that their DSP would continue to be paid (subject to income tests) and that they would continue to get access to the Pensioner Concession Card. Effectively, the DSP would become an in-work benefit for such people.

There are three risks from this approach. First, people who would have left the DSP anyway at 30 hours or more would continue to get a partial DSP, meaning a fiscal cost for government with no economic or participation offset. The currently low outflow from DSP suggests that this is not a large group.

The second is that people may attempt to become eligible for the DSP given its higher in-work benefits than alternative social security payments. However, the entry work test is now relatively tough (the 15 hour rule), the Australian Government has introduced better assessment procedures and new impairment tables are to be implemented. That suggests that it would be relatively hard for someone with a significant capacity for working 15 hours or more to enter the DSP to take advantage of its subsequent lenient work test. *Nevertheless, it would be critical that this risk should be monitored were the Australian Government to relax the exit test.*

Thirdly, a potentially unintended impact of encouraging work by a DSP beneficiary is that other working members of the household may reduce their work. There was evidence of this for the UK Working Tax Credit (Tripney et al. 2009). However, many DSP beneficiaries are in households with no working person, so the effects may not be that great.

The benefit gap

The gap between allowances (such as Newstart) and disability benefits have been widening, reflecting the different indexation arrangements (as highlighted in the Henry Tax Review). The widening gap, combined with the absence of activity testing on the DSP, makes the DSP attractive to people on lower benefits.

The issue of the differential indexation arrangements raises complex issues, because while higher allowances would reduce incentives for transitions to the DSP, they would also increase incentives for joblessness in the first place, and would have significant fiscal implications for government. It is even possible that higher allowances might ultimately increase DSP numbers because, even if the transition

rate from unemployment to the DSP fell, the stock of people on unemployment benefits might have risen sufficiently to counteract this reduction in transition rates.

Against this backdrop, the Australian Government should determine the appropriate indexation arrangements for allowances and pensions. In part, the transitional approach, (b), canvassed above could partly mitigate the effect of the gap between the two benefit arrangements.

6.4 Work bonuses and other approaches to address the fixed costs of working

It costs money to work. People must pay for transport to and from work, wear appropriate clothes, may need child care (and need to transport children to and from a child care centre), may have to buy tools of trade and purchase more expensive meals. Many of these costs are fixed costs. For example, transport costs on any given day must be met regardless of whether a person works one or ten hours. There is compelling evidence that households can reduce spending after retirement significantly without any drop in material wellbeing — an indicator of the importance of such fixed costs (French and Jones 2010).

Moreover, short hour jobs may involve the same number of hours of travelling as longer hour jobs, reducing the effective pay rate for a job. So, suppose that person A works one hour a day for five days a week at $15 an hour and travels one hour per day. Unless they enjoy travelling, their effective hourly wage rate is $7.50 an hour. In contrast, person B working six hours a day, five times per week and with the same travel times and hourly wage rate receives an *effective* wage rate of around $12.90 an hour. Notably, person A's effective wage rate would rise to $12.50 an hour if he or she could work five hours bunched together in just one day. Accordingly, the importance of fixed costs depends on how hours are bunched, not just how many hours are worked overall in a given week (Dechter 2009).

Short-hour jobs are often the most suited to people with disabilities, and so fixed costs are particularly likely to reduce the financial incentive for working for this group. Potential policy remedies are:

- work bonuses provided for any job, regardless of the hours of work
- employment matching services that take into account job proximity and the bunching of hours (including the potential for working from home)
- adequate and accessible child care. Not surprisingly, there is evidence that the fixed costs of working are particularly high for women with young children (Callan et al. 2007).

The last is clearly outside the remit of this inquiry, and there are already significant subsidies to child care.

It may be worthwhile investigating whether existing disability employment matching services take sufficient account of the location of jobs or their bunching, as this may well be a significant factor in securing a job at all, or in sustaining it. Collecting systematic evidence on the effectiveness of such job matching would be likely to be a low cost measure.

The issue of work bonuses is complex, and a recent paper found that while there is no consensus, the evidence tends to suggest a small effect on re-employment (van der Klaauw and van Ours 2011) However, most empirical work in this area relates to:

- the unemployed (who are already looking for work) rather than those outside the labour market
- work bonuses that only reward people who maintain a job for a given period, rather than a 'sign on' bonus
- tax and benefit transfer systems that are quite different from Australia's.

There may be grounds for experimentation with sign-on bonuses for DSP beneficiaries who get a job, regardless of the hours of work — simply to encourage the first step in greater labour market involvement. Given the low re-employment rates of DSP beneficiaries, the cost of transfers to people who were going to get a job anyway would be small, and the risks to government low. The potential for at least a trial is worth investigating.

6.5 Social impact bonds and other innovative approaches

Every person on DSP has contingent liabilities attached to him or her:

1) From a taxpayer perspective, the liabilities are the expected future payments of the DSP and other income support payments. For instance, for a person aged 18 years and using the DSP until retirement, the present value of the DSP payments are around $500 000 (and more over a lifetime when higher aged care and age pension costs are added). This is probably a reasonable estimate of the income benefit liability for many people acquiring a disability when young, since exits are rare and, when they do occur, are often temporary or to other income support payments.

2) From a broader perspective, the economic liabilities (or social costs) are much more complicated to assess. They include the inefficiency costs of raising DSP income transfers, the forgone value of wages lost due to the existence of the DSP (less the value of leisure for those on DSP), any unanticipated private lower health and wellbeing outcomes from being jobless, and external effects on others (such as the additional costs of health, justice and other community supports that occurs for marginalised groups; and the impacts on the future opportunities of children of people on DSP). Simple or partial measures of these economic costs — such as lost hours of work — are poor indicators of the effects of the DSP (or other welfare policies).

Ideally, policy should be aimed at balancing the benefits of the DSP (the value of safety net income insurance) against the costs set out in (2). That is not easy since many aspects of (2) are hard to measure. In contrast, (1) is far more straightforward to estimate and could be the target of standard public policy.

However, public policy in this area has several disadvantages. Governments:

- do not always have the money to invest in social projects, especially during times of fiscal pressure, even if they ultimately save them money.

- are constrained in the sorts of solutions they can offer. For instance, they can rarely use the marketing tools of businesses, they often have poor links to employers or community groups at the local level, and they can be encumbered by paperwork and procedural requirements

- are often reluctant to invest in risky, but potentially high returning, projects because of the political consequences of failure. Yet, most genuinely novel innovations in the private sector have high failure rates, with a few producing sufficiently high returns to cover the costs of the failures

- are just one source of ideas on the best policies to achieve better outcomes. Non-government organisations and others often have innovative ideas about better social policies, but lack the power or funding to trial them.

For that reason, it can be useful to get others to act as agents for government in opening up innovative ways of creating opportunity for people with disabilities.

As an illustration, suppose that under current DSP rules, Jack is expected to be jobless and on DSP for life, costing at least $500 000 to taxpayers. Suppose that a employment service business says to government: 'Give me $300 000 and I will get Jack a job he would like to stay in and that he would prefer to the DSP'. The firm gives a warranty that if it fails in this it will refund all of the residual value of its promise. The firm can do this because it has a good 'product' — it has worked out

how to engage Jack and an employer. It might do this with wage subsidies, motivational training, support for the employer, wage bonuses and other incentives. Jack is better off because if the firm succeeds, his income rises and he enjoys the social benefits of working (and if the firm does not succeed, Jack would be no worse off because he would be able to resume receipt of the DSP). Taxpayers are better off because the lifetime transfers are lower. Society as a whole is better off because tax distortions are lower, because some of the external costs associated with the use of DSP are reduced and because there is a community value in knowing and being with Jack that are absent when he is isolated at home.

The question for policy is how to achieve such hypothetical contracts with government similar to those involving Jack. Governments reward NGOs for achieving 'good' outcomes using many approaches.

Direct outcome payments to service providers

Under most 'pay for results' arrangements, the Government directly pays service providers for their outcomes (such as the outcome payments paid to Disability Employment Service providers who get jobs for their clients).

However, this model presumes that the service provider can self-finance themselves prior to achievement of the desired outcomes. This may be difficult if the provider is a small operation geared to a niche need in the local community or if the outcomes are over the longer term. Notably, payments to Disability Employment Service providers relate to jobs that last 13 or 26 weeks, which may stifle measures that secure longer-run job outcomes. Moreover, the levels of outcome payment are not usually directly related to the public savings of the outcomes.

Even so, there are grounds for properly structured and monitored outcome payments for agencies achieving good economic outcomes.

Social Impact Bonds (SIBs)

SIBs (sometimes also referred to as 'pay for success' bonds) represent another approach to stimulate better social outcomes (figure 6.8).[12] They differ from the conventional 'pay for results' model in that the government contracts with a private sector financing intermediary (a social impact bond-issuing organization or SIBIO)

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[12] Strickland (2010); Disley et al. (2011); Liebman (2011); Chapman (2011); and the Centre for Social Impact (2011).

to obtain social services (such as local employment services, training programs, mentoring or any service aimed at achieving some desired outcome).

The SIBIO issues 'bonds' to private investors who provide up-front capital in exchange for a share of the government payments that become available if the performance targets are met. The SIBIO uses these operating funds to contract with service providers to deliver the services necessary to meet the performance targets. In some cases, it would be possible for investors to engage NGOs directly (a model proposed for a NSW SIB by the Centre for Social Impact 2011, p. 9).

Figure 6.8   **How social impact bonds work**
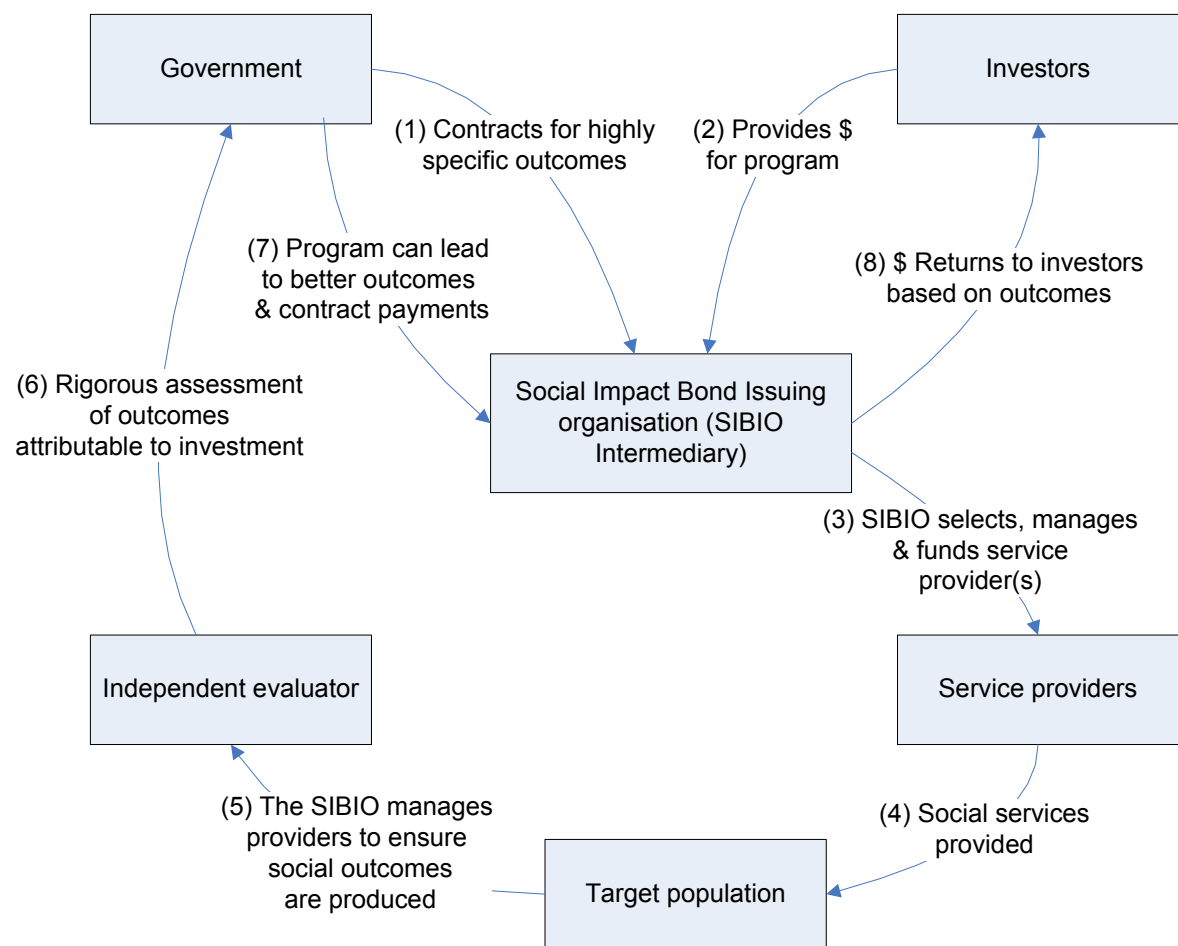
Data source: Adapted from Glahn and Whistler (2011).

The government makes no or little payments to a SIBIO that fails to achieve its nominated targets or it may pay the SIBIO based on some share of the savings to government attributable to the services purchased by the SIBIO. While referred to as 'bonds', they do not offer fixed returns, and may produce no returns at all if the SIBIO does not make good investments. Accordingly, SIBs are more like equities.

The risks of SIBs are borne by the investors and the SIBIO, and not service providers or governments.

Apart from their capacity to overcome any financing problems for nimble and innovative service providers, SIBs can motivate new ways of achieving outcomes, and encourage investment by parties that are jointly interested in the financial returns of their investments and in the social outcomes these purchase. These would include charitable foundations with liquid assets and ethical investment funds. Large businesses may also be willing to participate with a lower return rate, noting that such businesses are often linked to foundations or have one of their own (for example, the KPMG Foundation). The SIB model also encourages rigorous data modelling, quality control and careful choice of service providers because the SIBIO and the private investors lose their returns if they do not secure good outcomes.

The first use of SIBs was by the UK Ministry of Justice in 2010 to achieve low re-offender rates for people released from Peterborough prison. The six-year SIB pilot scheme is run by Social Finance (the relevant SIBIO), and aims to prepare around 3,000 short term prisoners for their lives post-release and will work with them to prevent a return to a life of crime. If these services are successful and re-offending drops by more than 7.5 per cent within six years, investors receive a payment representing a proportion of the cost of re-offending. The payment will increase based on the reduction in re-offending with the total cost of the project capped at £8 million. The investors were primarily foundations and charities.

The US Government has included provision of $100 million for trials of a 'pay for success bond' as a part of its proposed 2012 budget. The NSW Government proposed social bonds in the juvenile detention system, families at risk and in the disability area. While not raising the issue of social bonds per se, one participant in this inquiry (Peter Drach, sub. DR945) noted that the funds used to pay for the DSP could be more profitably used to provide employment supports. This is what social bonds would seek to do.

SIBs are relatively new and sophisticated instruments. This complexity (combined with the difficulties in writing contracts, avoiding cherry picking and curbing fraud) suggest the need for careful implementation. An early report on the UK Peterborough prison pilot (Disley et al. 2011) indicated some of the complexities of, and skills required to manage the SIB model, which would be useful for any Australian trials. (The study was addressed at implementation issues, not at the outcomes for re-offending.) As part of proposed SIBs in NSW for the juvenile detention system, families at risk and disability, the Centre for Social Impact (2011) undertook a detailed assessment, with professional financial and legal advice, of

how SIBs could be used in Australia. The Centre saw the SIB model as workable and found that investors were receptive to it.

Innovation payments

A further option is innovation agreements for enterprises that develop effective models for engaging people on DSP in jobs or social activities. During this inquiry, the Commission has come across highly innovative jobs created for or by people with disabilities that draw on the person's capabilities and preferences, which could easily be overlooked by adopting a conventional approach to encouraging employment. One example is Jackson Richards who works in a courier business under the supervision of his carer (Sally Richards, sub. 26). Another is a person with schizophrenia who makes elaborate carefully designed products for a niche market, work that suits the episodic nature of his disability, can be undertaken at home, and avoids formal workplaces that involve people telling him what to do. The above represent individual and family innovations. It may also be possible to provide grants to encourage more systemic innovations in employment, with the knowledge then becoming public property to be used by other not-for profits or by government agencies without IP payments. The Commission has recommended an innovation fund for service providers, but other types of innovation agreements involving other groups may also be feasible. Such arrangements would need to be complemented by diffusion of the lessons to people with disabilities, carers, the community, and specialist disability and mainstream providers.

6.6   Engaging employers

In evaluating welfare reform, DEEWR (2008) noted:

> However, in general, employers did not regard people with a disability as a potential labour pool to help fill shortages. Perceived barriers to their employment included an inability to perform certain tasks, unreliability and unpredictability, lack of assimilation or integration into the workplace, potential insurance implications, and the need to allocate additional resources to deal with them. A particular issue was the extra time and investment which was needed with people with a disability: employers claimed that they just did not have the time required.

It is likely that some of these judgments reflected stereotypes (which themselves could be a target of policy — see below), but regardless, any perceived disadvantage of an employee will affect an employer's willingness to hire and train.

Carefully targeted wage subsidies, training allowances, provision of worker's compensation subsidies (if risks are deemed to be higher) and employer support

may reduce employer barriers to taking on people currently on DSP and other income support benefits.

Some of these features are currently encouraged through disability employment services (DES — which the Australian Government revamped in 2010). DES includes (potentially ongoing) support for employees with a disability. Employment service providers have strong incentives to actively engage with employers because the service providers receive outcome payments for securing 13 week and 26 week job durations for people with disabilities. Unlike past arrangements, these services are no longer capped, and the evidence shows slightly stronger involvement by Disability Support Pensioners in these services, though still only involving around 3 per cent of the relevant stock of people (DEEWR 2011b, p. 26).

Employment outcomes are still relatively low, with only around 14 per cent of a cohort of DES clients obtaining a job of at least 13 weeks over a six to nine month period, while a significant share (30 per cent) of clients were indifferent, not satisfied or very dissatisfied with the services they received (DEEWR 2011b, p. 27, p. iv). DEEWR will complete a full evaluation of Disability Employment Services in 2012-13, which should guide policy in this area (p. 1).

In the 2011 Budget, the Australian Government announced additional measures to assist employment for people with disabilities, including wage subsidies of $3000 to employers providing jobs to people with disabilities in open employment and a $2000 incentive payment for employers who employ a person under the Supported Wage System (to be implemented from 1 July 2012). Both subsidies require that the person works for at least 15 hours a week and that jobs last at least 26 weeks.

Given the significant policy changes already announced in this area, and the forthcoming evaluation of Disability Employment Services, the Commission has not explored policy options in this area in great detail. However, a critical issue in any incentive arrangement is securing long-term employment outcomes. 26 week outcomes may be the springboard for longer-term jobs, but the research discussed in appendix K suggests that many people go back to the DSP after a spell in a job. This raises the question of the factors precipitating job loss, and the measures that might address these. It is notable that the Social Impact Bonds discussed above have maturities of years, rather than the current six-month horizon for outcome payments paid to service providers and incentives to employers. Prima facie, there are grounds for longer-run support of employers and more enduring wage subsidies for employing people on the DSP. The community initiatives discussed in chapter 4 would also play a role in creating networks that people with disabilities could use to gain employment and in encouraging businesses to employ people.

Changing business practices and attitudes

There remain enduring stereotypes of people with disabilities that affect their likelihood of getting jobs. Governments cannot pay to eliminate stereotypes and social marketing by government shows mixed results. Key businesses, business organisations and local community leaders may be better able to promote to other businesses the capacity for and value of employing people with disabilities.

Some corporations have acted unilaterally, introducing policies that require such employment. In some instances, businesses and organisations have acted as part of a network. For example, the Australian Network on Disability is a not-for-profit organisation, resourced by its members to involve people with disabilities in all aspects of business (as employees, customers and suppliers). Companies such as Westpac, IBM Australia and Qantas are members (as are many public sector organisations).

It may be that arrangements of this kind could be a nucleus for the greater engagement by businesses with employment and other participation outcomes for people with disabilities. A possible strategy is greater engagement by government with lead businesses and business groups, with the goal of formulating a broader corporate disability employment strategy run by business (a kind of job compact). This would be a low cost measure for government. Businesses often are willing to participate in social programs if it aligns with their business interests, helps bolster the community's view of them, and increases cohesion and morale in their workforce.

As ACCI has emphasised, any attempts by government to promote the employment of people with disabilities through engagement with the business community should be business-savvy:

> The promotion of employment of PWD (people with disabilities) does not use business language or business communication networks. Credible modelling of costs and other risk factors, as well as promoting the positive aspects of employing PWD, is required in a concerted campaign over a longer period of three years to address erroneous perceptions and attitudes. Realistic industry profiles of skills needs would enable a targeted approach to be taken in certain industry sectors. Support through business focussed tools, workshops and networking could also further promote employment of PWD. Practical "how to" approaches, written in business language, not bureaucratic jargon, would also improve the chances of increasing employment outcomes. (ACCI 2008)

6.7   An anomaly: the treatment of the blind

The blind automatically qualify for the DSP and do not face a means or assets test for the pension. This means that they can receive the benefit regardless of income or wealth. This is an inherently anachronistic view of the capabilities of the blind. With a shift to a service-oriented economy and leaps in technology, the expectation should be that blind people should be well educated and have jobs, and not be expected to be pension beneficiaries. For example, electronic Braille readers, software developments and other assistive technologies have lowered the barriers to employment. Automatic DSP provision to the blind should not be seen as a concession, but as locking in dated and discriminatory expectations about their capabilities. Some have told the Commission that it would be hard politically to eliminate this concession. From the viewpoint of the modern approach to disability, it is harder to see how it has been acceptable to continue the automatic payment.

6.8   Using data for optimal interventions

One of the key functions of the NDIA is improved data collection and analysis (chapter 12). A particularly important role would be assessing the effectiveness of various interventions on the employment outcomes for people with disabilities. At the outcome level this would include whether a job was obtained, the hours of work, wages and the level of job satisfaction. On the input level, the nature of interventions, such as school to work transition programs, life planning, improved disability supports, specific employment support, and the role 'social bond' holders and DSOs could then be investigated for their impacts, controlling for the traits of the people with disabilities. Ideally, such data analysis should link with information about DSP recipiency to assess whether aspects of the DSP are likely to frustrate or enhance job outcomes. That would better inform the design of the DSP, as well as other interventions inside and outside the NDIS that may promote better employment outcomes.

Communicating changes to the DSP also requires an evidence-based approach

The changes described above would represent a major shift in policy on the DSP, and a key aspect of their effective implementation would be to ensure that people were aware of what it meant for them.

Centrelink provides accessible material on all of its payments and benefits (and online calculators), and many advocacy groups also inform people with specific

disabilities, but information is not knowledge. The DSP is a complex payment embedded within a labyrinthine tax and transfer system. The payment has been altered many times, includes a range of grandfathered arrangements, and interacts with many other tax/transfer arrangements (such as family benefits).

Complexity is problematic in several ways.

The calculation of the income effects of various tax/transfer arrangements (and the associated effective marginal tax rates) is difficult, but gives unambiguous answers. However, for many clients the effects of the system are unclear. Even sophisticated parties may find it hard to work out the optimal response to complex tax/transfer arrangements (as discussed more broadly by Toder 2011). It is possible (though untested) that people on a benefit may be unaware of their greater capacity for working while retaining a partial benefit.

The implication is that an elegantly designed arrangement may not have its desired effect if people do not understand it. The empirical evidence suggests that many people with disabilities are not well educated (chapter 2) and that their family carers struggle already with the demands placed upon them.

This complexity means that people may make decisions that are not based on correct information. For example, some participants in this inquiry were not aware that people could retain a pensioner concession card for 12 months if they stopped receiving their social security benefits.

Complexity also creates uncertainty. Once people are not sure about the effects of working (by themselves or a family member) on their DSP benefits, their behaviours are likely to reflect that uncertainty. In particular, doing nothing is often a reasonable strategy for a risk averse person. Evidence from behavioural economics adds the additional insight that:

> People are heavily influenced by default positions and have a strong bias to loss relative to their starting point. So they will be influenced much more by potential losses from changing behaviour than by potential losses from not changing it. (Toder 2011, p. 11)

These problems of complexity and uncertainty would be reduced were the tax/transfer system to be simplified, but that is a difficult task in its own right. Given that, from a practical perspective, policy should be framed in a way that recognises people's uncertainty and misunderstanding about the workings of the DSP and the associated tax/transfer system.

One of the advantages of social bonds as an incentive arrangement is that through experimentation, non-government agencies may be better at finding the best way of communicating the benefits of employment.

That said, government agencies, like Centrelink, will have the main role in delivering and communicating the significant changes to the DSP. Disability Employment Service providers will also have a role in explaining the changed context of the DSP to employers, especially given that social bonds may create highly flexible and innovative arrangements. Accordingly, there are strong grounds for a sophisticated evidence-based approach to ensure that people understand a new system (a testable issue) and to understand how people's actual (rather than assumed) responses vary depending on how the changes are communicated. Any information should be in plain English, and any forms people would have to use in a new DSP system should be as simple as possible (a goal the NDIA itself would have to meet — chapter 9). There is a developing literature in the consumer policy arena that can guide such an evidence-based approach to communicating policy changes effectively (PC 2008).

6.9   Some other presumptions should be re-assessed

Despite past reforms, there is a strong degree of inertia in the design of the DSP and the presumptions underlying these. There are grounds for the re-appraisal of the:

- level (and nature) of assets and income tests for access to the DSP, including consideration of whether the same tests should apply regardless of age and whether the significant exemptions for housing wealth should be re-evaluated in the light of innovative government or private equity withdrawal arrangements. These issues are highly complex. On the one hand, people with significant asset holdings might be regarded as having a capacity for greater self-reliance. On the other hand, changes in asset tests might reduce the incentive effects for saving and raise issues of fairness for people who may have few assets to draw on over their lifetimes. However, increasingly there are questions about people's capacity to self-fund at least part of their aged care from assets, and similar considerations might apply for people who enter the DSP at older ages prior to retirement. Current arrangements represent a judgment about the balance between the various equity and efficiency issues raised above. The issue could warrant re-examination, without making a judgment about where that balance should lie

- appropriateness of the many grandfathering arrangements for the DSP. This makes the system very complex and hard to explain to recipients. Grandfathering is appropriate when people make long-term commitments based on government

policy of the day (for example, in relation to retirement savings or decisions that are costly to reverse), but are less clearly justified in the case of income support payments. It is not clear why two people with identical characteristics (age, gender, location, level of impairment, skills and so on) should be treated differently in respect of their eligibility for income support payments or the extent to which they have incentives for working, simply because one got on to the payment before the other. It may well be that those who have experienced longer durations on the DSP will have lost more of their job skills than those who are new to the payment, but Job Capacity Assessments are intended to assess that. The OECD (2010, p. 17) has mounted a case for re-examination of grandfathering in those countries (like Australia) where it would be legally possible to eliminate it

- appropriateness of structuring the DSP in the same way as the Aged Pension, despite the payments having very different functions

It may be that existing arrangements should be retained, but there would be value in testing that proposition.

6.10 Some caveats

Any policy changes would need to be mindful of the administrative costs of change. The DSP recipient population is around 800 000, and individually tailored arrangements and increased review rates can require significant administrative resourcing, and the risks of payment and other errors. For example, there were large teething problems with the introduction of the UK Working Tax Credits (which included specific arrangements for people with disabilities) resulting from overpayment and delayed payments.

A further issue is the impact of classification errors. Any policy that uses at least partly subjective assessment to place people into different categories where the benefits and requirements are different will inevitably involve classification errors. The greater the difference in the requirements and benefits, the more these errors matter. For example, imposing job search requirements and time-limited payments for someone with a severe and chronic mental health problem would involve significant stress and uncertainty for someone who was already highly disadvantaged. That suggests careful investment in assessment tools (and these are being altered now) and active monitoring of outcomes for people.

6.11 More scrutiny of the DSP is needed

The DSP is the major working-age social security payment in Australia and the single most important source of safety net income for nearly a million Australians. It annual cost to taxpayers is currently around $14 billion. Since its beginnings early in the 20th century, disability benefits have presented successive Australian Governments with many policy dilemmas. Eligibility conditions, assessment methods, the provision of employment supports, and payment levels and structures have been adapted, depending on the policy imperatives of the day.

The creation of a well-funded NDIS fundamentally changes the context in which the DSP sits. In particular, the NDIS is about ensuring people get reasonable, not rationed, supports that maximise people's potential. Tiers 1 and 2 of the NDIS also encourage better integration of all people with disabilities with the community (broadly defined). In many respects, the currently structured arrangements for the DSP are a product of a medically focused 'I cannot do' model of disability. It sits uneasily with the NDIS, as well as with the reality that Australia is about to experience slowing growth in the labour force as the population ages.

This chapter has floated some options for reform, but it cannot address all of the complex issues associated with the DSP. Given the scale, complexity and importance of this payment, and people's diverse views about it, there are strong grounds for a public inquiry into the pension to see how it could be re-engineered to produce better outcomes, not least for those people who often appear to be imprisoned by it for life.

RECOMMENDATION 6.1

The Disability Support Pension (DSP) should not be funded or overseen by the NDIS. The Australian Government should reform the DSP to ensure that it does not undermine the NDIS goals of better economic, employment and independence outcomes for people with disabilities.

Reforms to the DSP should aim to:

- *encourage the view that the norm should not be lifelong use of the DSP, among:*
  - *people with non-permanent conditions*
  - *people with permanent conditions who could have much higher hopes for employment participation*
- *redefine the DSP as a transitional disability benefit, not as a pension, for those with some employment prospects, while retaining the pension for those with low employment prospects*

- *reduce the disincentives to work while on the benefit by reducing benefit taper rates, permanently relaxing or removing the work test for people already receiving disability benefits, and trialing 'sign-on' bonuses for those on DSP who gain paid work*

- *provide greater support to employers to encourage employment of people with disabilities, including greater wage subsidies*

- *tap private innovative arrangements for greater economic and social participation of people on the DSP through social bonds*

- *improving data collection and analysis for monitoring outcomes for people on the DSP and the interventions that produce the largest impacts.*

The above reforms should not be limited to new entrants into the DSP.

As a general principle, all people with disabilities should face the same eligibility test for the DSP. However, the longstanding automatic qualification of blind people for the DSP should remain for current recipients of the pension, but should not apply to new applicants.

While the Australian Government should consider the early implementation of some of the above measures, it should also establish a public inquiry into the DSP to:

- *develop the best path to implementation of the above options, where they cannot be put in place quickly*

- *assess how the DSP could be further redesigned to be compatible with the social and economic participation goals of the NDIS.*

6.12 What about the Youth Disability Supplement?

People with disabilities under the age of 21 years receive the Youth Allowance, rather than the DSP, but are eligible for the Youth Disability Supplement (of $110 per fortnight) due to the 'additional costs associated with having a physical, intellectual or psychiatric disability'. However, the goal of the NDIS is to meet all the reasonable needs of people with a disability, raising questions about the rationale for the supplement for those people eligible for funded support from the NDIS.

One possible response would be to take into account the supplement in determining entitlements under the NDIS. On the other hand, the Youth Disability Supplement does not require assessment of the additional costs that young people may face because of their disability. Despite its ostensible function, it appears to act largely as an income support measure, rather than one targeted at specific disability costs. In

that context, the current arrangements should remain, with the supplement left as part of the income support system.

7   Assessing care and support needs

Key points

- The assessment process would:
  - assess the nature, frequency and intensity of an individual's support needs, regardless of how these might be met. While the process would be person-centred and forward looking, it would be focused on what was reasonable and necessary
  - consider what willingly and reasonably could be provided by informal carers. Informal carers who met a large share of a person's support needs would receive their own assessment if they wish
  - translate identified needs into a person's individualised package to be funded by the NDIS, after taking account of natural supports.

- The NDIS would periodically re-assess people's needs as their circumstances changed, especially at key transition points like leaving school, getting a job, moving out of home, or losing a natural support.

- A coherent package of tools (a 'toolbox') should be employed to determine the support needs and funding for a person covered by the scheme. Different tools would be suited to particular needs for support (for example, the need for aids and appliances compared with attendant care). Any tools used by the NDIS should be rigorous, valid (testing what they purport to), reliable (giving consistent results) and cost-effective.

- Governments should not delay implementation of the scheme in the absence of 'perfect' tools. The NDIS would use the best available tools in its initial stages, with the later development of better tools.

- Excessively tough use of the assessment tool would be unfair, but 'loose' use would threaten scheme sustainability. To guard against both:
  - assessments would be conducted by allied health professionals approved or appointed by the NDIA and trained in the use of the tools. They would be continually assessed for their appropriate use of the assessment tools
  - the assessments would not be 'rubber stamped'. Prior to making budgetary decisions, the NDIA would confirm that the particular assessment followed the appropriate protocol, and was consistent with a 'benchmark' range of assessed needs for other people with similar characteristics. Deviations outside the norm would require further investigation
  - any tools employed would be continually monitored and refined.

7.1 Introduction

One of the primary functions of the NDIS will be to provide individualised, funded supports. A robust process for determining who gets what will be critical for both scheme users and administrators. The assessment process must provide a reasonably close estimate of a person's support needs and the resource allocation to achieve them. It should avoid being too generous or too tough. The process must be fair, rigorous and safeguard against exaggerated claims of support needs.

At the most general level, the assessment process will be about identifying the supports that would allow a person to fulfil a range of functions, such as participate in their community in keeping with personal goals and aspirations. However, there are many issues to resolve regarding the design of the assessment tool(s) including:

- what is being assessed, and across what 'domains' or range of life activities (section 7.2)

- the purpose of the assessment process beyond indentifying an individual's support package (section 7.3)

- desirable features of assessment tools, such as validity, reliability and rigour (section 7.4).

Having regard to the intended role of assessment tools in the context of a NDIS, it is useful to then consider:

- the range of tools currently available (section 7.5)

- whether a single tool will be universally appropriate or whether the scheme should employ a 'toolbox' (section 7.6).

The remainder of the chapter considers a range of issues relating to the tools' use, such as:

- who should conduct assessments (section 7.7)

- when, over the course of an individual's life, assessments should take place (section 7.8)

- whether carers should have their own assessment (section 7.9)

- how a 'typical' assessment process might work, and the importance of calibration and checking to ensure fairness and scheme sustainability (section 7.10)

- how to ensure that tools are applied rigorously, including safeguards and processes for adapting and refining them over time (7.11)

- the transition to a fully developed toolbox (section 7.12).

7.2 What is being assessed?

Needs, wants and aspirations

An obvious first question to pose with respect to assessment is 'what is being assessed'. The scheme should meet reasonable *needs* (chapter 5). Broadly speaking, Victoria's Transport Accident Commission (TAC) and the NSW Lifetime Care and Support Authority (LTCSA) have this as their objective. In these schemes, the assessment process focuses on needs rather than wants. The TAC for example, states: 'The needs of every person are different, and the TAC looks at each case individually when determining what to pay' (TAC 2011). While the NSW LTCSA notes that 'you will get what you need, not things that are simply nice to have' (LTCSA NSW 2011).

But defining and determining 'need' is by no means straight forward. There is a danger that people will ratchet up their claims for support by presenting wants as needs.

The United Nations has noted the complexity involved:

> Defining and determining need is easier said than done. It is not value-free, as who determines it, how it is determined and for what purpose it is done, will all affect the outcome. Neither the methods used to identify needs nor the concepts of social needs have been clearly defined. (ESCAP 2003)

A similar view was put by Anglicare Australia:

> Throughout the social policy and justice histories needs have played an integral role for the planning and development of policy and program responses. However over the course of those histories there has never really been a consensus on what needs are and there is even more contention over the derivation of particular types of needs. (sub. 594, p. 6)

A number of academics such as Maslow (1954), Harvey (1973) and Bradshaw (1972) have attempted to 'unpack' the concept of need. Of those, perhaps Bradshaw's work is the most informative from a social policy perspective. Bradshaw distinguishes between four types of social needs — normative, felt, expressed and comparative (box 7.1). This framework is relevant in disability policy. As Anglicare observed:

> … the needs identified by Bradshaw, particularly perceived [felt] and normative needs resonate most closely with the types of need identified by Anglicare Australia network members. (sub. no 594, p. 6)

> ### Box 7.1　Unpacking the concept of need
>
> Bradshaw's framework involves four different ways of thinking about 'need'.
>
> **Normative need** is defined by reference to 'appropriate' standards or required levels of services or outcomes determined by expert opinion. Individuals or groups falling short of these standards are defined as being in need. But normative need is by no means absolute, as Bradshaw observes, normative need 'may be tainted with a charge of paternalism'. Moreover, experts may have different and possibly conflicting standards.
>
> **Comparative need** is determined by comparing the resources or services available in one area — be it a community, a population group or individual — with those that exist in another. A community, population group or person is considered to be in 'need' if they have say more health or social problems, or less access to services, than others. The main problem with the concept of comparative need are its two underlying assumptions — first, that similarities exist between the areas and second, that the appropriate response to the 'problem' is to align service levels. This need not hold true, for example, when both areas experience chronic shortages for a particular service.
>
> **Felt need** has a subjective element and is defined in terms of what individuals state their needs to be or say they want. It can be defined easily by asking current or potential service users what they wish to have. But felt need by itself is generally considered to be an inadequate measure of 'real need'. For example felt need can be inflated by users' own high expectations.
>
> **Expressed need** is defined in terms of the services people use. It is based on what can be inferred about a person or a community by observing their use of services (or waiting lists for services). A community or person who uses a lot of services is assumed to have high needs. While a community or person who does not, is assumed to have low needs. But expressed need is influenced by the availability of services — a person cannot use or put their name down on a waiting list for a service that is not offered.
>
> *Source*: Bradshaw (1972).

Taking account of aspirations

While the assessment process would primarily be about assessing an individual's needs, it should not disregard their aspirations. The Commission sees merit in the approach employed in the United Kingdom whereby:

> The purpose of a community care assessment is to identify and evaluate an individual's presenting needs and how these impose barriers to that person's independence and/or well being. Once eligible needs are identified, councils should take steps to meet those needs in a way that supports the individual's aspirations and the outcomes that they want to achieve. (UK Department of Health 2010, p. 20)

The intention would be to assess 'reasonable and necessary' support needs, but within this objective, the assessment process would consider people's aspirations. There was some support for this approach among participants:

> Valued Independent People support the Commission's findings that assessment should be focused on needs and in particular, reasonable needs. We agree with the Commission's findings that individual's aspirations should also be taken into account. (Valued Independent People, sub. DR932, p. 9)

Aspects of life

Individuals lead multi-faceted lives and so a second question to consider is how broad ranging the assessment process should be. Many assessment tools are designed to provide a rounded picture of an individual's needs and related circumstances. The tools themselves are a collection of scales and questions, which are often grouped in common or related life areas referred to as 'domains'. Examples of domains that are potentially relevant for assessing care and support needs include, but are not limited to, self-care, mobility and communication.

The International Classification of Functioning (ICF) — the World Health Organisation's (WHO) framework for measuring health and disability at both individual and population levels — lists nine 'activities and participation' domains of relevance:

- communication — communicating by language, signs and symbols, carrying on conversations, and using communication devices and techniques

- mobility — walking, running or climbing, changing location or body position, carrying, moving or manipulating objects, and using various forms of transportation

- self-care — attending to one's hygiene, dressing, eating and looking after one's health

- domestic life — carrying out everyday tasks such as acquiring necessities (like a place to live and goods and services), preparing meals, caring for household objects and assisting others

- interpersonal interactions and relationships — relating with strangers, formal and informal social relationships, family and intimate relationships

- learning and applying knowledge — learning, applying the knowledge that is learned, thinking, solving problems, and making decisions

- community, social and civic life — engaging in community, civil and recreational activities

- general tasks and demands — carrying out single or multiple tasks, organising routines and handling stress

- major life areas — carrying out responsibilities at home, work or school and conducting economic transactions.

Each of the nine domains (for example mobility) consist of facets or blocks (such as walking and moving) within which are nested groups of second, third and sometimes fourth-level categories (figure 7.1).

Figure 7.1   **The International Classification of Functioning, Disability and Health**

Activity and Participation Domains (showing the details behind one heading 'mobility')
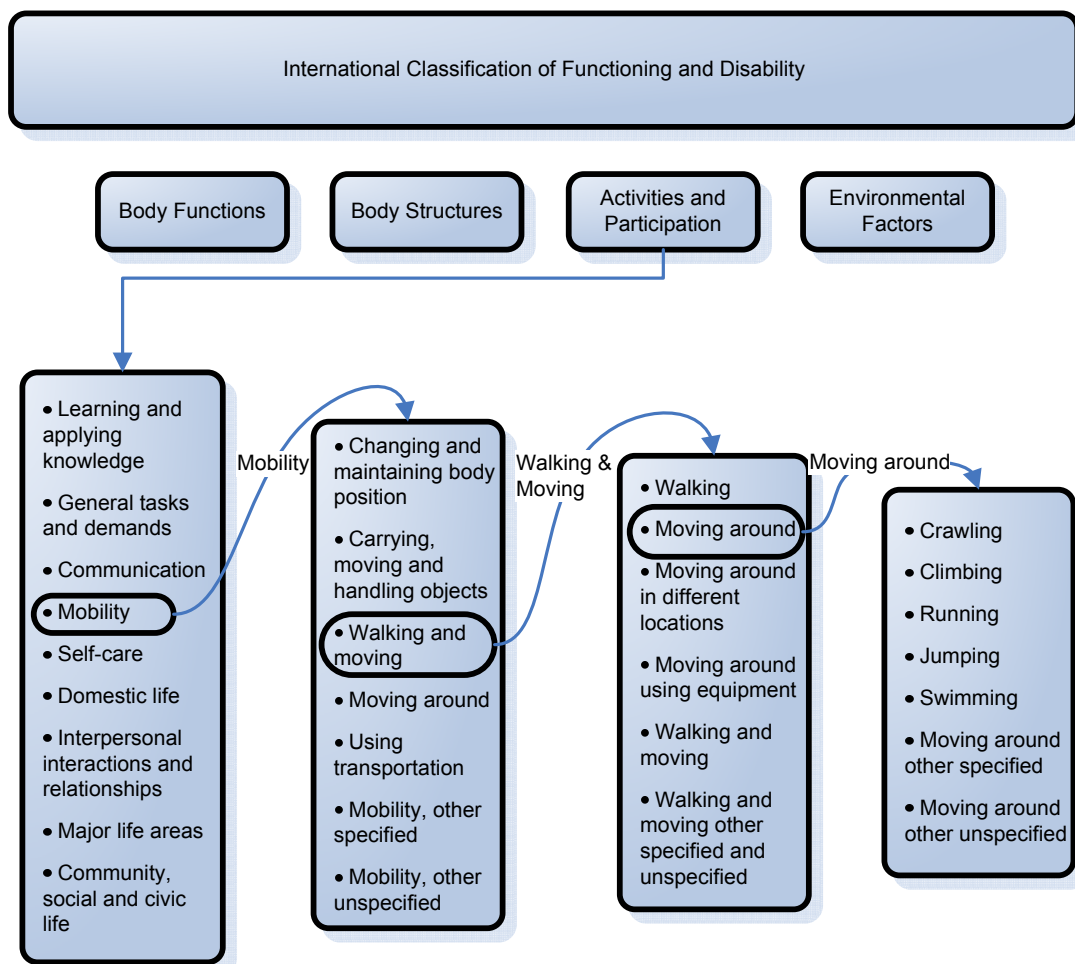
Source: The World Health Organisation, ICF Online, http://apps.who.int/classifications/icfbrowser/.

The ICF is a comprehensive and robust *framework* not an assessment tool itself. The WHO (which developed the ICF) noted that:

> The ICF is impractical for assessing and measuring disability in daily practice; therefore, WHO developed the WHO Disability Assessment Schedule (WHODAS 2.0) to address this need. (Üstün et al., 2010, p. 3)

The implication is that rather than replicate all elements of the ICF framework, any assessment tool would incorporate the best mix of indicators or relevant domains of need. The preferred assessment tool(s) would still be consistent with the overarching ICF framework.

In addition to encompassing elements of self-care, communication and mobility, the assessment process should include aspects of learning and applying knowledge, and community and social participation. To do otherwise, might mean the support needs of some individuals were systematically overlooked:

> Many in the Autism population frequently experience problems with assessment instruments that overestimate their abilities and underestimate their need for assistance. This is largely because measures of mobility and communication that form the basis of many tools do not pick up (and are not designed to measure) the severe and disabling impact of Autism on daily functioning. There are many people with Autism who have no problems with mobility or spoken language (have a normal IQ) but are severely impaired in their ability to synthesise information, to understand their social environment or to make informed decisions. They remain very vulnerable individuals in need of continuing support to function in daily life. The Autism Association is greatly concerned at the potential for an assessment tool that will under-estimate the needs of the Autism population or, indeed, exclude them from eligibility for support. (Autism Association of Western Australia, sub. DR795, pp. 2-3)

7.3 What is the purpose of the assessment process?

As Owen et al. (2005) noted, 'Assessment is a valuable intervention in its own right, and is not just the entry point into service provision'. The assessment process can provide an opportunity for individuals to articulate their care and support needs, identify issues that need to be addressed in any personal plan, and be used to collect data. Indeed, in the context of a NDIS, the assessment process will fulfil a number of functions.

Determining whether an individual would receive individualised supports

A short upfront module would establish whether an individual would receive NDIS-funded, individualised supports (figure 7.2). This stage would be waived for

some sources of disability that resulted in significant and unambiguous care and support needs — such as quadriplegia, Down syndrome and neural tube defects — or where the scheme had already identified opportunities for cost-effective early interventions across a group of individuals. Having this initial assessment would reduce overall costs as some people will not be entitled to individualised supports and will not require more extensive assessments. (Tier 2 services may be more appropriate for their needs.)

Determining the service offering

A comprehensive component would consider the supports that would allow a person to fulfil a range of *functions*, such as participate in their community. This component would be supports driven, and so would not solely focus on an individual's diagnosis or what they cannot do.

Assessments would be person-centred, taking account of people's unique circumstances. Consistent with the ICF framework, the assessment process would identify support needs across a range of life activities, and would take into account the interactive effects of an individual's health condition (and impairment), their desired activity and their context (including environmental and personal factors).

The assessment process would identify the type, intensity and frequency of support needed, regardless of how these needs might be met. Moreover, assessments would provide a dynamic account of an individual's support needs, including having regard to fluctuating needs and anticipating changes that can be expected to occur. (For example, as the result of skills development, ageing, or a health condition that is progressive.)

Determining what reasonably and willingly could be provided by unpaid carers and the community

At present, informal care, such as that provided by unpaid family carers and friends, accounts for the overwhelming majority of hours of care provided. Access Economics estimated that the total value of informal care amounted to around $30.5 billion in 2005.[1] No scheme is likely to fund the full cost of this care, so natural supports will remain an important part of the care and support response.

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[1] This reflects the value of resources that would need to be diverted each year from the formal economy, if all hours of informal care (for people of all ages) were replaced with services purchased from formal care providers and provided in the home.

But informal care arrangements need to move to a more equitable and sustainable footing. The pressure on carers should be lessened by more and better services. This approach is consistent with that advocated by the House of Representatives inquiry into better support for carers:

> Importantly, the Committee understands that with adequate levels of appropriate support in place, most carers wish to continue to provide care for as long as they feel able to do so. It is therefore in the best interests of all concerned — carers, care receivers, governments and society — to share the responsibility of providing care more evenly. If realised, this will allow carers and their families to participate more fully in society through engagement with education, employment and social activities. (SCFCHY 2009, p. x)

Under the NDIS, the focus would be on supports that could be *reasonably and willingly* provided by unpaid family carers and the community. For example, it would not be reasonable to expect elderly carers to provide the bulk of the support, but it would be appropriate (in most instances) to expect parents of a young child to provide 'passive' overnight support and for a reasonable period during the week, as this is what all parents do for their children.

In gauging a person's *appropriate* natural supports, the assessment process should have regard to:

- how much unpaid support is currently being provided or is likely to be provided

- the impact on family members, including young carers and other current or potential carers providing support

- the level of care and support (if any) current or potential carers want to provide.

The question of whether carers should receive their own assessment is addressed later in this chapter.

Determining an individual's budget

The assessment process will need to identify a budget associated with meeting the assessed needs of individuals (after taking account of any reasonable natural supports). Crucially, there would be an obligation for the system to deliver the funding determined by the independent assessment. This feature is an essential element of avoiding the chronic underfunding that has beset past allocation systems.

An individual's budget could be derived, through a 'bottoms-up' approach, by costing all of the support needs identified by the assessment process (after taking account of natural supports). As a very simple example, were a person assessed as needing 10 hours of attendant care per week, but their partner was happy to provide

two hours, and the cost of attendant care was $30 per hour, their budget would be $240 per week (8 hours x $30 per hour).

As budgets will be attached to assessments, it will be important for the scheme to monitor patterns in assessments to test whether these reveal any unwarranted cost pressures (for example, those arising from defects in the assessment tool or permissive use of the instruments). (The need for, and benefits of, systematic checks are discussed further in section 7.11.)

Determining suitability for self-directed funding

The assessment phase would substantiate the capacity of the person or carer to self-direct funds. This would not be a feature of the assessment tool per se, which would be about identifying needs, but would be part of the interaction with the person with a disability during the assessment phase.

Providing a referral to other schemes

Under the current fragmented system, many programs have unique eligibility criteria and assessment systems. But as a number of participants have remarked, this often results in people contacting several agencies or service providers to request a service, providing their personal details, explaining their circumstances and being assessed multiple times (chapter 2). Bringing *specialist* disability services under a single umbrella, the NDIS, will go a long way to reducing this fragmentation and the consequent need for overlapping assessments.

However, the care and support needs of people with a disability are broad-ranging, and the NDIS is not intended to address all of them. There are good reasons for the scheme to focus on disability specific needs, with *mainstream* services such as education and employment remaining outside its scope (chapter 5). But the ongoing distinction between specialist and mainstream services should not make for an overly complex system in which assessment effort is duplicated. Rather, assessments should be portable across the system — subject to protection of privacy — so that people do not have to repeat information for different providers or government agencies.

Where there is extensive overlap in the nature of information being provided, the NDIS should reach agreement with other departments or agencies to either act as the sole assessment point, act as a point of referral or to share information, subject to strict privacy safeguards. The following examples *illustrate* some of the different ways in which this could be put into place:

- *The NDIS acts as the sole assessment point and agent* — say the information collected via the NDIS assessment was sufficient to also establish that an individual was entitled to a disability parking permit, the NDIS could *act as an agent* for state and territory road authorities and *issue* the permit.

- *The NDIS acts as the sole assessment point and provides a referral* — say the information collected via the NDIS assessment was sufficient to establish that an individual was also entitled to a disability parking permit, the NDIS would provide a referral and state and territory road authorities would issue the permit without undertaking an assessment of their own.

- *The NDIS shares information with other departments and or agencies and government-funded service providers subject to strict privacy safeguards* — say the information collected via the NDIS assessment *partly satisfied* the information requirements for a disability parking permit, such that further information was needed. The NDIS would share the relevant information with state and territory road authorities, who would then *add to* it in order to satisfy their own requirements. State and territory road authorities would then issue the permit.

The NDIA and mainstream providers should identify opportunities to employ these and other models for information sharing, in order to reduce the paperwork burden on people with disabilities.

Providing data for program planning and cost management

Administrators of the scheme need to establish whether costs and revenues are in tune and, if not, the best response. They need to know what is safe, what works, for whom, when and how. They need to know whether the benefits of given services and interventions are worth the costs. The assessment process would be an important source of data for program planning, high-level reporting, monitoring and judging the efficacy of interventions. It would also assist in forecasting the likely long-run liabilities for the scheme — a major focus for the management and sustainability of the NDIS.

7.4 Desirable features of assessment tools

There is no universally agreed tool for assessing the care and support needs of individuals. There is however, reasonable consensus about the attributes that any assessment tool must have. These include validity, reliability and rigour.

Validity and reliability

In order for assessment tools to be generally considered effective, they must be both valid and reliable. The key aspect of assessing validity is to pose the question: 'What is the tool for?' and ask whether it meets that purpose. For example, in the context of an NDIS, the assessment tool is not intended to measure needs per se, but needs that must be funded by the scheme.

Validity is measured in a number of ways, including by reference to a gold standard measure which has been used and accepted in the field. Another related aspect is the responsiveness of the tool or its capacity to detect change in a person over time. This is an important feature in the disability care and support context, as individuals' needs change.

A reliable measure is one that measures a construct consistently across time, individuals, and situations. A good measure should produce consistent results when the test is repeated within a reasonably short space of time (test-retest reliability) and when different assessors use the instrument to assess the same individual (inter-rater reliability). In order to be valid, a measure must be reliable, but the converse need not be true (box 7.2).

Box 7.2   **Making sense of 'reliability' and 'validity' with examples**

Just because a measure is quite reliable, this does not also make it valid. Take for example a metre long ruler, but assume instead that the ruler is in fact 120 cm long. Every time the ruler is used to determine the height of a person or object, it systematically underestimates height by 20 cm for every metre. A child, for example, who according to this measure is one metre tall, would actually be 120 cm tall.

But this error does not affect the reliability of the ruler. The results would be quite consistent if repeated a number of times (test-retest reliability) or if several different people used the ruler to measure a given person or object (inter-rater reliability) despite being obviously incorrect. In short, this particular ruler would provide a quite reliable but totally invalid indication of height.

Source: Adapted from Carmines and Zeller (1979).

Aside from validity and reliability, there are a number of other factors to take account of in establishing a tool's suitability. Guscia et al. (2006a) identify susceptibility to manipulation, completion time, assessor training requirements and ease of administration more broadly. Owen et al. (2005) also highlight ease of administration and applicability. Finally, in the context of an NDIS, a tool needs to be nationally consistent.

Rigour

As Harries (2008) notes, a dilemma for funding bodies in the context of individualised funding is that some individuals will overstate the extent of a disability in order to receive increased levels of funding. (This need not be by the person with disability. Under current arrangements, for example, service providers might face an incentive to overstate people's needs to get more funding.) In some cases, people might be conscious of what others receive and may inflate their own claims.

An Australian study conducted by Guscia et al. (2006b) investigated whether assessment tools obtained different results for different purposes. They found that the assessed support needs of individuals were much greater when they were assessed for funding purposes compared to when they were assessed for research purposes.

There are a number of ways to reduce the risk of such 'gaming'. These include the use of professional assessors, careful calibration and gatekeeping and the monitoring of data. But the choice of tools can also affect the scope for gaming. Harries (2008) notes that the use of objective and auditable measures of need can reduce the risk of gaming. It has been suggested that the use of objective functional measures are potentially less susceptible to manipulation and therefore may be more appropriately suited to funding purposes (Dyson et al. 2000 as reported in Guscia 2006a and Harries 2008).

Where people receive an entitlement to supports rather than a budget to purchase those supports, the incentive to overstate needs is reduced. For example, a person would face little incentive to exaggerate their need for assistance in showering, if that only resulted in more showers (rather than a bigger budget).

Applicable

Applicability refers to whether the tool can be applied to a particular target group. Some tools for example, target particular disabilities such as intellectual disability, while others target people of certain ages, such as children. Given the target population of the NDIS (chapter 3), the assessment tools will need to be applicable for individuals of different ages and with a wide range of levels, types and combinations of disabilities.

It is important that any tool not unfairly discriminate against people from Indigenous or ethnic communities. As noted by The Victorian Equal Opportunity

and Human Rights Commission, 'assessment tools and processes must be culturally robust' (sub. DR885, p.3).

A number of participants raised concerns about the applicability of assessment tools. They were worried that the assessment tools employed by the NDIS would fail to capture fully their particular needs.

The Commission considers that the NDIS should only use a tool to assess the needs of particular groups where its reliability and validity have been established for that group. Recognising the importance of applicability, key groups have already been working with the developers of assessment tools. For instance, the Royal Society for the Blind is currently working with the University of Adelaide on the D-Start Assessment Trial (sub. DR826, p. 13).

Practicability

Practicability refers to the ability of a tool to be applied in a given situation or context (Owen et al. 2005). In the case of a NDIS, a tool will be used for both screening prospective users and determining an individual's package of supports and the budget associated with meeting those supports. In the first instance, a tool that is quick and easy to administer might be preferred. In the second, given the complexity of the task and the need for the outcome to be highly valid and reliable, it would be appropriate for the scheme to invest relatively more time and/or effort in undertaking the assessment. This suggests a role for either a hierarchical tool or multiple tools (section 7.6).

The skills required by staff that implement the tool also affect practicability. A tool that is easier to administer and requires less training of staff, while still producing reliable results, may be preferred to one which requires extensive training of assessors by accredited trainers.

User fees and copyright

Increasingly, the developers of tools are charging license fees for their use. Given the number of people who may receive individualised supports under the NDIS (around 411 000) and the regularity with which assessments will occur, whether a user fee must be paid each time the assessment tool is used will be a consideration. Hence, in its draft report, the Commission suggested that any tool should be in the public domain. The Centre for Disability Studies argued quite strongly that this was an unnecessary (and potentially problematic) criterion:

The majority of national and international jurisdictions do not make publically available the algorithm that is used to compute assessment scores into resource allocations. As much as greater transparency is required in the public arena regarding how resource allocations are made, if it is widely known how items in an assessment are weighted in a funding allocation algorithm, then potentially it is easier for people to inflate their scores to gain maximum funding in the required areas and it may/may not be detected that they are gaming on the assessment process. Although there are examples of people returning funding not required, it is also well known that other situations exist where persons or case managers have exaggerated support needs in order to receive higher funding when resources are scarce, and cases where everyone seeking services through particular service providers are scored in the high or very high brackets. (Centre for Disability Studies, sub. DR992, p. 4)

The Commission agrees that an assessment tool need not be in the public domain. But considers that, over the longer-term, the NDIS should oversee the development of its tools (and ideally hold copyright), since such tools effectively determine resource allocation and because the NDIS would have the best evidence for their ongoing development. The tools should also be made available at no cost to researchers wanting to develop them further.

Efficiency

An efficient tool is one which collects sufficient information to assess support needs in the most economical manner. Assessing need can be time consuming and costly for an agency and the individual and family concerned. It is generally considered best to use the shortest tool available that still meets appropriate standards of reliability and validity.

Nationally consistent

Under existing arrangements it is relatively common to find instances where individuals with similar support needs in different states (and even in the same state) receive quite different care and support packages. (The reasons for this are discussed fully in chapter 2.) Not only is this situation inequitable, it hinders people's ability to move between states. Substantially increasing the quantum of disability funding would not resolve these problems. Recognising this, governments have stated that they will move towards a national assessment model.

There are (at least) two options for achieving greater national consistency and enabling portability. The first involves setting national guidelines for a common assessment approach. Guidelines might list criteria for choosing tools, include a requirement that tools be able to produce core summary data or information, or

outline a preferred assessment process. This resembles the option employed in the United Kingdom. But it is not clear that this response has resolved their portability and inter-jurisdictional equity concerns:

> People with the same needs receive different levels of care depending on where they live. Local authorities across England use the Fair Access to Care Services (FACS) guidance, issued by the Department of Health, to assess and determine eligibility for services; this aims to make such decisions more transparent. However, different authorities interpret the FACS criteria differently and so they differ in the levels of need they support. Some authorities provide support for care packages for people with moderate or higher levels of need, whereas some only provide support for the higher levels. (UK Green Paper 2009, p. 42)

The second approach builds on the first, but also specifies a 'toolbox' that would be employed nationally. The Commission favours this approach, since it would ensure more equitable access to nationally funded support services and allow portability of funding across borders when people move.

7.5 The current suite of assessment tools

There has been little investment within Australia in the development or refinement of assessment tools that provide a rounded picture of individual's needs across a range of support types. That is because there has been little incentive to do so — the fractured and highly rationed nature of the system means individuals are typically assessed for a narrow subset of services, and assessed need does not translate into entitlement. That said, all governments have agreed to simplifying and improving the consistency of assessment processes and some jurisdictions have recently begun developing and piloting new tools.

The process of starting from scratch to develop a new assessment tool in any field is time-consuming and expensive. As Owen et al. explain:

> A large pool of draft items needs to be written. These need to be tested in a pilot study. The best items are then selected on their psychometric performance, the structure of the tool is analysed to ensure it covers the necessary domains, including reliability, validity and norm development. (2005, p. 21)

Where possible, it makes sense to use existing tools that capture the life areas or domains of interest.

There are well regarded tools that could be employed by the NDIS for assessing certain needs (table 7.1). Though generally, these tools focus on a narrower range of *supports* than will be offered by the scheme. For example, they do not typically assess home and car modification needs.

Moreover, some tools focus on a narrower subset of *disabilities* than is relevant for the scheme. The Functional Independence Measure for example, is designed primarily to be used in rehabilitation settings, while the Supports Intensity Scale is targeted at assessing support needs of individuals with intellectual disability. Both I-CAN and D-START are intended to assess the needs of a broader group of individuals, though both are still in the relatively early stages of development and are not yet widely used. More detailed descriptions of the main support need assessment tools can be found in Appendix B.

Table 7.1   **Summary of relevant assessment tools**

Tool	Intended purpose and target population	Life areas or 'domains' covered	Ease of administration (assessment time)	Current use
D-START	Assess needs, capabilities and aspirations of people; resource allocation Adults with different types, levels and combinations of disability	• medical and health • activities of daily living • behaviour • functional skills • personal risk • environmental factors	Hierarchical model with short and long assessment options Mainly for use by trained assessor (45-90 min)	Being trialled by the South Australian Government
FIM	Assess an injured person's function Adults in rehabilitation settings. (Wee-FIM caters for children)	• self-care • sphincter control • locomotion • transfers • communication • social cognition	Trained assessor with some clinical qualification (medicine, allied health, nursing) (around 30 min)	Used internationally
I-CAN	Assess and report on the support needs of people with intellectual or multiple disabilities (the developers are currently investigating the tool's application to those with traumatic brain or spinal cord injury)	• physical health • mental and emotional health • behaviour • health and support services • applying knowledge • communication • self-care, domestic life • mobility • interpersonal relations • life long learning • community and social life	Trained facilitator guides a semi-structured group self-report process Hierarchical model with short and long assessment options (30-120 min depending on complexity of need)	Currently used by some NGOs and by teams within government in some states

Table 7.1   (Continued)

Tool	Intended purpose and target population	Life areas or 'domains' covered	Ease of administration (assessment time)	Current use
ICAP	Assess adaptive and maladaptive behaviour to determine type and amount of support needs Can be used for determining eligibility, planning and in funding reports	Adaptive and maladaptive behaviour with the former covering: • motor skills • personal living skills • community living skills • social and communication skills	Assessor requires no formal training but should self-study manual (20-30 min)	Widely used in the United States
SIS	Assess frequency, type and duration of support needed. Adults with intellectual and developmental disabilities	Behavioural, medical, and life activity with the latter covering • home living • community living • lifelong learning • employment • health and safety • social activities • protection & advocacy	Staff resource use is intensive. Trained staff required for reliability (1 hour but can be up to 2.5 hours)	Used by several states in the US and a number of Canadian provinces as well as in around 14 other countries
SNAP	Measure the support needs of individuals with different disability types and levels of severity in receipt of accommodation and day support services	• personal care • physical health • behaviour support • night support • social support	Assessor requires no specialised training but must have good knowledge of the person (10-20 min)	Has been used in NSW to guide funding of residential and day support services, and was trialled by the South Australian Government

7.6 A single tool or a 'toolbox'?

The assessment process will need to be applicable for individuals of different ages and with a wide range of levels, types and combinations of disabilities. However, as noted in the previous section, many current assessment tools tend to be developed on the basis of a single disability type (such as intellectual disability) or service type (such as attendant care or home modifications) and so lack the flexibility or breadth of coverage required by the NDIS. A simple and common response to this problem is to employ a toolbox rather than a single tool.

In order for this model to work effectively, a thorough benchmarking and mapping process would be required. The aim being to ensure that all relevant activities were covered, that there was no overlap, and that where individuals were assessed for the same support using different tools, the outcome was equitable. The assessment process must be both coherent and equitable if it is to gain broad user acceptance.

While this approach may appear disjointed, it is preferable to a situation in which the 'tool is made to fit the task' and reliability and validity are sacrificed. There was support for the idea of a toolbox:

> ANGLICARE Sydney welcomes the toolbox approach. People with disabilities are a diverse group, including within sub-groups of disability. One tool will never address all people's support needs even within the one sub-group. A toolbox approach would allow an assessor to access a range of profiles/questions that suit the person being assessed. ANGLICARE Sydney's experience… has shown us that one tool does not fit all… We have one assessment tool that has a number of profiles however they don't always address the support needs of the client. These needs are usually drawn out in conversation and rapport building by the case-manager. (Anglicare Sydney, sub. DR799, p. 11)

> PHCS agrees that good assessment practice is complex, and that it likely takes the form of a suite or a 'toolbox' rather than a single assessment tool. As the draft report describes, there are many tools currently available both in Australia and internationally. Every person is different and should be at the centre of any kind of assessment suite is used. (Perth Home Care Services, sub. DR906, p. 5)

7.7 Who should conduct assessments?

Who conducts needs assessments can have big implications for both the reliability of the results and the extent to which an individual seeking support feels that they are central to the process. Typically, assessments of need have been conducted by trained assessors. Almost all of the tools outlined in section 7.5 are administered

this way (though some have self-report elements). The evidence shows that this produces higher rates of reliability.

But self-assessment is increasingly being advocated as a way of actively involving and empowering service users. And a number of participants in this inquiry have called for its use:

> It is essential that a self-assessment tool be developed, to enable people with disabilities to identify the supports they need in order to fulfil their goals and to participate in society. (Madden et al., sub. 493, p. ii)

> [The] Level of funding for individual disability support should be determined through a self assessment approach. (Physical Disability Council of Victoria, sub. 534, p. 5)

While self-assessment is widely advocated, it is not clearly defined or understood. In its simplest form it refers to:

> An assessment that is completed by the subject of the assessment without the immediate involvement of professionals, or a professionally employed layperson. (Griffiths et al. 2005, p. 17)

But beyond this, there is little agreement among researchers or practitioners about its precise meaning. Griffiths et al. proposed that self-assessment of care needs must have, as a minimum:

- *self report* as distinct from examination or observation

- *self completion* by the individual concerned rather than by a professional, layperson or family member

- *self as the beneficiary* of the assessment as distinct from provision of a survey response for population needs assessment.

Self-assessment has been used in many ways and for many groups of people. As Madden et al noted that is a long history of using self-reported data in Australia:

> The development of new processes and tools … should draw on Australian statistical experience, and on new developments around the world. For three decades Australia has relied on statistics reflecting self-reports of the need for assistance and indeed the PC relied on these data in preparing costs estimates for the proposed NDIS. (Madden et al, sub. DR942, p.8)

While self-report has been used in surveys, there are few examples of its use in the area of resource allocation.

How accurate is self-assessment?

The desirability of self-assessment has not been well explored in the area of health and less so in the area of social support. One major study was conducted by Griffiths et al. (2005) (commissioned by the National Health Service in the United Kingdom). Griffiths et al's research suggests that the accuracy of self-assessment in social care remains largely untested:

> No evaluations of the accuracy of self-assessments in the domains of comprehensive or life and social skills were found. (2005, p. 92)

While the suitability of self-assessment in social care has not yet been rigorously evaluated, early experience from the UK has revealed problems with its use. A review of the Individual Budgets Pilot Programme found that case managers were not confident that self-assessment alone would adequately capture individual's needs:

> Most IB [Individual Budget] lead officers felt that some degree of professional assessment was necessary in addition to self-assessment. Having both views was believed to produce a more accurate assessment of needs and offered an opportunity for useful dialogue between the service user and care coordinator. Further, a small number of care co-ordinators and team managers had more serious doubts about the value of self-assessments and reported that it was often necessary to assess needs independently of service users, in order to establish 'what people's needs were as well what their own perception of what their needs were'. (Glendinning et al. 2008, p. 147)

As Griffiths et al. observes, self-assessment relies on a single subjective source, and an individual's own perception of their need can vary from that of professionals (this is consistent with the views put by Bradshaw, box 7.1). However, the review of the Individual Budgets Pilot Programme was suggestive of more systematic divergences:

> A number of sites had experience of older people, and people with mental health problems in particular, under-assessing their own needs; in part this was felt to be a consequence of older people having low expectations, or people with mental health problems being in denial about their needs, or not perceiving their actions or behaviours to be anything unusual. In contrast, people with physical disabilities, sensory impairments or learning disabilities were felt to be more likely to over-assess their needs. This may come from a longer history of campaigning for greater rights, choice and control, particularly among physically disabled people. (Glendinning et al. 2008, p. 149)

Some participants recognised that self-assessment remains a largely untested area, but thought that its use should be investigated:

> while self assessment sounds like a good idea and one that would enhance a sense of dignity and independence in the person with a disability who is assessing their own

support needs, a number of research reports are cited from the UK indicating that there is a need for caution in proceeding with self assessment, and in particular, that there is already evidence to suggest systematic distortions in self assessment depending on the type of disability and demographic characteristics. It is stated, in our view correctly, that self assessment remains largely untested … Since self assessment would have benefits in terms of dignity and independence for the person with a disability who is assessing their own needs … it is a way of assessment that should be investigated. (Dr Neil Kirby, sub. DR1060, p. 12)

Does self-assessment deliver greater user involvement and partnership?

One of the rationales for self-assessment is the view that it provides greater opportunities for self-definition of needs and desired outcomes; and increased opportunities for users to determine for themselves how they want those outcomes to be achieved.

But as Griffiths et al cautioned:

> Benefits should not be assumed and in particular the use of self-assessment should not be equated with user involvement and partnership. Generally more clarity is required when advocating self-assessment … the partnership is embedded in how the assessment is used, not the assessment itself. (2005, p. 12)

The Commission considers that the assessment process should be collaborative, but is cautious of the benefits attributed to self-assessment.

Keeping the person with the disability front and centre

Assessment should be carried out as a collaborative process, and in a way that is understandable for the person seeking support so that they are able to:

- gain a better understanding of the purpose of assessment and its implications for their situation
- actively participate in the process
- identify and articulate the outcomes they wish to achieve (a support plan will also be key here)
- identify the options that are available to meet these outcomes and to support their independence and well being
- understand the basis on which decisions are reached.

Maintaining professional objectivity

In order to promote independent outcomes, assessors should be drawn from an approved pool of allied health professionals. Assessors should also be independent of the person being assessed to reduce the potential for 'sympathy' bias. This means that health professionals — GPs and others — with past treatment and support responsibilities for the person, would not undertake assessments. It is clear from the experiences of VCAT appeals on TAC benefit decisions that treating professionals are often placed in an invidious position when asked by their patients to make an assessment that determines the person's eligibility for benefits.

Participants expressed some concerns about the independence of assessors, preferring to have someone with knowledge of the individual undertaking the assessment.

> … in my view, taking the assessment process too far away from experts who have the best view of the needs of the person who is living with the disability. I think it would be wrong to completely remove treating doctors from the assessment process. I would suggest that any assessment should be made taking careful consideration of the expert advice provided by any treating doctors. (Paul Petrie-Repar, sub. DR988, p.4)

As noted elsewhere in this chapter, while the individual undertaking assessments would be independent, it would important to involve other interested parties (a so called circle of support) in the assessment process. Ideally, these would be people who were familiar with the care and support needs of the individual, they might include family members, carers and direct support professionals. Moreover, the assessment process would draw upon existing medical reports.

As in New Zealand, assessors would be mentored in their first six months of assessments, and all assessors would be regularly assessed to ensure comparability of outcomes. This would prevent assessors from developing their own criteria for assessment, and avoid outcomes such as 'sympathetic bracket creep'. Assessors would be approved or appointed by the NDIA for the purpose of conducting NDIS assessments and their approaches to assessment would have to be aligned with the objectives of the NDIS (which is another reason why a person's general practitioner would not be a suitable assessor). Assessors would be properly trained in the use of the tools and in listening to the input of participants.

Many participants were supportive of assessments being undertaken by an approved pool of allied health professionals. However, they also pointed to the need for experience, particularly with respect to more complex cases:

> … our experience shows that the vast majority of assessment decisions of this kind are straightforward and non controversial based on available information, context and functional assessments. It is the complex and 'by exception' situations which require a

more resource intensive process. An assessment panel with the option to draw on specialists is suggested. (Victorian Coalition of ABI Service Providers Inc., sub. DR804, p. 8)

7.8 When should assessments occur?

Before being able to access individually tailored supports, new entrants to the scheme would undergo an initial assessment. That process is intended to provide a dynamic account of an individual's support needs, so that the needs of people who have fluctuating and or longer terms conditions are properly taken into account. Even so, it would not be possible to anticipate all changes to an individual's care and support needs over time. These changes would need to be identified through a periodic reassessment of need. Reassessments will be an important way of making sure that people are able to access the right mix of supports at the right time.

The timing of reassessments depends on a number of factors, such as the nature of the disability, the age of the person and any major life transitions. But it is possible to identify some timely opportunities for reassessment.

For children acquiring disabilities at birth (or revealed in early infancy), key assessments points might be:

- at the time the disability is first identified

- at the point of entry into schooling (around 5-7 years of age)

- at the point of entry to high school and puberty (around 11-13 years of age)

- at the point of transition to adult education (between 15 and 18 years of age)

- at the point of transition to adult work (between 15 and 25 years of age)

- at major life transitions, such as marriage, divorce, moving out of home or losing a natural support.

These examples are not intended to be exhaustive — reassessments should occur when an individual's circumstances have changed, or are about to change, such that a review of their care and support needs is warranted. For example, an individual might approach the scheme to have their need reassessed following a period of ill health.

Scope for reassessments was advocated by a number of participants:

> The level of support required should be reassessed regularly to ensure that services and supports provided continue to be appropriate for meeting the person's needs, and also be able to be reassessed, and adjusted as required in response to changing needs or circumstances. (Jewish Care (Victoria) Inc, sub. 355, p. 3)

... reassessment of need should occur regularly enough to ensure responsiveness to changes over the life course. (Down Syndrome Victoria, sub. 492, p. 3)

Where an individual's disability may undergo change – degeneration or improvement, reassessments and reviews should be available as needed. (Youth Disability Advisory Service, sub. 487, p. 10)

While having an up to date picture of care and support needs is important, it should not result in unnecessarily burdensome processes (subs. 487 and 26). Much of the information collected at the initial assessment would still be relevant in a reassessment context, where this is the case, it should be used.

It is clear from submissions that a balance will need to be struck with respect to conducting reassessments. On the one hand, reassessments need to be sufficiently frequent that they reflect the foreseeable needs of individuals. But on the other hand, assessments should not be so frequent, so as to leave people with the sense that they are perpetually being assessed. As the Spinal Injuries Association observed:

The Association's experience also highlights the need for responsive re-assessment of people when their needs change. These situations may be in time of crisis for an individual (death of a main unpaid carer, health, career and relationships) and this reassessment needs to be timely and responsive.

While the need to ensure that appropriate supports are being provided to individuals, the NDIA needs to make certain that people are not assessed unnecessarily, as historically people with a disability, particularly those with lifelong disabilities, are re-assessed on many occasions … (sub. DR928, p. 2)

A fully-fledged reassessment might not always be required. Baptcare Tasmania uses 'active monitoring' as part of their involvement in the Gateway system:

The active monitoring role is about contacting people proactively to see whether or not their needs have changed. So if we think about an older carer with an adult, something that we find happens very often is that our next contact with someone in that situation might be when things have become really difficult for the carer - perhaps they're in hospital or some crisis has happened and they're unable to care for their adult child.

A key thing around this model is to say, 'If you're self managed in the community, we'd like to be in touch with you perhaps every six, nine or 12 months to see whether your needs are changing and to touch base with you and to provide a safety net around whether or not the case plan that's in place remains suitable and whether or not all options that might be supportive for you are in place at this point in time,' so that we hopefully are managing those changes that take place that very often people won't ring and tell you or contact you about until things have become quite difficult or in crisis. (Baptcare, Transcript, p. 59)

Shifting the emphasis towards wellness

One of the major criticisms of the current system is that is not forward looking. It fails to anticipate changes in people's needs over time, with the result that many people are either unsupported or poorly supported through major life transitions. It also fails to systematically explore 'what might be'. Opportunities for improving independence or functioning are not systematically assessed on either an individual or group level.

NDIS supports should be provided in a way that maximises an individual's functioning and independence. That does not mean that people should go without the support they need, but rather that they should gain a greater sense of control over their lives. It could be as simple as an attendant carer 'doing things with' a person rather than 'doing things for' them.

In some cases, that might mean individuals will need to learn or relearn the skills necessary for daily living. For those individuals where skilling or re-skilling is not appropriate the aim would be to minimise functional losses or future dependencies. (As might be the case with some degenerative conditions.) The assessment process would be a way of identifying these opportunities. This should be a primary focus of the assessment process when people first enter the scheme or when they are reassessed following say a period of ill-health.

This approach is similar to that adopted in a number of other jurisdictions. For example, the NSW Attendant Care and Physical Disability Unit (ACPDU) operate a 'transition model' which, is designed to provide clients with an opportunity to build skills. While not aimed exclusively at any particular client group, it is thought that individuals with an acquired brain injury will most likely benefit from this type of intervention. The New South Wales Department of Human Services noted:

> The Transition Model is a component of the Attendant Care Program (ACP) where a person may be approved for an interim period (3 or 6 months). During this time they will receive support from an ACP service provider skilled in working with people with their specific needs with the aim of assisting them to improve and reduce the hours required to support them in the community. The service provision will be reviewed for progress, improvements and likely level of ongoing support required. (ADHC NSW 2010, p. 1)

In the United Kingdom, in some cases, a 'skills building' phase precedes an assessment of longer term needs:

> Before proceeding to determine eligible needs, councils should consider whether an individual might benefit from a short period of re-ablement or intermediate care to increase what they are able to do for themselves before an assessment of longer-term need is undertaken. (UK Department of Health 2010, p. 18)

If the NDIS is to do this effectively, the assessment process must not only focus on the supports needed to maintain the person in their present situation but also on those required to make them more independent. Moreover, assessors will need to be kept up to date on best practices:

> To ensure optimal outcomes in terms of independence for people with disabilities and reduced costs for government, there is a need to ensure that assessors of support needs and those implementing support to increase independence and reduce long-term costs are kept aware of best practice as it evolves over time. Such information and periodic updates concerning bench marks and best practice need to be made available to assessors and service providers on an ongoing basis rather than as information that would be available only after a major evaluation of the assessment. (Dr Neil Kirby, sub. DR1060, p. 2)

7.9 Should carers have their own assessment

As noted earlier, the current disability system places an unreasonable reliance on family carers and one objective of the NDIS is to change that imbalance. Even so, many people will still want to provide care and support to family members with disability, but may need support to sustain their caring role (or to relieve the isolation and stress that often comes with that role). The question of supporting carers is discussed more fully in chapter 15. But anticipating that chapter, the Commission considers that there should be greater assistance for (unpaid) carers through properly funded training and counselling services. This chapter deals with how to go about identifying those support needs.

The role of carers will already form part of the assessment process. As noted in section 7.3, the assessment process should gauge a person's *appropriate* natural supports — those which could be reasonably and willingly provided by unpaid family carers and the community. When it becomes apparent, as part of that process, that an informal carer will provide a substantial share of the care package, the Commission considers that carers should receive their own assessment if they wish.

The role of a carer assessment would be to consider the sustainability of the caring role and whether the carer would benefit from their own supports, such as counselling or training (for example, a carer may request training in relation to safe lifting or dealing with challenging behaviours). (The need for respite services would be fully appraised as part of the individual's assessment in consultation with the carer.) The aim would be to support the relationship as well as the carer.

The consultation with the family as part of the assessment process should also explore the need for:

• assistance with long-term/ life-long planning, particularly for adults with intellectual disabilities living at home with elderly parents[2]

• family/sibling counselling where there are high levels of carer stress.

Responses to family needs should be tiered, with referrals to local support groups for those with less significant needs, and access to NDIS-funded specialist assistance where the needs were high.

This is not a novel approach. A number of jurisdictions have carer assessments or are working towards them. For example, in the UK, carers who provide, or intend to provide, a substantial amount of care on a regular basis can request an assessment of their needs as carers, independent of the needs of the person they provide care for.

But processes for doing so are not well established. Within the UK for example, processes have differed from council to council. Some jurisdictions incorporated a carer's assessment into the main service user's assessment. While in other areas, carers were assessed separately. In part, because it was considered that informal carers may feel unable to answer questions about their ability to cope honestly given the person they cared for would see their responses.

As Seddon at al (2006) remarked:

> Our research findings consistently demonstrate that carers appreciate being able to talk privately about their caring role and to raise personal issues that may be difficult to discuss in the presence of the cared-for person. (p. 1345)

Some called into question the value of a carer assessment conducted in the presence of the person they were caring for. For example, one participant in Seddon's research noted:

> I wouldn't say anything detrimental in front of [cared-for person]. Having a carer assessment in front of the cared-for is a waste of time. (p. 1345)

There was broad support among participants for carers having their own, separate assessment:

> Should the needs of all caring families be separately assessed? 75% of surveyed carers responded affirmatively… Carers have the bulk of the care, the responsibility for decision making in many cases, and many do not have outside unpaid carers to assist. The quality of the care they give can be very much affected by their own personal needs/ ill –health / lack of sleep / lack of rest generally. (Carers Australia, sub. DR1045, p. 4)

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2 The importance of long-term planning was underscored by the Senate Community Affairs References Committee in its report Disability and Ageing: lifelong planning for a better future (see for example recommendation 12).

7.10 How assessment might work in practice

The proposed structure of the NDIS as a central point of assessment and referral (as outlined in figure 7.2) would be a major improvement over the fragmented systems seen in various jurisdictions. Moreover, it is not a completely new concept, as it shares many similarities with Tasmania's recently implemented Gateway. These similarities have been noted by both the State Government and organisations involved in delivering the Gateway:

> In general, the proposed model of operation for the NDIA reflects the way in which the Gateway services operate in Tasmania in terms of assessment and referral of people with disability to specialist and mainstream services. (Tasmanian Government, sub. DR1032, p. 10)

> As per our presentation to the Commission in Hobart on 4 April, 2011, Baptcare wishes to highlight the similarities of the Report's proposed model to the newly implemented Tasmanian Disability and Family Support Gateway… The Gateway is a centralised intake point for people with a disability. The intake point provides a seamless entry point to a broad range of community support services as it is delivered through a collaboration of integrated community service organisations. The Gateway provides information and options that assist people to navigate the system. Based on a comprehensive assessment, we channel people into mainstream or specialised support systems as is appropriate to their needs. (Baptcare, sub. DR788, p. 1)

The Tasmanian experience will be a useful example of how to implement structural changes similar to those proposed by the Commission. Those involved in delivering the Gateway system note that much of the feedback received regarding the first months of system has been positive (sub. DR788).

Practical considerations

It is likely that people who approach the NDIS for funded supports will have a range of questions, which focus on more practical considerations. They will want to know things like, 'What can I expect?, What should I bring?, How long might it take?, Who's involved?, What happens in the interim? and What happens if I don't agree with the outcome?'. The remainder of this sections aims to give a sense of how things might work in practice.

What to expect

Once it is apparent that a person is seeking, or is a likely candidate for individualised supports, they should be provided with an early planning and information package. This would provide individuals with a clear idea about what to expect and when, as well as materials to assist in early planning. It would help them

to engage early on in the process, to think about their care and support needs and how they might best be met. The information package would also include information on the option of having a Disability Support Organisation (DSO) assist them to implement their support package. Material should be provided in a range of accessible formats such as DVDs and brochures.

What should I bring

Where possible (and with the individual's permission) the scheme should make use of existing medical reports. Ideally, people seeking individualised supports would make these available at the initial screening stage.

Who is involved

Individuals should have scope to involve other interested parties (a so called circle of support) in the assessment process. Ideally, these would be people who were familiar with the care and support needs of the individual, they might include carers, family members, and direct support professionals. Individuals could also elect to involve DSOs (figure 7.3)

How long might it take

Individuals should not have to wait excessive periods for their care and support package to be finalised. Where possible, streamlined processes should apply. The NDIA should report annually on this metric.

Figure 7.2   **Suggested initial assessment process**

There would be a public information campaign prior to the commencement of the scheme, and its rollout would take place over five years. Public information sessions would inform people about how the assessment process and the scheme will work.

Person approaches the scheme, in person or by phone or email to seek a funded package

Short set of questions to determine whether the person is likely to be eligible for a funded package or whether there is a alternative service that could help them

Person needs information services

Person is directed to information services on web or where appropriate, information provided by a trained NDIS advisor

clearly meets criteria

'Warm referral' required

Trained staff would employ their network of contacts to provide a 'warm referral' and would actively connect individuals with the services they require outside of the NDIS

person likely to be eligible for NDIA services

The NDIA provides information on 'where to next' including on the self report questionnaire and the assessment process. Information would be provided in a range of accessible formats including brochures and dvds

Tier 3 assessment process

Figure 7.3   **Suggested assessment process for tier 3**

Following on from figure 7.2

The NDIA provides information on 'where to next' including on the self report questionnaire and the assessment process. Information would be provided in a range of accessible formats including brochures and dvds

Person (or their carer or family member) fills in a self report questionnaire (including an initial personal plan) or meets with trained staff who fill in the form based on the person's responses or views. The person can provide permission to obtain medical information and to contact medical practitioners/specialist service providers if confirmation/clarification is required

A trained assessor reads the self report and the required medical reports (with a clear focus on using existing medical reports). Considers the current supports provided. Assessor contacts the person to advise what information will be needed at the assessment

The assessor and the local area coordinator visits the person to better understand their circumstances. The local area coordinator will have regular on-going contact with the person.

A meeting between the person, their carer (if appropriate) and the trained assessor to assess needs. A separate assessment of the needs of the carer if they wish.

Trained assessor sends assessment to NDIA after any necessary clarifications or checks

NDIA costs the assessment and compares the assessment to the benchmark average profile of needs to see if it looks right. NDIA contacts the assessor for any clarifications

Person disagrees with package

Individual referred to internal review process, where a new person reviews the assessment

The NDIA determines a draft support package. This will indicate for example the hours of attendant care, the aids and appliances to be funded, the supports for community participation. This is then subject to discussion with the person, their Local Area Coordinator, the trained assessor and where a person elects, a DSO. There will be scope for small adjustments to be made.

matter not resolved

matter resolved

Matter now investigated and reviewed by the Inspector General (see chapter 9)

Person agrees to package

NDIA finalises package of supports. Person informed.

matter resolved

The person can now choose to take charge of their package through self-directed funding of their budget (chapter 8), or have one or several service providers provide funded supports to them, or have a DSO manage their package.

What happens if I don't agree with the outcome

Following the assessment of support needs, individuals would be informed of their support package. This step would detail the nature, frequency and intensity of support they had been assessed as needing. In the event that a person disagreed with the outcome, there should be some scope for minor adjustments to be made, without necessitating a full reappraisal. Failing this, individuals could ask for a review. (Chapter 9 has proposed a layered approach to appeals, to be overseen by an independent statutory officer, the Inspector-General, who would have the legal capacity to direct the NDIA to alter a decision.)

What happens in the interim

Where it becomes clear that the time required to complete an assessment of care and support needs will substantially exceed the norm, there should be scope for the NDIS to provide services on an interim basis. This might be the case where say an individual with complex needs disagrees with an initial assessment outcome.

7.11 Diligent use of the assessment tool

Any tool that is used to inform decisions that impact on the lives of individuals or is used to guide the allocation of substantial sums of public money must be carefully examined and continually improved.

The increasingly generous use of assessment tools by assessors would risk diluting resourcing, be unfair, undermine community acceptance of adequate public funding and threaten scheme sustainability. But the opposite situation (a progressively more conservative use of the assessment tools by assessors) is equally undesirable. After all, the goal of the NDIS is to properly fund the reasonable assessed needs of people with a disability. The Commission considers that a range of safeguards should be put in place to guard against these two outcomes.

- Assessments should be designed to be as objective as possible and, as noted above, assessors would be assessed themselves for their appropriate use of the assessment tools.

- Assessments would concentrate on the reasonable and necessary supports people require. People would be asked what they had received under the old system. This would focus people on reasonable expectations about the packages they would receive (and in most cases, people would get more). That information would also be useful in modelling the impacts of the new system.

- Data would be collected to assess the reliability and validity of the assessment tools, and the tools would be subject to a regular cycle of evaluation and if necessary recalibration.

- The assessments would not be 'rubber stamped'. Prior to making budgetary decisions, the NDIA would confirm that the particular assessment followed the appropriate protocol, and was consistent with the 'benchmark' range of assessed needs for other people with similar characteristics. Deviations outside the norm would require further investigation. That means that the NDIA would detect and adjust excessively hard or soft assessments before people got their individual package.

7.12 The transition to a fully-fledged assessment toolbox

As noted earlier in this chapter, the process of starting from scratch to develop a new assessment tool in any field is time-consuming and expensive. But as Madden et al. observe:

> The cost of developing disability assessment tools can be considerable, but applying 'ready made' tools to the wrong measurement question is likely to be more costly. It is important to follow the statistical adage that an exact answer to the wrong question is inferior to an approximate answer to the right question. (sub. 493, p. 15)

Madden et al. recommend a staged approach to the identification and implementation of a preferred assessment tool(s), beginning with a process for identifying and evaluating nominated tools against agreed selection criteria. In the event that a suitable tool could not be identified, agreement could be reached for the temporary use of existing tools while further development of an assessment tool takes place. They went on to note:

> The greatest risk in the area of assessment is the speedy adoption of an irrelevant instrument; the financial costs could be considerable, and later re-direction of such a large program very difficult for a range of reasons. (sub. 493, p. 17)

There is no ideal tool to use in the NDIS, reflecting the relatively limited research into generic assessment tools (noting that the imperative for developing robust assessment tools across the full spectrum of disabilities is weak in the presently heavily rationed system). In the lead up to the implementation of the scheme, the implementation taskforce and the NDIA should progress work on the toolbox and ideally identify tools that are valid and reliable across the full spectrum of disabilities. In any case, Governments should not delay implementation of the NDIS in the absence of 'perfect' tools. Accordingly, the NDIS would use the best

available tools in its initial implementation phase, with the later development of better tools.

Working within the framework of the International Classification of Functioning, Disability and Health (ICF), the assessment process undertaken by the NDIA should identify the supports required to address an individual's reasonable and necessary care and support needs across a broad range of life activities, and should take account of an individual's aspirations and the outcomes they want to achieve.

The assessment process should be a valuable intervention in its own right, rather than just an entry point to supports. The process should:

- *draw on multiple sources of information, including:*
  - *information provided by the individual with a disability, including their aspirations and requirements for supports*
  - *information provided by an individual's circle of support, including family members, carers and direct support professionals*
  - *information on the current support provided both formally and informally*
  - *current medical information on the person with a disability*
- *assess the nature, frequency and intensity of an individual's support needs. The process should be person-centred and forward looking and consider the supports that would cost-effectively promote people's social and economic participation, rather than only respond to what an individual cannot do*
- *determine what supports outside the NDIS people should be referred to, including referrals to Job Services Australia providers*
- *consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports')*
- *translate the reasonable needs determined by the assessment process into a person's individualised support package funded by the NDIS, after taking account of natural supports*
- *provide efficiently collected data for program planning, high level reporting, monitoring and judging the efficacy of interventions.*

RECOMMENDATION 7.3

The assessment tools should be valid and reliable, relatively easy to administer and exhibit low susceptibility to gaming. The tools should be employed nationally to ensure equitable access to nationally funded support services (and allow portability of funding across state and territory borders when people move).

RECOMMENDATION 7.4

Assessments should be undertaken by trained assessors engaged by the NDIA. To promote independent outcomes, assessors should not have a longstanding connection to the person. The NDIA should continually monitor and evaluate assessors' performance to ensure comparability of outcomes and to avoid 'bracket creep'.

RECOMMENDATION 7.5

The NDIA should periodically reassess people's need for funded support, with a focus on key transition points in their lives.

RECOMMENDATION 7.6

Where an informal carer provides a substantial share of the care package, they should receive their own assessment if they wish. This should seek to identify their views on the sustainability of arrangements and the ways in which the NDIS should support their role, including through the initiatives recommended in recommendation 15.3.

RECOMMENDATION 7.7

The consultation with the family as part of the assessment process should also explore the need for:

- *assistance with long-term planning, particularly for adults with cognitive impairments living at home with elderly parents*

- *family/sibling counselling where there are high levels of carer stress.*

Responses to family needs should be tiered, with referrals to local support groups for those with less significant needs, and access to NDIS-funded specialist assistance where the needs were high.

The NDIS should establish a coherent package of tools (a 'toolbox'), which assessors would employ across a range of disabilities and support needs (including planning and active support, attendant care, aids and equipment, and home modifications).

The assessment tools should be subject to ongoing monitoring, as well as a regular cycle of evaluation against best practices, including the ICF framework, and, if necessary, recalibration. The scheme should have systematic internal mechanisms to ensure that anomalies can be analysed and addressed.

The NDIS should use the best available tools in its initial implementation phase, with the ongoing development of best-practice tools.

8   Who has the decision-making power?

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Key points

- People should be given much greater power and choice in a new system, with the objective of giving people greater flexibility and control over their lives — with the ultimate goal being greater wellbeing. Consumer choice is one aspect of power.

- There are strong rationales for a consumer choice approach, since people know their needs better than others, it can increase pressures on suppliers to perform, and people value choice in its own right. There are two broad ways of exercising consumer choice:

    - At least over the medium run, the most important would be for consumers to be given an individualised package and to choose one or more service agencies to provide the supports in the package. People could switch providers if they did not meet their needs well. If they wanted, they could get support from intermediaries (Disability Support Organisations — DSOs) in making their choices.

    - For those who wish to and are able to, people would be given the opportunity to cash out their package, and purchase their own supports ('self-directed funding'). People could obtain support from intermediaries to help them plan their package and/or to handle administrative tasks. People could employ the support workers they want (and when), and could trade off some services against others, but they could also choose to buy pre-packaged supports from specialist and mainstream providers.

- The evidence strongly suggests a wide range of positive wellbeing outcomes from self-directed funding for people with disabilities and their carers, including higher satisfaction with life, more independent living, better continuity of care and lower levels of abuse and neglect. Self-directed funding appears to cost no more than traditional models of care, and may well cost less.

- The individual budget for self-directed funding should include all goods and services covered by the NDIS, except non-recurrent expenditures, those where specialist knowledge is required for informed choices (such as early intervention therapies) and emergency supports.

- Those using self-directed funding should be able to make their own decisions about how to spend the budgets, subject to the approval of a funding proposal that sets out the broad areas of spending. People should be able to hire their own support workers. However, while there is some evidence of benefits, hiring family members should be limited to short-term arrangements or where exceptional circumstances apply until the risks are assessed through a careful trial.

- The NDIA and DSOs would need to provide support to people with disabilities and front-line workers to assist the adoption of self-directed funding.

- A range of safeguarding mechanisms are appropriate, including assessing people for their suitability for self-directed funding, minimum accountability requirements, complaint mechanisms and oversight by local area coordinators.

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In any disability system, someone makes decisions about who gets support, what people get, and when and how they get it. Who has these powers and how they are used, can make a large difference to the quality and efficiency of decisions, and people's sense of value and their participation in society. Historically, the power has been largely exercised by service providers and government officials (the 'service-centred' model), with little real decision-making power given to people with disabilities, their carers or families.

As in many other areas of social policy, governments are tending to move away from traditional service-centred arrangements by modifying disability programs to take account of the preferences of the people receiving them and to give them greater power. The ideal, if not always the reality, is to shift people from passive 'service recipients' to consumers and citizens.

This chapter is about various ways in which the NDIS could give people the capacity to make many of their own decisions, even if they choose not to do so. Section 8.1 sets out what 'person-centred' approaches mean, and discusses the role of consumer choice as one element of those approaches. Section 8.2 defines the most evolved form of consumer choice (self-directed funding). The chapter then examines the rationales for self-directed funding (section 8.3) and empirical evidence about its effects (section 8.4 and appendix E). The remainder of the chapter considers how to design a workable form of self-directed funding in the NDIS (sections 8.5 to 8.14).

8.1 Person-centred approaches

The concept of so-called 'person-centred' and 'independent living' approaches originated in North America in the late 1980s (O'Brien and Mount 1989; Mount 1992; Garner and Dietz 1996; O'Brien and O'Brien 2000). It is based on the view that people with a disability should be recognised as active participants in the community, needing support to achieve their lifetime goals based on their strengths:

> The person-centered approach creates a team of people who know and care about the individual with a disability, who come together to develop and share a dream for the person's future, and who work together to organize and provide the supports necessary to make that dream a reality. (Garner and Dietz 1996)

One way of distinguishing personalised systems from service-centred approaches is to think about how people ordinarily make decisions. Most people have the chance to live lives that are largely determined by their own decisions, within the limits imposed by their ability, local environment and budgets. They think about what they might want from life and make decisions that help them get there. They decide

where they might like to live, who they would like to live with, and what job and employer they would like. They decide how to spend their leisure time, where to buy things from and the role they will play in the community and as citizens.

That is not so for many people with disabilities (or their carers) because others make and fund so many decisions central to their lives (see Stancliffe and Lakin 2005, p. 204 for relevant studies). In a survey of Australians with disability, the Julia Farr Association found that 51 per cent of people had no choice about who provided personal support and 28 per cent had no choice about where they lived (Julia Farr Association, sub. 494, p. 3). One participant in this inquiry provided a vivid example of her limited choice as a parent of a child with severe autism:

> A respite service which I am offered (for example a five-hour service at a centre for my son in a group) … may fall on a date on which I cannot use the service; its duration may be too long (eg a five hour outing is difficult for my son who is better able to cope with a 2–3 hour outing); I have to spend 2 hours in total driving to and from the centre to drop off and pick up my son; the activities they undertake may be too hard for my son and it is in a group with people with unusual behaviour so my son may be physically harmed by others in the group … These disadvantages sometimes become so great that I refuse even this small service because the costs outweigh the benefits. Due to lack of alternatives, I sometimes accept such a service but pick up my son hours earlier than the scheduled end time in order to mitigate the problems of the service. This causes terrible waste in the system because funds are expended to provide a much longer service than we actually receive. (name withheld, sub. 74, pp. 7–8)

The intention of person-centred approaches is to maximise, as much as reasonably possible, the capacity for people with disabilities to take control of their lives. People with a disability and carers can be given more power in many ways. They include: the obligation of providers and others to treat them with respect; genuine opportunities for employment and other forms of social participation; challenging stereotypes and other attitudes that marginalise people; packages of support that suit the person (as for any other consumer); and the appropriate allocation of funding to meet their support needs. As an illustration of the importance of the latter, a person who has to wait months or years for an appropriate wheelchair has little capacity for genuine independence (Samantha Peterson, sub. 581, p. 1). Much of this report is about how to give people genuine control over their lives. However, this chapter focuses on one aspect of power — the capacity of people to have decision-making power as consumers, and in the case of self-directed funding, control of their budgets. As Sally Richards noted:

> Having control over the money is the best way of giving people power. Otherwise, we are forever fitting (or not fitting) into programs and services that might not suit us but which are all that is on offer. We are told things like … 'your son is too old/young; you are out of area; we have no places left; you don't fit the criteria; you must bring your own funding; we have a waiting list; you are not in the priority group'. (sub. 26, p. 5)

Any responsive system gives people a variety of models of choice and power, a point emphasised by many participants. For example, BaptistCare said:

> … options [should] include various models that range from the choice for individuals to have their supports managed by an organization through to shared management with an organization to managing their full funding without organizational support. This will enable the continuity of ranges of support that individuals require based on their own situations and skills. (sub. DR852, pp. 25–26)

The Commission proposes an 'individual choice' model, in which people with a disability or their guardians could (subject to some checks) choose how much control they wanted to exercise. There would *not* be one approach that forced people to either take full control or none (as some participants thought), and nor would people be required to exercise choice without support. The Commission envisages two broad approaches to choice.

Self-directed funding

Under one approach, people would have the choice, subject to some conditions, to cash out their individualised package of supports and manage their own budget. While we use the term '*self-directed funding*' to describe this type of choice, others use this term to denote a broader model of choice, or use other terms altogether for consumer budget control (see later).

The essential feature of self-directed funding is that people *could*, if they wished, shift the cash value of one component of their individual support package to another component and have considerable freedom in shaping the supports that suit their individual and evolving needs (subject to the conditions discussed later in this chapter). For instance, they might decide to forgo some hours of personal care for a greater amount of community access. If they wanted, people could employ the support workers they wanted (and when), at wages they jointly determined with the worker, rather than having to purchase personal support services through specialised disability providers. This capacity to trade off resources from one part of their support package to others is the key point of differentiation from other consumer choice options.

However, self-directed funding would not force people to assemble all their own supports. They might get the support of intermediaries (disability support organisations or DSOs — chapters 9 and 10) in planning their supports and managing the administrative aspects of self-directed funding, such as workers' compensation coverage for employees. Or the person may sometimes pay service providers for a package of supports, if the provider was able to provide a cheaper or

better suite of supports than that obtained by a person assembling their own suite from many suppliers.

'Choice of provider' will be the norm for many

While the flexibility and power bestowed by self-directed funding would appeal to many, it is likely that most people would elect an alternative, simpler option for exercising choice (for reasons discussed further below). Under a 'choice of provider' option, people would be given an individualised package of supports (*not a budget amount*) after assessment and consultation by the NDIA. People would have a designated list of individualised supports in their package described in quantity terms (such as 20 hours of personal care a week, 5 hours of community access, and so on). The package would be like a booklet of vouchers representing each of the separate items of support, rather than an aggregate budget.[1] (The reasons for using vouchers are discussed in chapter 9, but one advantage is that a person would be certain that they would get their entitled supports under a voucher, but less so with a budget.)

People would have power to take their vouchers to a service provider/s (SPs) of their choice, with the support of DSOs if they wished. The NDIA would reimburse providers at a rate regulated by the NDIA. Service providers would be expected to respond to the individual preferences of their clients, with people able to choose the services that meet their needs. People could switch DSOs and SPs if they did not meet their needs well. They might choose one SP for one support need and another SP for another need. They might ask a DSO to bring together the package of supports and the best SPs on their behalf. A DSO or SP would only act for a person with a disability where that person had chosen to assign them that responsibility. The point is that the person with a disability would still have a lot of control, but would have a limited capacity to trade-off different components of their support package.

Sometimes, through bargaining, the person might secure, say, 11 hours of personal care with their 10 hour voucher. For example, that might occur if a service provider wished to encourage customer loyalty, as in many other markets, or if a DSO secured a good volume discount by acting on behalf of many consumers. Whether that happened would depend on the degree of competition, the marketing strategies

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[1] While operating like a book of vouchers, the process would not literally require a physical book of vouchers as some participants thought. Rather, it would be an entitlement to supports that people could obtain from accredited providers of their choice.

of service providers, and the level of the regulated price.[2] (There is another variant of the 'choice of provider' option that would also give people this flexibility. However, it faces some practical impediments in the shorter run — box 8.1.)

Box 8.1   A variant of the 'choice of provider' option?

Under a possible variant of the 'choice of provider' option, the NDIA could give people their individual package components in separate dollar 'parcels' rather than as entitlements for quantities of supports. This would not be self-directed funding because it would still limit people's capacity to trade off purchases *between* the separate components, which is the hallmark of self-directed funding. Accordingly, someone might receive $500 personal care budget a week, which they could only spend on personal care and a $150 community access budget earmarked for community access. (This is like specific-purpose budgets commonly used by business and other enterprises that wish to control spending in separate silos. It is the approach used for special purpose payments by the Australian Government to state and territory governments.)

The advantage of this approach is that it gives people an easier potential to trade off supports *within* a specific budget area or to negotiate a better price or service offering from a provider (a point made by Ron Joachim, sub. DR704). (As we discussed above, people could still achieve this with vouchers, but in a less easy way.) As an illustration, someone might decide to buy 10 hours of support in the evening (where hours are more costly), rather than to buy 15 hours of support during the day (when hours are cheaper) because they valued evening hours much more than day hours.

However, this variant would entail some administrative complexities for the NDIA in accounting for spending. Moreover, in the absence of price controls, the person, not the NDIA, would bear the risk of any market power exercised by service providers. This suggests that such a variant would be problematic as a default arrangement. In this context, the Commission considers that 'choice of provider' should be achieved through entitlements to quantities of supports, rather than through a suite of earmarked budgets. However, as discussed in chapter 9, this variant could emerge over time. In the mean time, people could still elect to move to self-directed funding with its greater freedoms and responsibilities.

What are the main differences between the 'choice of provider' and self-directed funding options?

The main differences between the two broad ways of achieving choice are the level of risk, the amount of effort and the scope for choice.

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[2] It may also be desirable for people to use personal support vouchers relatively flexibly so that they could sometimes trade off hours of support during the day for (say) hours in the evening or on a weekend by giving up more of their vouchers for the more costly options.

Choice of provider is like consumers selecting a restaurant. They do not cook the food, but they do get to choose the restaurant that suits their preferences, and know they will be able to afford a good meal. They will not go back if the food or service is poor. In contrast, a pure form of self-directed funding is like a person buying their preferred ingredients and cooking the meal. He or she would have the freedom to choose when to cook, the exact recipe, cooking methods, and utensils. However, it would involve a lot of work and they could make mistakes.

Of course, there is also the third option of taking charge of some aspects of your support (saying hiring your attendant carers), but leaving other matters to your chosen broker or service providers (akin to eating at home and at other times in a restaurant). The point is that the person with a disability would ultimately be in charge.

Figure 8.1 provides a map of the more detailed options people would have. People would have many ways to choose supports. If they used 'choice of provider' (option 1), some would obtain the pre-packaged supports directly from providers — (1) and (6). Others would ask for advice and other support from a DSO — (1), (6) and (7). And others would ask a DSO to do it all for them — (1) and (8).

If they chose self-directed funding (option 2), some would take an entirely DIY approach, purchasing the supports that meet their needs — (2) and (3) in the diagram — 'pure' self-directed funding. Others would get the support of a disability support organisation — (2), (3) (4) — or work very closely with a disability support organisation under a shared management arrangement— (2) and (5). And some people might take a mixed approach, cashing out part of their package (2), but using (1) as the route for purchasing another set of supports.

The 'choice of provider' option has many advantages. It is relatively straightforward to implement and does not require the kinds of safeguards that would be required for self-directed funding. It would still have many of the benefits identified later in this chapter for self-directed funding (table 8.1).

Figure 8.1   **There are many pathways for choice**
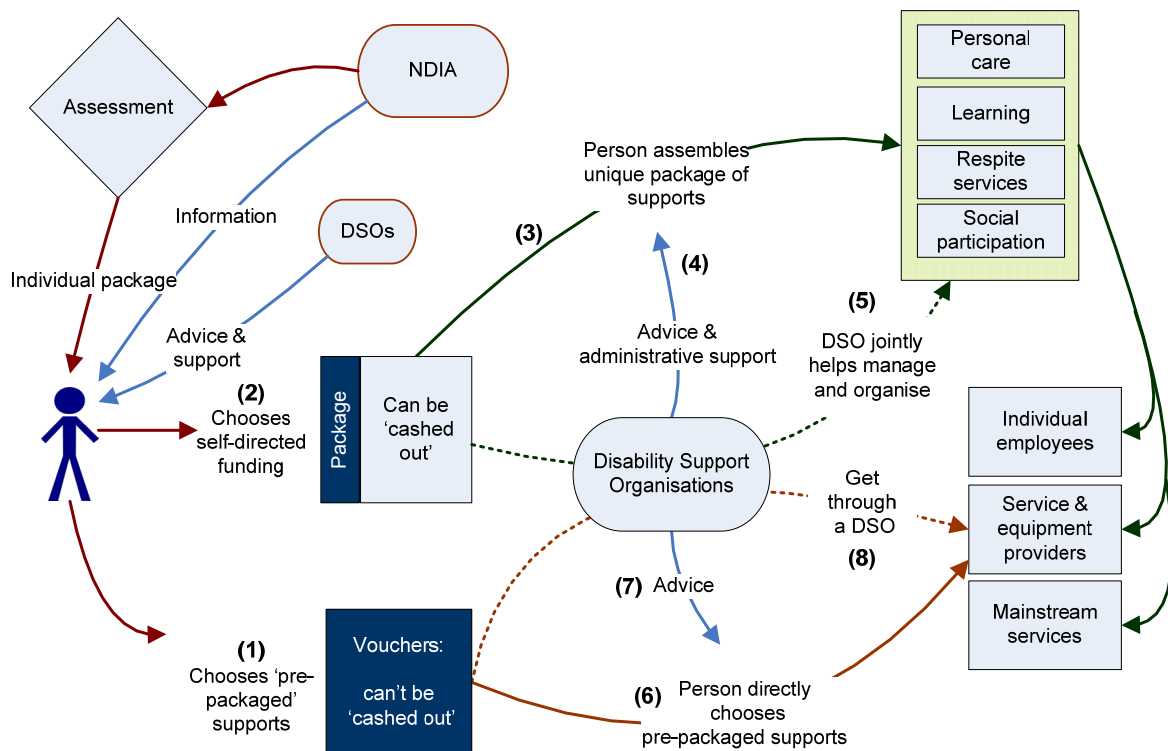
Table 8.1   **'Choice of provider' and self-directed funding have significant benefits, but different drawbacks**

	Category	Option 1 Choice of provider	Option 2 Self-directed funding
(1)	Gives people sense of control over their lives	●●●●	●●●●●
(2)	Allows choice of specialist service providers and the option to move	●●●●●	●●●●●
(4)	Introduces competitive pressures	●●●	●●●●
(5)	Gives people flexibility	●●	●●●●
(6)	Allows people to trade off items	●	●●●●
(7)	Is easy to use and does not require support from others	●●●●●	●
(8)	Involves low levels of risk to the person and the scheme's probity	●●●●●	●●●
(9)	Imposes low management costs on the NDIA and service providers	●●●●●	●●
(10)	Is cost effective overall	●●●●	●●●●
(11)	Allows easy engagement with mainstream services	●●	●●●●●
(12)	Can work well with limited responsiveness by disability services market	●	●●●

●●●●● Excellent   ●●●● very good   ●●● good   ●● fair   ● poor

a The scales are based on judgment and evidence from various studies of self-directed funding. For example, the reason that choice of package is easy to use (item 7) is that it just involves choosing a provider and being able to switch, whereas self-directed funding involves reporting requirements, being confident about managing a budget and employees, and being able to use mainstream services (this is why people may engage DSOs to help them).

These include the value of choice per se, portability across providers, pressures on providers to perform better, and a greater capacity to meet people's preferences than current block-funded arrangements. It would be easy for the person to use because the service provider(s) selected by the person would be responsible for ensuring the delivery of the relevant part of the support package, with no administrative burdens for the person. Moreover, unlike self-directed funding, it would give people an entitlement to a quantum of supports rather than a dollar value of supports, which means that the person would not bear the risk of any market power exercised by service providers.

Its relative simplicity means that the 'choice of provider' type of consumer choice would probably be the most common way in which people would exercise power, at least initially. Many would find self-directed funding too bothersome or complicated, and would be happy to choose the DSOs and SPs and let them bundle supports for them. Several participants pointed this out:

> Not everyone wants or is able to administer individual funding. Certainly, as you get old you feel the need to let go of the reins. (Meredith Dewar, sub. 317, p. 1)

> … [choice] isn't necessarily about that you can't use traditional services, it's about people knowing what support they have got, what the funding is and then choosing a range of management options. So it's not that people who don't want to manage funding would miss out. (Samantha Jenkinson, trans., p. 982)

> While individual support packages may for some provide the best option … this is not necessarily the preferred option for others. Packages can add to the burden of an already over-burdened family and add little value if in reality the services and support required are not available, inadequate or precluded by geography. (JacksonRyan Partners, sub. 30, p. 5)

> [Reflecting the need for information, and the unknown and changing needs of the child, the] CDA recommends that the Commission evaluates whether self-directed funding for children or young people with a newly diagnosed or acquired disability is appropriate. (Children with Disability Australia, sub. DR1007 , p. 17)

Self-directed funding (option 2) is more flexible than 'choice of provider' and gives people more opportunity to use mainstream services with ease or to engage their own employees. For these reasons, many participants in this inquiry strongly supported the inclusion of self-directed funding as an option in the NDIS.[3]

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[3] Just a sample includes: the Australian DeafBlind Council (sub. 35, p. 12); Ben Lawson (sub. 103); Susan Harris (sub. 190); John Pini (sub. 96); Action for Community Living (sub. 508); Pave the Way (sub. 528, p. 6); NSW Government (sub. 536, p. 75); the South Australian Government (sub. 496, p. 10); Yooralla (sub. 433); and Leisure Connection Association (sub. 306, p. 3). Community consultations undertaken in South Australia found that all participants were in favour of individualised funding or self-managed care (Disability Advocacy and Complaints Service of South Australia, sub. 267). However, some participants

However, self-directed funding involves many more complexities and practical issues than option 1. Moreover, the experience in the United Kingdom suggests that take-up may be initially slow. In England, just over 10 per cent of people aged under 65 years completely manage their own budget — such as by hiring their own employees and purchasing mainstream services directly. The share has been growing rapidly and some local councils have much higher rates than this. Under the NDIS, the pace of adoption of self-directed funding can be expected to grow as people gain confidence in the new system, as the market evolves, and as the system provides more support for exercising choice (for example through DSOs).

Choice about choice

In the Commission's consultations, some said they were worried that people would be obliged to use self-directed funding.[4] The Commission emphasises that this would not be the case in the proposed NDIS.

> Not all disabled people and their families have the capacity or want to be involved in the arrangement of support staff, day care options, accommodation … (Carol Franklin, sub. DR721, p. 4)

Moreover, some people may only use self-directed funding temporarily. Some people may want one-off payments at certain points in their lives or at a given time of year (for example, to purchase short breaks for the carer, education services or equipment), without having to have ongoing budget holding responsibilities. This arrangement is now common in the UK (Davey et al. 2007, pp. 47ff).

On the other hand, some participants thought that the Commission's suite of options were too narrow. For example, the Victorian Government argued that:

> … the use of vouchers would create unnecessary administrative processes both for people attempting to use one to negotiate better value or more tailored services, and for disability service providers, who would be required to collect, record and submit vouchers for payment from the NDIA. The use of vouchers may also limit or prevent the ability of people with disability to choose non-disability or universal service providers, who should have a role in any market-based approach to disability services. (sub. DR996, p. 30)

However, the 'choice of provider' (voucher) option proposed by the Commission would be only one item on the menu of person-centred approaches. Under the broad umbrella of self-directed funding, people would, in fact, be able to choose the

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were more cautious about aspects of self-directed funding (for example, the Attendant Care Industry Association, sub. 268).

[4] And some participants understood that it would be optional, but that people on the ground may not realize this (Physical Disability Council of NSW, sub. DR832).

alternative options proposed by the Victorian Government — direct payments (or 'pure' self-directed funding); purchasing through or with the advice of intermediaries (DSOs); or purchasing of a self-determined package from a suppliers(s) — but people would need to jump through the administrative hoops (discussed later) to have this flexibility. The Commission's approach is to provide a variety of options for exercising choice, but to include one simple, no-fuss option that would appeal to many people.

Given its complexities and the challenges in achieving uptake, the design of workable self-directed funding arrangements is the main concern of this chapter. The chapter (and appendix E) also discusses the role of person-centred planning, which is an essential aspect of self-directed funding, but has a more general value.

8.2 Defining 'self-directed funding' in more detail

Arrangements in which the government gives people with disabilities or their carers the option of getting a budget to spend on goods and services they want come in many forms and have many labels. Among others, these include self-directed funding, individualised funding, self-determination, individual budgets, direct payments, self-managed funding, consumer-directed care, personal budgets, cash for care and vouchers.

The terms do not always mean a precise set of arrangements, which makes it hard to compare studies on their effects and to analyse the extent to which policy really gives people much power. In some contexts, these different terms involve similar, but subtly different arrangements. For example, in the United Kingdom, there are three different types of self-directed funding.[5] Western Australia uses a tiered set of funding arrangements, which includes option 1 above as an element of self-directed funding. These tiers entail different administrative responsibilities for people depending on the option they choose. A recent study of the effects of Australian 'individualised funding' approaches included many service models that, while providing greater choice, were sometimes far removed from the concept of self-direction common in overseas schemes (Fisher et al. 2010).

In Australia, policymakers and governments have often used the term 'individualised funding' to describe the determination of funding at the individual

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[5] These are *Direct Payments* (the cashed out value of community care services, with the person having full responsibility for purchasing, hiring and any statutory obligations), *Personal Budgets* (in which people receive a notional budget, but can have administrative and purchasing responsibilities met by local authorities) and *Individual Budgets* (which are like direct payments, but pool more funding sources into the budget, such as equipment services).

level (DHCS ACT 2007; Attendant Care Industry Association, sub. 268, pp. 5–6), but without the person necessarily having any control over their package, or even having the package tied to them. This would define individualised funding as the absence of block funding. For example, disability employment services are characterised as 'individualised funding' in Australian national statistics (see below), because individually conducted Job Capacity Assessments determine referrals to different services and entitlements. Disability employment network providers get case-based payments rather than block funding. However, individuals have limited control over what happens to them or how resources are spent once the referrals are made. The same contrast between determination of funding at the individual level and real consumer power was a major criticism in the evaluation of the original Individual Support Packages offered by the ACT Government (Maher 2003). Some participants in this inquiry have made much the same point, arguing that the term 'individualised funding' has become 'emptied of its initial intent', and can relate to arrangements in which people with disabilities have limited say (National Federation of Parents, Families and Carers, sub. 28, p. 5).

Given the ambiguity of the term 'individualised funding' as used in Australia, the Commission has instead used the term 'self-directed' support throughout this report, with its key aspects being:

- resource allocation based on assessment of the individual's needs and aspirations

- the capacity for informed and genuine choice by people with disabilities or/and their family

- access to their own individualised budget (usually with the money in a specified bank account)

- the power for the person to tailor the mixture and type of services they get, subject only to their overall budget and to reasonable administrative constraints on spending options. For example, tailoring would include choice of own carers, the capacity to organise innovative respite and social participation options, and to choose supported accommodation that meets their needs. This goes beyond the capacity for a person to negotiate supports with their provider and to choose (and switch between) their service providers, though that would remain important.

In this chapter, the term self-directed funding is used to describe all arrangements with these features,[6] but recognises that there are other ways of giving people more

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6 Several participants distinguished between self-directed funding and self-managed funding (Valued Independent People, sub. DR932 and JacksonRyan Partners, sub. DR717). For example, Valued Independent People defined the former as choice intermediated through

choice than giving people budgets. Indeed, as noted above, it is expected that initially most tier 3 participants in the NDIS will choose individual packages, rather than budgets.

8.3 Reasons for self-directed funding

There are several strong in-principle reasons for giving people with disabilities, or those closely associated with them, power over the funding allocated to them and the flexibility to build their own package of support.

Social norms and legal considerations

Australian social norms generally accept that people should be able to run most aspects of their lives. It would be inconsistent with those norms to put them aside for people with disabilities or their families. Moreover, laws now include the principle of self-determination, which means that the presumption is that people with a disability would make (or at a minimum inform) the key decisions about their lives. For instance:

- the first principle of the United Nations Convention on the Rights of Persons with Disabilities (to which Australia is a signatory) is 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons' (United Nations 2006)

- the Victorian *Disability Act 2006* sets down principles that include people's right to 'exercise control over their own lives' and for disability services to be 'flexible and responsive to the individual needs of persons with a disability [and] maximise the choice and independence of persons with a disability' (s. 5). This right is not an absolute one, as indicated by subsequent specific sections that introduce caveats related to the practicability of achieving full choice (for example, section 52(1)).

Information economies

People have different, complex and changing preferences about their lives — their food, clothes, jobs, education, hobbies, friends and partners — that are not cheaply or easily observable by others. This is true for even the most apparently simple products. A social worker might observe that a person likes tea. But they are less

another party and the latter where people manage the funds directly. The Commission sees self-directed funding as a broad set of options that would encompass these two forms.

likely to be able to remember what type they like, or whether they like it strong, sugared, with milk, in a mug, very hot, after or before breakfast or both. Nor would an external agent know how, given a finite budget, a person might trade off one preference against another. So, individuals know a lot more than others about how to meet their own preferences, and in turn, this is likely to lead to better outcomes for them (greater economic 'efficiency'). This is why in most cases, a large degree of weight is appropriately given to the power of people to make their own decisions. The same principles hold for people with disabilities or their families.

There are several qualifications to this general proposition, which apply to people generally — not just those with disability:

- some vulnerable people may have preferences that lead to harm for themselves or others. (Examples among the general public would include driving dangerously, illicit drug taking and excessive alcohol consumption.)

- the choices people make to meet a given preference may be based on inadequate or false information, or on faulty cognitions. For instance, people may want to treat a debilitating cancer by using a well-marketed, but ineffective therapy, when a cheaper and more effective one is available. Further, consumer knowledge may be sufficiently limited for some specialised, highly complex services that experts need to act as gatekeepers to ensure that people get the services that genuinely meet their needs ('credence' goods). This may apply to some complex health/early intervention services used in conjunction with disability services. Notably, no health system allows people to choose any therapeutic substance they want without some controls. That said, the bulk of disability services would not require third-party screening

- the NDIS — especially in its early years — will need to build some people's confidence in exercising power, and to provide supports that give people more control. Disability Support Organisations would perform this role if people wanted it

- some people with disabilities are not able to make all of their own decisions (as is the case with profound intellectual disability). In that case, decisions about their well-being will often be made jointly with or by their primary carers, who are usually familiar with the strengths, goals and other preferences of the person with a disability. However, while such carers will usually have the best interests of the person with a disability at heart, that will not always be the case. Like all people, carers (and people with disabilities) are not perfect, and sometimes will act in a way contrary to the interests of the person they are supporting (see later).

These caveats suggest that, just as holds in the community at large, sometimes others may need to provide advice or even override the preferences of people with

disabilities or their carers (as, for example, occurs with regulations about drug use in the community as a whole). However, the general presumption is that people with disabilities, their primary carers and others would be able to make better decisions than people removed from their daily lives.

Competitive pressures

In most consumer contexts, absence of genuine choice tends to result in lower quality and more costly services, less product variety and less innovation. In contrast, consumer control of budgets through self-directed funding, or even the *option* of controlling budgets, creates incentives for suppliers to satisfy the needs of consumers, given that they would otherwise lose their business. That in turn typically leads to more complex markets, with suppliers developing differentiated products for different niches, promoting their products and advertising their prices and other relevant characteristics. The point is that competition is not just about achieving the lowest price,[7] but also encouraging the entry of new suppliers, quality service and the creation of new products that match people's preferences. An example in the United Kingdom is Shop4support, an online market for a large array of disability services.

As discussed above, the scope for full competition may not always be present when suppliers have market power, consumer knowledge is poor, where services are complex, or where the market context would be likely to lead to distorted consumer decisions. Markets may also take some time to develop, as will the capacities for making informed choices by people with a disability and their families (hence the need for supporting people in implementing self-directed funding). However, choice among specialist disability services may often still produce better outcomes even where markets are imperfect. ('Choice of package' would also be likely to create greater incentives for suppliers to perform better.)

Moreover, choice gives people with disabilities or their families a greater capacity to buy mainstream services (for example, to go to a film, rather than a specially organised event for people with a disability). That has several implications. It:

- provides more pressure for responsive service by specialised agencies because it broadens the scope for competition
- means that people with disabilities get higher quality services. As all people consume mainstream services, it requires only a small number of these to be informed and demanding consumers to elicit responsive services by a supplier to

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[7] In theory, block funding or regulated prices *might* lead to low prices.

benefit consumers more generally, including those with disability. So, it is better to be in a broad group that includes more of these demanding consumers than a narrow group in which there are smaller numbers. In effect, mainstream services adds the power of other consumers to those of people with disabilities

- expands the type of services people can receive

- may reduce social exclusion and marginalisation as people participate in the activities enjoyed by the community as a whole.

However, the role of mainstream services should not be overstated. As argued by JacksonRyan Partners (sub. 30, pp. 4–5) they may play a limited role for many people with disabilities. Many people will mainly acquire services from specialist disability providers.

The value of choice per se

The capacity to exercise choice can represent a valuable 'good' in its own right for many people, as revealed by the efforts people make to secure such freedoms. Many people would prefer to make their own decision on something, even if a benevolent outside party were to make exactly the same decision on their behalf. And, even if people end up asking someone else to choose for them, the option to make a choice remains valuable. The value of having (real) choices per se has been confirmed in a number of empirical analyses of choice in health care (Barnett et al. 2008). However, there is some evidence that people do not always value choice when there are too many options — choice 'overload' (Schwartz 2004) — or when the choices relate to lowly preferred options — 'fake' choices (Botti and Lyengar 2004). Providing support to people with disabilities to form personal plans may help to avoid choice overload, while maximising the scope for people with disabilities to determine how they spend their funding avoids the problem of fake choices.

A caveat: there are social tradeoffs when someone else pays for a person's choice

The above four factors suggest that for the *given* budget that the NDIA allocates to a person under self-directed funding, there are potentially strong ethical and economic arguments for the person with a disability (or people acting on their behalf) to control how it is used. However, it does not imply that it is efficient for taxpayers to meet *all* of a person's preferences, regardless of the cost. (Of course, a person could add any of his or her own financial resources to meet needs not satisfied by taxpayers.)

This reflects the fact that the resources allocated to a person with a disability is funded through compulsory taxation of the community, who also have goals that they wish to achieve (buying a house, getting an education, being part of their community). Moreover, governments have to allocate the finite funding they are able to raise among many competing community needs (hospitals, roads, defence, addressing disadvantage and so on), and cannot meet all of them, even were they to increase taxes. Consequently, spending by governments is a zero-sum game — if someone gets more, someone else gets less. Many families without disability also struggle to meet their aspirations. For example, one participant pointed out that in many other areas of government services, such as education, there are limits to meeting all the preferences of children (D. Holst, trans., p. 255).

In that context, and as emphasised in chapters 5 and 7, the funding of the NDIS is based on people's reasonable needs, not wants.

8.4   Impacts, benefits and costs of existing self-directed funding arrangements

There is now widespread evidence about the impacts of self-directed funding on people, and its costs, risks, and effective implementation, based on its use in many settings (summarised in table 8.2). Self-directed funding has been adopted in countries with otherwise very different frameworks for social welfare provision (Arksey and Kemp 2008; Townsley et al. 2010). There has also been piecemeal and generally small-scale implementation of self-directed funding in Australia, which helps guide the wider application of this funding approach (appendix D).

A detailed analysis of the impacts of self-directed funding is in appendix E, but the key findings are that:

- people with disabilities derive significant benefits from greater control over their budgets and lives, with their needs better met, greater life satisfaction, more interaction with people and the community, higher quality and continuity of care, with positive or no changes in their health status. As one participant remarked in this inquiry, self-directed funding 'was a huge relief; the quality of support workers, and support services increased (name withheld, sub. 209, p. 1)

- family members providing support have greater confidence in care, satisfaction with life, less financial strain and improved health status

- employed support workers generally get better outcomes, though this is not uniform

- self-directed funding is likely to partly alleviate the (current and impending) shortages of workers in specialised disability services by shifting the emphasis to mainstream services and by allowing friends, people in the local neighbourhood (and potentially relatives) to be paid for services

- there is little evidence of major difficulties for service providers from self-directed funding over the long-run, but some evidence of transitional costs associated with new systems

- ongoing costs appear to be generally lower (and at worst no higher) than traditional agency-based disability systems, though there are significant upfront implementation costs. An individual example was given by one participant in this inquiry, in which the available package was $14 000 per year, but actual usage under self-directed funding was never more than $10 000 (Val Stone, sub. 228, p. 11).

Table 8.2   Summary of the impacts of self-directed funding[a]

	Person with a disability	Family members
Consumer and family benefits		
Met individual needs	Improved	..
Satisfaction with care	Improved	Improved
Sense of control over life/ empowerment	Improved	..
Community interaction (circles of friends)	Improved	..
Greater use of mainstream services	Improved	..
Quality of care/ confidence in care	Improved	Improved
Costs of supports	Down or no change	
Personal dignity	Improved	..
More independent living	Improved	
Abuse and neglect	Down	..
Satisfaction with life	Improved	Improved
Culturally and linguistically appropriate care	Improved	..
Providing care during non-business hours	Improved	..
Continuity of care	Improved	..
Employment and productivity gains	Improved	
Use of preventative care	Improved	
Use of hospital, other health services & residential care	Down	
Economic wellbeing	Improved	Improved
Health status	Improved or no change	Improved
More aids & appliances and home/vehicle modifications	Improved	

a These results are derived from the studies cited in appendix E. While they include studies from Canada, the Netherlands and Australia, they mostly relate to the Medicaid waiver self-directed funding programs in the United States and to direct payments in the United Kingdom.

The Victorian Government (sub. DR996, pp. 32–33) drew attention to the outcomes identified in its evaluation of its (phase II) trial of self-directed funding, finding that:

- 97 per cent were quite happy or very happy with the control over their supports since starting direct payments, as compared with 47 per cent prior to direct payments

- 90 per cent were quite happy or very happy with the quality of their supports since starting direct payments, as compared with 52 per cent prior to direct payments

- 91 per cent were quite happy or very happy with the involvement in the lives of family and friends since starting direct payments, as compared with 70 per cent prior to direct payments

- 84 per cent were quite happy or very happy with the involvement in their local community since starting direct payments, as compared with 62 per cent prior to direct payments.

Self-directed funding is now a common feature of international disability systems, and has grown in importance where governments have implemented it. There are few indications of major problems in areas where people perceive significant risks (an issue discussed later in more detail).

Given the strong rationale for self-directed funding and the weight of evidence indicating that it achieves greater benefits for lower or at least, no higher costs, self-directed funding should be an available option throughout Australia for people with disabilities. However, that still leaves open how any arrangements should be designed.

RECOMMENDATION 8.1

Governments should give people with disabilities eligible for benefits under the NDIS, and/or people who act on their behalf, various options for exercising choice, including the power to:

- ***choose service provider/s to meet their needs specified in their individual packages***

- ***choose disability support organisations that would act as intermediaries on their behalf when obtaining the supports specified in their individual packages from service providers***

- *'cash out' all or some of their individual packages if they wish, with the NDIA making direct payments to their bank accounts, and allowing people to purchase directly the detailed package of supports that best meets their preferences ('self-directed funding'), subject to the constraints set out in recommendations 8.2, 8.7 and 8.8.*
  - *the specific arrangements for self-directed funding should be underpinned by the principle that, subject to the assessed individual budget and appropriate accountability requirements, the arrangements should maximise the capacity for a person to choose the supports that meet their needs best and that promote their participation in the community and in employment*
- *choose a combination of the above.*

8.5 Design of self-directed funding

At the broadest level, self-directed funding involves people having significant control over their budgets. However, there are many issues about how to design self-directed funding and how it fits into a coherent disability system, encompassing:

- the division of power between a person with a disability and their families (section 8.6)

- the types of goods and services people may purchase and the ones where other parties still make purchasing decisions (section 8.7)

- how the arrangement would be sequenced and structured for people (section 8.8)

- its applicability in regional and remote areas (section 8.9)

- whether people could hire their own employees, and in particular whether this could extend to family members — a controversial issue in the Australian context (sections 8.10 and 8.11)

- the capacity of people to know how to use the system and to meet the administrative and legal requirements for employing people, and how governments and others can lower these costs or provide decision-making support to make self-directed funding a genuine option for people (section 8.12)

- the risks it may pose to people with disabilities, to support workers, to government and to service providers — and the best policy responses to these risks. An associated issue is whether all people should be eligible for self-directed funding (section 8.13)

- how self-directed funding should be implemented, taking account of the considerable transition issues (section 8.14).

8.6   Exercising power at the family level

The principle of self-directed funding is that where possible, decisions should be made as close to the person with a disability as possible, because such decisions are more likely to reflect the specific preferences of the person and their exact circumstances. In many cases, the decision-maker will be the person with a disability (though many will need support to exercise that role in the early stages of the NDIS — section 8.12).

However, where significant intellectual and/or mental health disabilities are present, people with disabilities may not be able to self-direct their funding by themselves. The Brightwater Care Group observed:

> [Self-directed funding] is potentially a high risk area, in particular for people who, by the very nature of their disability, display poor insight into their level of impairment and its impact on their skill base — including their financial management skills. (sub. DR752, p. 9)

That does not require that traditional agency-based service provision be the default model for support. As noted by My Place:

> All people, regardless of the nature or severity of their disability, should be able to access the scheme. Where the person is unable to make their own decisions, court-appointed family members or guardians should be appointed to assist them with the decision-making. There is good evidence, accumulated from local practice in WA particularly, that Individualised Funding is well suited to people with significant disability (although there is an uninformed contrary view abroad amongst a number of service providers who do not operate Individualised Funding services). (sub. 217, p. 7)

There are strong grounds for guardians (such as a parent or partner) familiar with the person with a disability to act as their agent under self-directed funding. Several participants pointed out the importance of a familiar party or 'trusted other' as the most appropriate guardian where the person with a disability cannot make informed choices (David Holst, trans., pp. 261–2; Carolyn Quinn, trans., pp. 834–5; Julia Farr Association, sub. 494, p. 19). For example, Carolyn Quinn noted:

> He can't make any choices about plans, life. … So I'm basically the one that needs to make those kinds of choices in his life. I want to be able to do that and I'm quite capable of doing that but the system frustrates you in being able to exercise that — what everybody else gets to take for granted. So I really want choice about how things happen in my son's life. The other thing that's disturbed me significantly about the way disability services have traditionally been provided is that there's almost an assumption

that service providers make better choices for people than their families do. I think that's intrinsically false.

It should be emphasised that guardians are obliged to take into account, to the extent practicable, the wishes of the represented person.[8] It should also be noted that while such carers will usually have the best interests of the person with a disability at heart, this will not always be the case. Like all people, carers (and people with disabilities) are not perfect. Some will act in a way contrary to the interests of the person with a disability or to the community, an issue that is relevant to accountability measures.

8.7 What services should be covered?

The Commission favours a significant capacity for someone to tailor-make their supports, and envisages that, subject to the exceptions discussed below, the assessed value of services covered by the NDIS (chapter 5) would be bundled into a single individual budget. A single individual budget also has the implication that governments would need to collapse any budgets currently dedicated to specific spending components into a single government budget (an observation made by Joyce Bellchambers, sub. 58, p. 1).

The rationale for an all-inclusive individual budget, rather than choices within spending silos, is that there may well be gains from people shifting resources from one basket to another. For instance, someone might want to use some of the funding earmarked for attendant care to buy a hoist or automatic bed turner to reduce future needs for attendant care. Subject to its cost-effectiveness, this was possible in a self-directed funding arrangement in the United States.[9]

What would be the reasonable limits to flexibility?

In theory, imposing any constraints on how people could spend their funds would be inefficient because it would entail administrative and compliance costs, and people could not choose things they value more than items on the list of 'approved' purchases. It could also undermine independence, initiative, innovation and trust. On these grounds, one option would be to pay individualised funding as untied income, as with income generally among the community, with the presumption that people would use funding for the purposes best suited to their individual needs.

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8 For example, see Section 28 of the *Guardianship and Administration Act 1986*, Victoria.

9 This was the Home and Community Based Service Physical Disability Medicaid waiver in Kansas in the 2000s (Kim et al. 2006).

In practice, this tends to be uncommon practice around the world. Austria, Germany and Italy appear to be relatively exceptional in providing cash-for-care schemes that are unregulated (Arksey and Kemp 2008). In Germany, people electing direct payment have their package of supports discounted by 50 per cent.[10] While not seen as a form of self-directed funding, the UK Disability Allowance is effectively an unrestricted payment — albeit involving relatively low amounts.

Most international arrangements for individualised funding involve earmarking, with people facing restrictions on where and how they spend their funds. In some countries — France, the United Kingdom and the United States — purchases must be in accordance with a care plan, but can otherwise be quite flexible. Existing Australian arrangements are similar. For instance, in Victorian and South Australian self-managed funds, people must keep individualised funding accounts separate from other money and must only spend money on recognised carers, respite services and other goods and services identified as legitimately disability-related. In some countries, such as the Netherlands and Sweden the self-directed funding is largely restricted to personal care.

The question is the nature of any constraints and how these would rationally be determined without destroying the underlying rationales for self-directed funding. The broad principle would be to maximise choice, while safeguarding the person and the scheme from excessive risks. (Some participants thought that any earmarking was at odds with the nature of publicly-funded income support arrangements, where historically people have had the freedom to spend the payments as they felt appropriate. However, that does not recognise that the purpose of the payments is different and income support arrangements are now subject to some controls.[11])

The NDIA would need to determine the appropriate boundaries for cashing out supports. Regardless of such constraints:

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[10] Nevertheless, a significant number of people take up the direct payment option (Schultz 2010).

[11] Income support payments act as a safety net for people on low income, rather than as a means for buying specific types of supports. The income is means and asset tested (unlike NDIS packages); is not aimed at purchasing support services, therapies or complex equipment; subject to relatively low ceilings; and, by virtue of the size of the payments must mostly be spent on basic needs, like food, clothing and accommodation. Moreover, quarantining for food and clothing *has* been introduced for some welfare payments in Australia following concern about the misdirection of payments away from essential purposes (*Social Security and Other Legislation Amendment (Welfare Reform and Reinstatement of Racial Discrimination Act) Act 2010*, No. 93, 2010).

- people should be able to seek variations from the norm if that were justified by likely positive outcomes. In that sense, it would be undesirable to draw up a definitive 'black' list of supports that should not be able to be cashed out

- people's packages would still be individually-tailored and reflect people's plans, aspirations and needs.

That said, there are several areas where cashing out individual support packages would generally be inappropriate.[12]

Ensuring the provision of essential goods and services

Providing self-directed funding as an untied budget would mean that people could choose to give up purchases essential to good outcomes. Such supports would include adequate aids, home modifications, employment supports and some clinical interventions. An example would be specialised job readiness services (for example, the two-year intensive readiness scheme funded and overseen by Disability NSW), which are important for good employment outcomes. Another example would be essential specialist therapies and interventions —such as the services of prosthetists and people able to provide orientation and mobility training for the blind. Several participants highlighted the need to exclude early interventions from self-directed funding or to caution against the use of the funding in areas where expert judgment was required.[13]

The only way of ensuring that essential supports are purchased is to include these in the package of supports, but not permit them to be traded off against other purchases. In effect, such separation is like making such essential supports free, in that consuming them does not displace other purchasing options. (Moreover, the individual budget would necessarily exclude some core goods and services earmarked for people with disabilities, but funded outside the scheme, such as mainstream employment services, health services, educational goods and services and public housing — see chapter 5.)

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[12] Economists often regard earmarked income as less valuable to people than untied income precisely because it restricts the capacity of people to make such tradeoffs. However, this is an area of expenditure where welfare outcomes from providing packages as pure income could actually harm the wellbeing and interests of people. This is an important issue in valuing the benefits to people of the package of supports they would receive from the NDIA (a matter examined further in chapter 20).

[13] Such as Valued Independent People (sub. DR932, p. 19), Children with a Disability Australia (sub. DR1007, p. 17) and MontroseAccess (sub. DR684, pp. 4–5).

The obverse side to services and supports needed to ensure good outcomes (which should not be able to be traded off against alternatives), are goods and services that are positively associated with harm. These are supports that should not be publicly funded at all. A sensible criterion identified by the Julia Farr Association (sub. 494, p. 18) is that these would be goods, like gambling and alcohol, that can sometimes be contributory to the incidence of disability or the deepening of disadvantage.

A cost-effective scheme relies on critical investments

Some purchasing decisions are long-run investments that are required to produce good outcomes for the person and that *also* increase the long-run cost-effectiveness of the scheme (such as a vehicle modification that saves on future taxi use, and that may allow a person to get a job). The high cash-out value, combined with people's common tendency to be short sighted, could increase the risks of cashing out such investment purchases. The experiences with lump sum payments in accident compensation cases illustrates this risk, with people often not putting aside enough funds to meet their lifetime needs (chapter 17). Notably, the purest form of self-directed funding would give people the present value of the future lifetime expected stream of their assessed entitlements — in effect a lump sum — with the problems these have. In that context, the NDIA should pay annual allocations of self-directed funding in monthly instalments paid in advance. That said, there could be broader lessons for self-directed funding from examining the experiences of people awarded lump sum compensation packages (Spinal Cord Injuries Australia, sub. DR786, pp. 7–8), as this may reveal some innovative practices.

Sometimes expert knowledge is required for informed decisions

Cost-effective choices among some supports require significant technical knowledge and evidence, which may be absent or limited among many people. Clinical services are those where clinical or expert knowledge is required in the appropriate delivery of the support (for instance, specialist disability physiotherapists and psychologists).

As an illustration, while the science is evolving, there are certain clinical protocols for appropriate early interventions for acquired brain injury and autism, which requires expert input. Notably, the *Helping Children with Autism* package from the Australian Government has specific requirements for eligible interventions, practitioner qualifications and program processes based on existing evidence (Roberts and Prior 2006). It would be hard to justify allocating NDIA funds to unproven or even potentially hazardous clinical interventions just because they represented self-directed choices. (The same limits to self-direction apply more

generally in the health system. People are not able to use public or private health funding for any-health related therapies they prefer or to cash out the funding for non-health purchases.)

People could still have some choice among approved therapies with similar efficacy, choose an accredited provider of a given therapy or use their own money. They and their agents (such as peak bodies) could also contribute to debates about new therapies through private advocacy. People and their family members could also have a greater role in self-management once they had received expert advice. In the latter vein, in 2005, the World Health Organization (WHO), the Associazione Italiana Amici di Raoul Follereau (AIFO), and Disabled Peoples' International (DPI) jointly initiated the 'New Paradigm of Medical Care for Persons with Disabilities'. The approach recognised some of the limitations of the traditional model of acute care for long-term health care, and particularly the insufficient role it gave to people with disabilities in managing their own care. There is evidence that this approach worked well in one test location for people with spinal cord injury (World Health Organization and the World Bank, 2011, p. 76). The point is that there can be a continuum of power, and that removing the capacity to 'cash out' all package elements does not remove the capacity for people to have control over their lives.

People sometimes need quick and emergency supports

Sometimes people need support they cannot pre-specify, which, by definition, cannot be cashed out of an individual support package. For instance, this includes crisis supports or other unanticipated needs (like family counselling or emergency respite), and supports needed before assessments are finalised.

Accountability

Completely untied funding may create incentives for people to overstate their needs, undermining the integrity of the assessment process and leading to adverse fiscal and welfare impacts. The tools used to assess people for their needs and the extent of their natural supports are not perfect (chapter 7). To some extent, they rely on information provided by the person with a disability and their family. Once that is the case, it becomes possible for someone to err on the side of greater revealed needs and to underestimate the availability of natural supports, leading to larger individual support packages (with concerns for the fiscal sustainability and fairness

of a scheme). The incentives to do that are greater if people can treat the funds like ordinary money, and spend it on anything they want.[14]

In addition, the availability of high levels of untied payments may unwittingly encourage the persistence or exaggeration of an injury or disability — with adverse long run impacts on enablement (an example of so-called compensation 'neurosis' as happens with compensable injuries). This does not imply that people with disabilities are innately untrustworthy, but rather that, as a group, people with disabilities are like everyone else when responding to incentives. (To think otherwise is to adopt an inherently stereotyped view of disability.)

Moreover, were people given the complete latitude to trade off essential supports against other purchases, and did not actually purchase an essential support, then the NDIA would feel compelled to allocate additional funds to provide them. This would reduce any personal impacts of poor decisions, thereby lowering people's incentives to choose carefully ('moral hazard'), and decreasing the scheme's cost effectiveness.

Finally, the capacity to completely cash out individual support packages raises probity risks (perceived and real). The less open to scrutiny and the greater the value of untied payments, the greater is the risk of fraud and the inappropriate use of what is public money. Any significant abuse of funds — with funding sometimes exceeding $150 000 annually for a person with high care needs — would risk alienating public support for any form of self-directed funding and may jeopardise the scheme itself.

There should still be a lot of latitude

Requiring some constraints does not mean losing much flexibility in self-directed funding. Many times people take too narrow a view about what would be an appropriate support. Few would contest the legitimacy of spending on traditional respite services or personal care. However, some spending categories, especially community access, do not have clear boundaries. For example, could a movie ticket or a gym membership ever be appropriate?

From one perspective, movie tickets are customary goods that most people buy with their own money. The wider the set of permissible goods, the more self-directed funding resembles untied funding, with the problems identified above.

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[14] The fact some might do this need not reflect fraud (though that is a risk), but the desire given the uncertainty about actual future needs to have a buffer amount that can be spent on any option.

However, looked at from a broader angle, without adequate support, many people with disabilities are unable to participate fully in society in ways that most people take for granted. Even buying ordinary things — movie tickets, attendance at a class, going to the football, joining a gym or theatre group — can be very effective ways of achieving the goal of community participation compared with costly specialist alternatives (and these often could not be afforded through income support payments). One participant noted that a scheme should cover leisure costs:

> … because a person with disability requiring constant or frequent care [is] rarely employed. They have a lot of leisure time to fill and they need to be supported to engage with the community. (name withheld, sub. 74, p. 10)

The Commission knows of one woman with an intellectual disability where going to a movie means learning and maintaining skills (catching public transport), engagement with the public (buying the ticket, sitting with others in the theatre), and the creation of a sense of independence. The money spent on a movie in this case may be much more cost-effective and appropriate than some disability-specific services. In this particular instance, it was a fraction of the cost of the alternative disability services, she enjoyed the activity much more than specialist services and liked that fact that it was not a segregated activity (Val Stone, sub. 228, p. 4). Notably, a NSW day program (Life Choices), which is *not* run through direct payments, includes many entertainment options (including movies, sporting clubs and concerts). It would be problematic to allow such options when a service provider acts as the intermediary, but not to permit them when a person controls their own budget.

The problem of drawing the boundaries for 'disability' expenditures under individualised funding reflects the broadness of the goals of contemporary disability policy — achieving independence, community engagement, ordinary life skills and citizenship for people with disabilities. Given these broad goals, and people's diverse needs and preferences, it would not be sensible to be overly prescriptive about where the money should be spent, but to stipulate a few exceptions (as discussed earlier) and put in place other approaches to deal with the risks of unrestrained choice (section 8.13).

The experiences in various self-directed funding programs in Australia and in other countries suggest considerable benefits from an accommodating approach by authorities about flexibility (for example, Carmel Laragy, sub. 84, p. 2). One Australian user of self-directed funding gave an illustration of the benefits of creative use of funding:

> Tim turned 21 and like any young man he's entitled to the rite of passage of a 21st birthday. Self-management allowed me to do something that was absolutely inconceivable any other time. I was able to employ [someone] for a small number of

hours … to do some social education informally with him in preparation for his 21st birthday. It worked sublimely. He got the issue, even though his cognitive capacity is quite limited … and he had a ball. … But no other place except self-management allows you to do that kind of thing. So the system needs to have that flexibility to deal with that kind of life issue. (C. Quinn, trans., p. 836)

Another submission pointed out that self-directed funding provided personal assistance for a person to regularly visit a cemetery for cultural and faith-based reasons, which would not have been otherwise possible (National Ethnic Disability Alliance, sub. 434, p. 33).

A further aspect of desirable flexibility would be the capacity to save a proportion of an annual entitlement to spend on future needs. This has the advantage that people can plan ahead. It would also reduce incentives to spend all of an entitlement, even on lower priority needs, because the funds would otherwise be lost. The Commission considers that a capacity to carry over 10 per cent of the self-directed funding budget to the following year would be appropriate. Similarly, there should be a limit to the accumulation of surpluses — say to two years — with any further surpluses returned to the NDIA. Allowing people to accumulate significant reserves by adding successive 10 per cent surpluses year after year would bring into question the accuracy of the assessed package of supports.

Some considered a 10 per cent limit in carryover as reasonable,[15] while others argued that the limit was too low or prescriptive.[16] Some participants pointed to other considerations in determining the appropriate degree of flexibility in spending over time:

- Some saw a capacity to accumulate surpluses as important for making infrequent equipment purchases (Cerebral Palsy Alliance, sub. DR682, p. 4; the South Australian Council on Intellectual Disability, sub. DR1016, p. 9). However, as discussed earlier, the Commission considers that any large non-recurrent expenditures would be met directly when needed from people's individual support packages, but could not be cashed out to purchase other supports.

- Others noted that people with episodic disability — such as those with mental health problems or certain chronic diseases — may benefit from more flexible arrangements that allow them to access a 'support bank' when their needs are greatest (for instance, the Australian Federation of Disability Organisations, sub. DR953, p. 28; and the Australian Federation of AIDS Organisations and the National Association of People Living with HIV/AIDS, sub. DR969, p. 7).

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[15] Physical Disability Council of NSW (sub. DR832, p. 13).

[16] Perth Home Care Services (sub. DR906, p. 16); WA Individualised Services (sub. DR800, p. 14) and Disability Advocacy Network Australia (sub. DR1010, part B, p. 19).

In the absence of analysis of scheme outcomes and performance, there is little guidance for prescribing arrangements in this area. The Commission has adopted a cautious approach, specifying the 10 per cent figure in line with current practice in Victoria (appendix D). The Victorian model also includes some limits on the accumulation of surpluses. However, as with many other details of the NDIS, the appropriate flexibility in this area should be re-considered after the rollout of the scheme, when more evidence will be available.

8.8 The process for accessing self-directed funding

Clear structures would need to apply to self-directed funding to make it easy to communicate how it would work for people, ensure fairness and meet reasonable accountability requirements. As an illustration, any system of direct payments (or arrangements close to these) would need to distinguish well enough between cases where it would be reasonable to spend money on entertainment services, and when that was not appropriate. If the risks were too high, some blanket rules might be appropriate. Nevertheless, completely avoiding risk would undermine the benefits of self-directed funding, and create many administrative and compliance costs. So how can the goals of accountability and flexibility be reasonably met? Probably the best approach would be to adapt the current Victorian model.[17]

Step 1 Assessment and budget determination

The individual budget for self-directed funding would be based on the formal individual assessment of the person's needs and would include the cashed out value of all goods and services covered by the NDIS, except those where specialist knowledge is required for informed choices. The prices for services underlying that budget would be based on efficient supply prices. For example, if an assessment indicated that a person needed 10 hours of attendant care a week, and the efficient supply cost for a typical supplier was $45 an hour in that geographic area, the budget would be $450 per week. (A more complex question is the estimate of the budget for appropriate accommodation, since different types of accommodation solutions have varying costs).[18] The parallel Commission inquiry into aged care

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[17] This model was advocated by several participants, for example, Northcott Disability Services, (sub. 376, pp. 11–12). But it was also seen by one expert in self-directed funding as 'cumbersome and resource intensive' because of its detailed planning and review process (Carmel Laragy, sub. 84, p. 5).

[18] Some participants pointed to concerns that self-directed funding would present challenges to creating accommodation infrastructure because suppliers would not be willing to invest without greater certainty about referrals (Disability Trust, sub. 230, p. 1). In other parts of the market,

discusses the determination of appropriate prices at length — and the NDIA would need to follow similar processes (PC 2011a).

The amount allocated to self-directed funding should be equal to the budget determined by the assessment process. Were a discount factor applied to self-directed funding then this would encourage supply by specialised disability agencies, against the principles of competitive neutrality and economic efficiency.[19] A potential objection to this might be that people using self-directed funding do not face some of the costs experienced by specialised providers — such as an office, the need to administer the funds, supervisors, a computer system and other overheads. However, people with disabilities would still have to undertake some of the functions performed by agencies (like administration), but would take the payment for these tasks in the form of a capacity to access more services. Moreover, to the extent that self-direction involves lower costs than specialist provision (say because a person's home is also their 'office'), then this is an efficiency gain that should not be penalised. Finally, people may choose to pay a DSO to undertake administration tasks on their behalf, and for this to be a realistic option, their budget must include an amount that allows them to do so.

Step 2 Set up a plan and funding proposal

The person would develop a personal plan and a funding proposal. If appropriate or desired, the person could do so with the help of their family, friends, others strongly connected to them or a disability support organisation (see below). This would be aimed at meeting the individual's aspirations and the outcomes he or she wanted to achieve, within the budget determined by the assessment.

The funding proposal could be reasonably flexible by specifying a range of spending options to achieve certain goals, rather than an excessively detailed breakdown of spending intentions. For example, where a person could not engage independently with the community, the proposal might say that the goal of community access would be achieved by going to the movies, attendance at a gym or swimming pool, participating in a community class or similar such activities, with a budgeted average cost of $40 a week. In this instance, the person would be able to choose among these options as they felt appropriate, but would not have to pre-specify which one he or she would use. In general, the goal would be to provide as much flexibility as possible related to the particular needs of the person.

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businesses are willing to invest in infrastructure, based on expected demand, *if the price is right*. So an essential aspect to infrastructure is ensuring that the budget amounts allocated to people reflect the prices needed to induce supply.

[19] However, in some circumstances, a discount may be appropriate, such as when self-directed funding is used to employ family members.

However, for the reasons outlined earlier, there would be a strong presumption that people would not be able to trade-off funding for essential aids and appliances and building and motor vehicle modifications against other spending options. However, people could direct some non-recurrent funding to other purposes if they could provide persuasive reasons for this as part of their funding proposal. The discipline of an approved funding proposal (described below) would prevent the practical dilemmas and risks of completely free choices about these high-cost non-recurrent spending items.

The NDIA would help in the formation of the planning and funding proposal by providing written resources and other guidance, as occurs in Victoria already. If the person wanted further assistance in planning or formulating the funding process, they could engage a DSO, which could provide specialist planners and other support for choice. Some participants specifically requested such a coordinator to assist with self-directed funding (for example, the Australian Leukodystrophy Support Group, sub. 564, p. 3).

Step 3 Getting the funding proposal approved

The funding proposal would allow considerable flexibility, but would also impose some disciplines on spending because the NDIA (or a panel, as suggested by Valued Independent People, sub. 201, p. 4) would have to approve the proposal or any significant alterations in it. The NDIA would pre-specify generally admissible supports, guided by the principles above.

A plan would get approval if it met some clearly specified criteria relating to outcomes for the person and for appropriateness. The guidelines used in various Australian and overseas jurisdictions could be adapted to create a national approach under the NDIS, such as the guidelines used in the Florida self-directed care program (Hendry 2008).

There would also need to be a reasonable degree of accountability for spending and an ongoing reassessment of the funding proposal to ensure its continued relevance and appropriateness. The way in which risks could be reduced is discussed in section 8.13, but the emphasis would be on the minimum required. Notably, some accountability can be useful to people. For example, one parent using self-directed funding in Victoria said that she found the accountability requirements 'quite helpful keeping you on track. It gives a little bit of structure ... ' (C. Quinn, trans., p. 842).

That said, another element of a flexible arrangement would be to allow a modest component of the individual budget — such as $30 a week (or a small percentage of their budget) — to be free of any requirements for receipts. This would have the

benefit of allowing people to meet expenses that are not readily invoiced (say, hiring a canoe) and for irregular and incidental 'employment' arrangements of the kind described later without any documentation. Notably, this kind of incidentals policy is already in place in the Netherlands (Wiener et al. 2007, p. 570, Phillips and Schneider 2007, p. 408) and the United States. For instance, three US states allow people to receive a small fraction of their allowance in cash for incidentals, providing the purchase plan states the overall amount and the types of goods and services people purchase.

Step 4 Leveraging the proposal with private funds

People with disabilities, their families or the community generally could add their own funding to the proposal. For instance, that could allow the person to buy a better wheelchair, a longer holiday or a dwelling in a more preferred location.

RECOMMENDATION 8.2

Self-directed funding should include the following key stages.

- ***It would be informed by any prior planning and aspirations expressed by the person during the assessment phase (recommendation 7.2).***

- ***The individual budget for self-directed funding would be based on the formal individual assessment of the person's needs. The budget should include the cashed out value of all goods and services covered by the NDIS, with the exception of those where cashing out would pose credible risks to the person and/or the sustainability of the scheme.***

- ***The person with a disability — and/or their support network or chosen disability support organisation — would create a personal plan and a concrete funding proposal to the NDIA that outlines the person's goals and the type of support that would be necessary and reasonable to achieve within the allocated budget.***

- ***The resulting funding proposal would require approval by the NDIA.***

There should be a capacity for a person to:

- ***obtain quick approvals for changes to a funding proposal***

- ***add their own private funds to a funding proposal***

- ***allocate the individual budget to any mix of preferred specialist and mainstream goods and services, subject to the requirements that the person spend the budget in areas related to his or her disability needs and consistent with the agreed funding proposal***

- *jointly manage their cashed out benefits with a disability support organisation ('shared management').*

RECOMMENDATION 8.3

The NDIA should pay annual allocations of self-directed funding in monthly instalments paid one month in advance, with the capacity for the person to 'bank' up to 10 per cent of the annual allocation to the subsequent year.

8.9 What about spending options in regional and remote Australia?

Some think that self-directed funding would be hard to achieve in regional and remote areas because of limited options for purchasing services (for example, the Attendant Care Industry Association, sub. 268, p. 6 and the Physical Disability Council of NSW, sub. DR832, pp. 6–7). This might be true in some cases. However, as discussed earlier, people would not have to take up self-directed funding, so they would not be worse off. Even if there were only one provider, the potential for self-directed funding would at least encourage entry by a new provider or the use of mainstream services as replacements for specialist services.

In many cases, however, people would still be able to use self-directed funding in regional Australia. My Place (sub. 217, p. 8) and Perth Home Care Services observed that the demands of people using self-directed funding can often be met in the country because:

> … the lion-share of supports that people with disabilities and their families seek are practical, everyday supports. These supports are generally available in most communities. (Perth Home Care Services, sub. 520, p. 7)

The evidence suggests that many of the patterns of spending by people with access to self-directed funding between country and metropolitan areas were similar in that state, suggesting comparable spending options were available. For example, Perth Home Care Services noted that the spending shares for aids and appliances, leisure support and personal care were very close between these two areas (sub. 520).

Advocacy Tasmania (sub. 483, p. 15) noted that Tasmania is the least urbanised state in Australia, with many small towns, but that (fledgling) self-directed funding arrangements still appeared to have worked well. A trial of a voucher for buying care in the United States[20] suggested that people in regional areas were still able to

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[20] This was the Medicare Primary and Consumer-Directed Care Demonstration in New York State, West Virginia, and Ohio.

buy services, but did so in a different way. People in rural communities were much more likely than urban dwellers to spend their voucher on non-agency workers compared with agency workers (Meng et al. 2010). Some of the reasons for this were shortages of agency workers in rural locations and the preferences of rural people for hiring workers they knew, rather than receiving services through formal agencies.

A potentially important aspect of self-directed funding relevant to regional Australia is the capacity to hire family members. This controversial issue is discussed at greater length in section 8.11 (and appendix G), but it appears that this flexibility can be a further way of reducing shortages of formal support workers in regional areas.

The difficulties in accessing specialised or even mainstream, services are accentuated for Indigenous people in remote areas. These problems are compounded further by:

- the high rates of disability in these communities, creating a higher level of incipient need

- the multiple sources of disadvantage that often affect such communities

- weakened informal support networks for people in some communities

- a cultural tendency not to identify disability or to access services when they are needed.

Together, these features present challenges for both traditional agency-based and self-directed funding arrangements for Indigenous people in regional Australia (an issue discussed in detail in chapter 11).

8.10   Employing people directly

A common feature of self-directed funding overseas is the employment of attendant carers or other support workers by a person with a disability (or their agent). Attendant care often comprises the main share of the recurrent costs faced by a person with a disability. An arrangement that allows people to hire people suited to them is a major source of the gains from self-directed funding. Many care services are 'low-tech, non-medical and do not require extensive training or oversight' (Kodner 2003, p. 2), which reduces the need for mandatory qualifications or for third party screening of people's choices.

Moreover, an essential aspect of the quality of support services is the extent to which support workers have an emotional connection and intangible skills

specifically suited to the specific person with a disability, which only that person can observe. For instance, in a major UK study of self-directed funding (Adams and Godwin 2008), people with disabilities listed the top three desired attributes of an employee as a friendly attitude (89 per cent of employers), a willingness to work flexible hours (78 per cent) and adapting to the specific needs of the person with a disability (77 per cent). In contrast, having an employee skilled in healthcare tasks or with work experience in social or health care was important to less than 30 per cent of people with disabilities. My Place found similar patterns in the use of self-directed funding in Western Australia, with people with disabilities preferring to hire people suited to their particular needs, often without formal qualifications (sub. 217, p. 6). On these grounds, there are strong arguments for employment arrangements to be an eligible part of self-directed funding. The Youth Disability Advocacy Service said that it has heard from many young people who want to be able to do this:

> … so that they can exercise more control over their lives and have a stronger say on how their supports are delivered and who provides this support. Directly employing support workers will not be everybody's choice, but we believe that it is an important option. (sub. DR989, p. 1)

On the other hand, some people think that direct employment is not appropriate because of the vulnerability of people with disabilities and risks to workers. These concerns are considered in detail in appendices E and G and section 8.10, but the evidence suggests that these perceived risks do not usually eventuate, and can be addressed through appropriate oversights. That said, in some instances, such as where workers require some kinds of specialist knowledge, such as upper bowel care, tracheostomy support and formulation of behaviour management plans, choice should be limited to workers having some credentials in the relevant skill (Attendant Care Industry Association, sub. 268, p. 8; Disability Discrimination Legal Centre, trans., p. 757).

A bigger concern may be that the responsibilities and compliance burdens associated with employing someone are so big that it is not a realistic option for many people with disabilities. One participant in this inquiry noted:

> … if a family carer or the individual endeavours to personally manage their funding they will need a commitment equivalent to a lengthy part-time job to find, engage and supervise care and support, as well as be accountable for income and expenditure. (Lorna Carroll, sub. 106, p. 3)

The administrative and compliance obligations for employment of people under self-directed funding depend on the exact nature of the employment arrangement, which can be complex to determine (appendix F). In many instances, self-directed funding would involve no superannuation, tax withholding or OH&S obligations,

which may well suit some of the flexible arrangements people might adopt. Such arrangements would be likely to cover arrangements in which:

- someone gets a neighbour to drive them to a gym class sometimes and pays them for doing so

- an adolescent helps babysit a child with a disability and gets $15 an hour

- a neighbour helps mow the lawn or clean the house most weeks and gets paid $20 each time

- a support worker provides an average of 10 hours of care a week in the home of the person with a disability, but with the amount of work and the times when it takes place varying with the needs of the person with a disability.

However, the full employer responsibilities would usually apply where people and families receive large funding packages and employ support workers for regular and substantial lengths of time. In those cases, people would either have to learn how to do this themselves (largely a fixed cost that may be low relative to the long-run benefits) or could contract a third party, such as a DSO, to undertake the tasks for them. Either way, it is likely that people with disabilities and their carers would need help in employing support workers, at least at the start of any employment arrangement. Section 8.12 discusses the supports people may need to self-direct.

An additional question is the best approach for vetting employment arrangements to ensure they meet the various statutory obligations. There are grounds for a two-tiered arrangement, in which the person with a disability would provide the relevant documentation to the NDIA for substantive employment arrangements in large employment packages, but with no or few reporting requirements for other forms of employment. This would be more akin to the situation outside disability, where small, sporadic and informal domestic arrangements like paying for a babysitter are not burdened with compliance or reporting requirements.

Employment of family members raises special issues of risk and benefits.

8.11 Paying relatives for care

Payment of family members has been a controversial element of self-directed funding, with concerns about abuse and unintended impacts on caregivers, people with disabilities and government budgets. In principle, these concerns are sound and some anecdotal cases back them up. There was a multitude of views about this matter by participants in the inquiry (box 8.2).

> **Box 8.2   Views from participants about paying family members**
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> Some participants expressed significant misgivings:
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> > [The Physical Disability Council of NSW] does not agree that the employment of close family members should be encouraged as this goes against the intent of accessing outside assistance, and may exacerbate family stresses. And as a consequence [the Council] has some general concerns about [the Commission's recommendation in this area], but more particularly with the risk of creating unrealistic dependencies between the recipient and family members, and not having plans that cater for the future. (sub. DR832, pp. 13–14)
>
> Nevertheless, most participants favoured some capacity for paying family members. However, their perspectives on the design and scope of the arrangements varied considerably.
>
> > The Autism Association of Western Australia believes that family members should be eligible to be employed as paid carers in some clearly defined circumstances. In particular, this should be considered as the preferred option where a sibling or relative takes on the long term care of an adult who would otherwise require out-of-home full time care in a congregate care facility; and where this arrangement is the choice of the person (or their advocate, where they are unable to represent themselves). … For many individuals, if given the choice between their home and congregate care, the person will choose their own home. It would be to great disadvantage of people with disabilities to rule this choice out of bounds because of some paradigm concerns. (Autism Association of Western Australia, sub. DR795, p. 4)
>
> One participant proposed its immediate implementation, with no trial (name withheld, sub. DR627, p. 6). The Association for Children with a Disability agreed with a trial, but subject to appropriate training (DR1022, p. 9).
>
> The Multicultural Disability Advocacy Association of NSW (sub. DR917, pp. 20–23) argued for a trial of paying family members for people from a non-English speaking background, noting the both the need for checks and balances, but also the implications of a 2010 New Zealand High Court case that established that withholding such payments could be discriminatory.
>
> Concerns about discrimination in certain contexts were also raised by the Australian Federation of Disability Organisations (DR982, p. 50) and the Gippsland Carers Association (sub. DR718, p. 5).
>
> Many agreed with a trial, rather than immediate implementation, but without the Commission's proposed reduction in the entitlement (Community Lifestyle Accommodation sub. DR880, p. 4; Baptistcare, sub. DR852, p. 39; Disability Advocacy Network Australia, sub. DR1010, p. 19; Perth Home Care Services, sub. DR906, p. 16; and Anglicare, sub. DR799, pp. 15–16).
>
> Others simply agreed with the recommendation (such as the Council of Regional Disability Services, Western Australia, sub. DR749, p. 4; and the Mental Illness Fellowship of Australia, sub. DR865, p. 2).

The international evidence generally finds that payment of family members is beneficial (appendix G). However, a study of Transport Accident Commission clients paying family members for attendant care (not self-directed funding as a whole) found that the overall costs of claimants paying family carers were greater (Kerr et al. 2009). Some countries have tightened the circumstances in which family members can be paid (appendix G).

Aside from the (relatively modest) Carer Payment and Carer Allowance, Australia has little experience in administering funding arrangements that permit payments to family carers.[21] This suggests a cautious approach (which was generally supported by participants in the inquiry).

- Carer Payment (and to a lesser extent, Carer Allowance) is already a payment to a family member (or others close to the person with a disability). These (or similar) payments should continue, though there are grounds for their inclusion in the overall self-directed funding package.

- The arguments about the risks from paying family carers relate to ongoing employment of resident family members. They apply less clearly to non-resident family carers and even less so to intermittent or one-off employment contracts. Accordingly, there are strong grounds for at least intermittent (rather than just recurrent) payments to non-resident family members, with less stringent accountability, for activities like respite and holiday care. For instance, one parent of a child with a disability, Sally Richards, was able to hire her sister for two weeks to care for her son and maintain his community participation while Sally went on holiday (trans., p. 400).

Moreover, the NDIS should conduct a trial of payments to resident and non-resident family members to test its risks, advantages, disadvantages and optimal design. The trial should use an appropriately rigorous scientific approach, drawing on the evaluations used in the United States 'Cash and Counseling' programs. The trial should include several safeguards:

- the part of any self-directed funding package relating to payments to family members should be discounted (for instance, by 20 per cent). This recognises that once self-directed funding allows family members to be paid, it creates stronger incentives to maximise these wages by understating the availability of natural supports or by overstating needs. A discount would reduce such cost-padding incentives and is a feature of the German system (appendix E). Some participants did not think that any discount should be applied (DisAbility Connections, sub. DR702; Perth Home Care Services sub. DR906; and

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[21] An historical exception is the Domiciliary Nursing Care Benefit, a precursor to Carer Allowance, but with little take-up despite its greater generosity (Howe 2007).

Anglicare sub. DR799). However, the Commission reiterates its cautious approach, noting that the evaluation of the trial could reassess the risks in this area in determining any appropriate future discount

- paid family care would initially be limited in duration (say 6 months), with continuation based on assessment of 'burn out' or psychological distress for carers, and the consequences of the arrangements for the independence of the person with a disability

- appropriate management of the risks. The Wisconsin *Guidelines for Paying Family Caregivers* 2003 provides a useful template for overseeing payment of family carers.[22] Among other things, the process included assessment of the competence of the carer, checks to identify any past abuse or neglect, training, education about the pitfalls of paid family care, a mandatory schedule of respite if caring is intense, and assessment of any economic stresses that may indicate the potential for financial abuse. The managed care team can decline authorisation on health and safety grounds if they are not satisfied that appropriate care would be provided.

RECOMMENDATION 8.4

There should be a capacity for people to recruit and employ their own support workers, subject to the proviso that these should not be close family members, other than when:

- *care is intermittent and provided by a non-resident family member*
- *exceptional circumstances are present and after approval by the NDIA*
- *the person is in the family employment trial spelt out in recommendation 8.5.*

RECOMMENDATION 8.5

There should be a trial of the employment of family members under self-directed funding to assess its risks, advantages, disadvantages and optimal design, with its wider adoption if the evaluation proves positive. The trial should use an appropriately rigorous scientific approach, drawing on the evaluations used in the United States 'Cash and Counseling' programs. For the trial:

- *the NDIA should determine that there are low risks from hiring relatives for each family in the trial*
- *the individual budget should be discounted by 20 per cent*
- *support should be initially limited in duration to six months, with continuation of any arrangement for a given family based on a short review*

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[22] http://www.dhs.wisconsin.gov/ltcare/Partners/PDFs/famcaregvrs.pdf

- *risks should be carefully managed to ensure appropriate use of funds and to safeguard people with disabilities and carers (recommendation 8.8).*

8.12 Take-up of self-directed funding and the need for support

The evidence from overseas is that relatively few people initially take up full control of their budgets when it is offered (Vick et al. 2006, p. 2; Carmel Laragy, sub. 84, p. 2), with particularly good evidence on this issue from the UK (appendix E). In England, the take-up of self-directed funding, while modest, is still increasing rapidly. Just over 10 per cent of all people receiving disability supports used self-directed funding, but nearly one in five of carers where they were the responsible person. These international experiences suggest that most people will not use self-directed funding initially, especially in those jurisdictions where arrangements for self-directed funding are in their infancy (such as Queensland). Nevertheless, take-up is likely to grow quickly, especially if people are supported in taking control over their budgets.

Some contributors to low take-up are not problematic. The evidence from abroad suggests that low take-up rates sometimes reflect satisfaction with delivery by specialised agencies. Self-directed funding is not an objective in its own right. If people make informed choices in favour of other arrangements then it should not be a policy goal to persuade them otherwise.

However, other reasons for low take-up are appropriately the target of policy. These include different levels of enthusiasm for self-directed funding among local authorities and service providers; reticence by frontline disability workers to promote it; lack of awareness that consumer-directed payments are an option; and perceived concerns about the risks to, and compliance costs for, users (Carr and Robbins 2009, pp. 6–7; Adams and Godwin 2008).

Inertia, uncertainty and lack of confidence may also affect people's willingness to take up self-directed funding. For example, one participant thought that a short-run cultural obstacle was the learned passivity of some people with disabilities, who were too long accustomed to command and control services:

> The disability service system has taught people with disability and their families to be dependent users of services, discouraging initiative and rewarding crisis. The system has often destroyed their dreams for their sons and daughters and until recently, most families have been immobilised in their ability to plan and think about the future because so much of the picture seemed dependent on the whims and changing policies of government. (Joyce Bellchambers, sub. 58, p. 11)

Compliance costs are also a significant issue because users have some responsibilities when they have greater choice and power. If consumers take *full* control of funding, they would be responsible for hiring any staff they want (section 8.10 and appendix F); ensuring that they have adequate public liability or other insurance; overseeing service provision; and accounting for spending.

The costs and uncertainty associated with these responsibilities act as a barrier to take-up of self-directed funding (as noted, for example, by Autism Spectrum Australia, sub. 443, p. 19 and Perth Home Care Services, sub. 520, p. 5). This is especially so when many people with disabilities and their carers are exhausted by their existing responsibilities. Moreover, people's willingness to invest in the upfront costs of self-directed funding (such as learning about obligations to employees) depends on some confidence that they will get funding in later years. This has not been the case in some existing schemes. Wesley Mission Victoria said:

> Through our current evaluation of the ISP Funded Facilitation program, we know that people feel uncertainty and anxiety about the continuity of funding — they worry that what they have in their current allocation may be taken away or diminished in the next allocation. (sub. 541, p. 12).

Moreover, a system with too many compliance costs may result in people still using self-directed funding, but not to its full extent. Adam Johnston, who participated in the NSW Attendant Care program (a trial of self-directed funding) said:

> My case should stand as an example of the inefficiencies in a system, whereby the recipient of funding declines to proceed with available, additional funding. This is because dealing with my own current personal circumstances and arrangements … is currently easier and less emotionally taxing, than engaging with the bureaucrats of the ACP. (sub. 55, p. 3)

A direct way of increasing people's willingness to use self-directed funding is to provide certainty about support entitlements through a transparent and rigorous assessment process (chapter 7) and to reduce compliance burdens where they do not undermine public accountability or the safety of people with disabilities or support workers. Reducing compliance burdens for people with disabilities using self-directed funding has the likely added advantage that it will lower the administrative costs of the NDIS. Bits of paper in one part of the system need to be read and processed in other parts, so cutting the bits cuts the costs.

A further way of facilitating self-directed funding is through effective support and training.

Effective support and training

The United Kingdom experience suggests that take-up can be improved through better support of people using self-directed funding, and training and commitment by front-line staff in government and other disability agencies (figure 8.2).[23] This was view more generally endorsed by Carmel Laragy (sub. 84) in this inquiry and by a range of other participants:

> We need more information, training and peer support groups to assist people to make choices and take more control. (Youth Disability Advocacy Service, sub. DR989, p. 1)

> Self directed funding options need to include development and implementation of appropriate support mechanisms for people with a psychosocial disability to ensure that they are able to effectively control decision making about their lives. (National Mental Health Consumer and Carer Forum, sub. DR960, p. 14)

> For self directed funding to be successful, it is imperative that increased information about how self directed funding could work and could be used be made available prior to and during the introduction of the proposed scheme. Many of the individuals we spoke with were suspicious of the proposal, concerned about fraudulent use and uncertain how this could be applied in their own lives. This reinforces the need for a well equipped information gateway as the one stop information source. (Blind Citizens Australia, sub. DR758, p. 16)

The Arkansas Department of Human Services, responsible for one of the three large experimental trials of self-directed funding in the United States, has argued similarly, observing that offering self-directed funding 'without the necessary counselling and fiscal services is a recipe for a disaster' (ADHS 2008). This was why the main US scheme for self-directed funding is structured as Cash *and* Counseling. Several participants in this inquiry have voiced similar views about the need for consumer supports to implement self-directed funding in an Australian context.[24] One noted:

> A lot of people with disabilities and families are coming from a background of being disadvantaged, poor, powerless, not used to actually making those decisions. So to expect that people might just jump into a system is, I think, a bit silly. There has to be some of those capacity-building things in place. (Samantha Jenkinson, trans., p. 982)

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[23] Steve Dowson (a UK-based social care consultant) argued that Direct Payments in the UK had low take-up because it required people to effectively 'opt out' of the disability system and organise their packages without much support (sub. DR1034). He saw the Commission's self-directed funding approach as adopting the same 'go it alone' approach, but the Commission proposes a model that would include support, and that would allow people to draw on the strengths of the existing disability system.

[24] Among others, these included Carer's NSW (sub. 244, p. 6); Samantha Jenkinson (trans., p. 982); Rhonda Held (trans., p. 409); Wesley Mission Victoria (sub. 541, pp. 11–12); and Maree Ireland (sub. 233, p. 4).

Figure 8.2   **How can take-up of self-directed funding be encouraged?**
Evidence from the UK experience
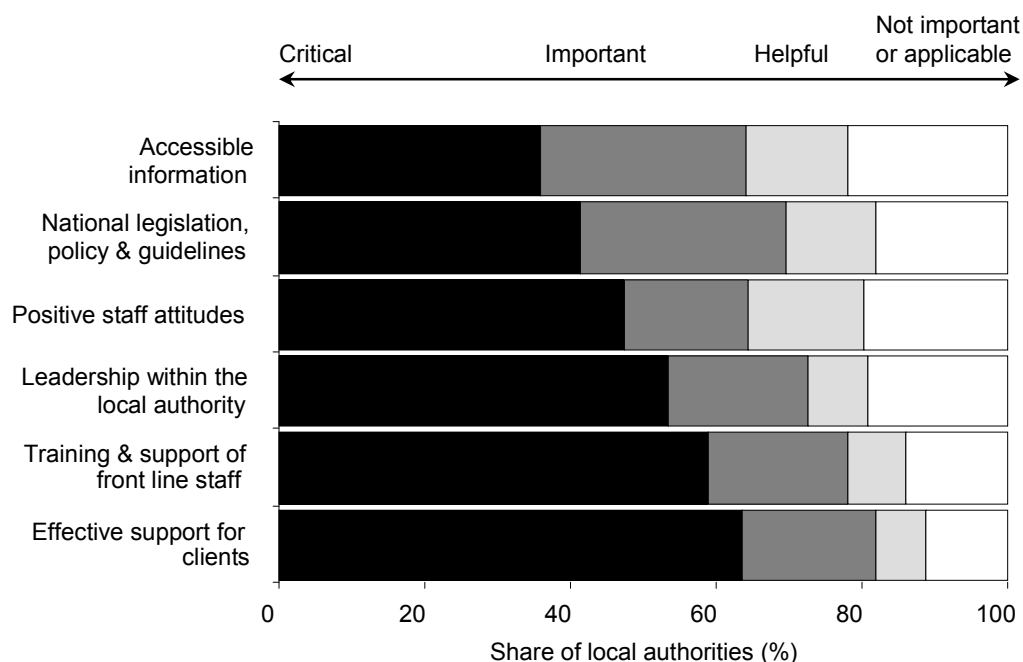
Data source: Davey et al. (2007, p. 100).

There are several critical elements of an effective support system.

One would be adequate support of people using self-directed funding — principally by disability support organisations or other parties contracted to people with disabilities. Where people wanted assistance, it would include helping them to draw up a funding proposal and addressing the main compliance burdens of self-directed funding. The overseas evidence shows that many people would like to self-direct the key elements of their budget — such as hiring their own support workers — but prefer to pay a fee for intermediaries to undertake the 'red tape' and administrative aspects of hiring workers or managing and accounting for the funds. This already occurs in some jurisdictions, for example, Allowance Incorporated in the ACT and New South Wales (sub. 130, p. 1) and Western Australia generally. However, it should be an optional feature of the NDIS since some people may not need such guidance. One participant in this inquiry already despaired of being 'smothered' by coordinators (Adam Johnston, sub. 55, p. 7).

A second element would be training of local area coordinators and other front-line government agencies in implementing self-directed funding — why it exists, how a plan is drawn up, knowledge about the supports for people with disabilities, and the risks. Drawing on their evaluation of the ISP Funded Facilitation program in Victoria, Wesley Mission Victoria argued that staff needed to be supported in implementing self-directed funding (sub. 541, p. 12).

However, regardless of whether people use a DSO to provide support during and after the creation of a funding proposal, there are grounds for the NDIA local area coordinators to play a role. They would provide 'light touch' guidance and fulfil a safeguarding role, recognising that public funding is at stake and that some people using self-directed funding are vulnerable.

Self-directed funding in a national disability scheme can draw — with adaptation — on extensive existing practical information and guidelines on how to provide support to all the agents affected by this funding model. Several Australian jurisdictions already applying self-directed funding have released practical guides, including a detailed manual from Perth Home Care Services (2010) and a handbook from the Victorian Department of Human Services (DHS Victoria 2009a). The Tasmanian Government emphasised the need to build on existing approaches in Australia:

> Transition to an NDIS would need to recognise the past and existing efforts of state governments in developing innovative approaches to services and funding. This includes self directed services and more autonomy about service choices and funding arrangements. There are examples of good practice currently operating across state disability service systems that could be used to build on, and enhance, future arrangements for disability services. (sub. 1032, p. 14)

In the United Kingdom, the Social Care Institute for Excellence and In Control has produced many different guides to personalisation geared to certain purchases, clients and service providers. The handbook produced in the United States by Crisp et al. (2010) represents an elaborate and pragmatic guide to setting up the appropriate types of supports, and in providing guidance for users, local area coordintaors and service providers.

There are strong grounds to draw from these existing guides in developing support arrangements for users (and any hosting agencies) and in informing them about how self-directed funding works. Equally, there is already a free, open source, software tool (the CDM or Consumer Direction Module from the US National Resource Center for Participant-directed Services) for administering self-directed funding,[25] which could be adapted for Australian use (and which could be made freely available on the NDIA's website).

There should be a continued evidence-based approach to reducing the barriers to the use of self-directed funding, as new research shows how different approaches may be effective. As an illustration, a small-scale pilot of self-directed funding in the UK

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[25] Among other things, the CDM allows the overseeing agency to keep track of participants in a self-directed funding arrangement (brokers/counsellors, fiscal agents, employees, medical providers, representatives/guardians); maintain case notes; generate spending plans; track participant expenditures; coordinate approvals, denials and appeals; and communicate with all participants.

among young people found that practice budgets helped people understand how to set budgets, and that shared experiences among families about self-directed funding plans helped people to realise what was possible and how to set up practical plans (Crosby and Fulton 2007, p. 35). More broadly, it would be critical for a disability scheme to systematically monitor take-up, determine why there may be variations by area, by the severity or nature of the disability, or by other traits of recipients, and then adjust the scheme design and administration accordingly.

The NDIS will subsidise the use of DSOs (at least initially) whose role, among other things, would be to help people create innovative plans (if they wish this).

RECOMMENDATION 8.6

The NDIA should:

- *inform people with disabilities and/or people who act on their behalf of the various options for self-directed funding*
- *encourage the formation of disability support organisations to support people in the practical use of self-directed funding*
- *provide support for people using self-directed funding, including:*

  - *easy-to-understand guidance about the practical use of self-directed funding*

  - *the provision of examples of innovative arrangements*

  - *standard simple-to-follow forms for funding proposals, hiring employees and acquittal of funds*

  - *making people aware of their capacity to contract out the administrative tasks associated with self-directed funding to disability support organisations*

- *provide training to local area coordinators, service providers and NDIA front-line staff about self-directed funding.*

8.13   What about the general risks of self-directed funding?

Quite apart from the special risks (and benefits) associated with employment of family members discussed in appendix E, there are many other perceived risks associated with self-directed funding. Since self-directed funding is public money, there must be at least some mechanism to ensure that people spend the money as intended and that there are no other significant risks to people's safety and

wellbeing. Leaving a system without adequate protections against these risks would undermine the integrity of a scheme and threaten its viability and pubic support. As National Disability Services noted: 'effort needs to be put into avoiding stories of funding mismanagement without being overly prescriptive' (sub. DR836, p. 17).

There are many possible sources of general risk from self-directed funding:

- people with disabilities or their families might deliberately or accidentally misuse the funds through theft, or by spending on goods and services unrelated to disability needs, an issue raised by several participants (for example, the Centre for Cerebral Palsy, sub. 290, p. 5; Anglicare, sub. DR799, p. 14). Some people with disabilities have to address addictions and substance abuse problems that may make it difficult for them to handle money directly (though other parties could act on their behalf). For example, there is empirical evidence that 68 per cent of people who experience traumatic brain injury have a history of substance abuse (Headwest Brain Injury Association of Western Australia, sub. 448, p. 6). And, while a small share of people with a disability have come into contact with the justice system, nevertheless some have (Holland et al. 2007; Office of the Public Advocate Queensland 2005; DIG 2009a, p. 110). For these cases, self-directed funding would require careful oversight

- people might exaggerate disability in order to acquire funds. This risk is reduced if funding is limited to disability-related supports identified in people's funding proposals and if this process is able to detect exaggeration and bracket creep. (Most people do not want unnecessary support, since it is often intrusive, although this would not hold for paid family carers.) Moreover, the strong process of assessment and governance arrangements of the NDIS also aims to control inflated claims (chapters 7 and 9). In particular, these risks could be moderated through systematic data analysis. Under the NDIS, people will be asked about their previous package and the supports they require, as well as many other aspects of their circumstances (such as condition, duration of disability, extent of functional limitations, family circumstances and so on). It would then be possible to develop a model that predicted people's budgets using this information. If a person requesting self-directed funding was to obtain a budget that, given their characteristics, lay well outside the range predicted by the model, that would require closer scrutiny of their assessed budget

- people with disabilities and their families are sometimes vulnerable — tired, isolated, poor, and in some cases, unable to complain due to their disability. Overall, rates of abuse of people with disabilities are multiples of those for people without disability (Hayes 2009), indicating their general vulnerability. Data from examination of referrals to the United Kingdom's Protection of Vulnerable Adults list shows that people with a learning disability were more

likely to be abused physically or sexually than those with a physical disability (Stevens et al. 2008, p. 45)

- on the other side of the coin, paid carers can also be vulnerable without the support of an agency, and may be exploited by people with disabilities

- some functions of self-directed funding — like hiring one's own carers — involves relatively complex administrative and compliance tasks that if not performed adequately, may leave the employer or the employee at risk (for example, inadequate workers' compensation arrangements) or, if funds are poorly managed, under-payment of providers (Glendinning et al. 2008, p. 205) or under-provision of important services

- people may be left with inadequate or no services if self-directed funding arrangements break down (a carer becomes unreliable or leaves), suggesting a need for backup 'last resort' services, which have to be funded.

As an illustration of their strength, the *perception* of such problems by officials and others — particularly of misuse of funding — held back the passage of legislation that would have allowed direct payments in the United Kingdom for a long period (Pearson et al. 2005). It is still a barrier to the practical expansion of self-directed funding in that country. In 2008, survey evidence suggested that more than one third of the social care workforce in the UK believed that the personalisation agenda was the wrong direction for adult social care (Mickel 2009b). More than 90 per cent of local authority social workers were concerned that self-directed funding would make people with disabilities more vulnerable. Similarly, officials in several trials of self-directed funding in the United States were initially anxious that beneficiaries might use the cash benefits to buy alcohol, cigarettes, drugs or gambling products, or that support workers hired under self-directed funding would neglect, exploit or abuse the person with a disability (Doty et al. 2007, p. 383; O'Keefe 2009).

These latter concerns partly reflect the fact that support workers hired under self-directed funding may be subject to little third-party scrutiny, potentially exposing people with disabilities to greater risks. In the United Kingdom, some people using direct payments have not been required to request Criminal Records Bureau and Protection of Vulnerable Adults checks for people they employ, while this is mandatory for formally employed staff (Stevens et al. 2009). In contrast, specialised services have, *in theory*, a greater capacity for delivering quality because they have accreditation processes, monitoring of staff and a reputation to maintain, which may not be present in transactions between a household and a paid carer in the informal, largely unregulated market. But 'in theory' and 'in practice' outcomes may diverge.

Perceptions aside, what is the evidence?

The evidence about the extent of risks is often anecdotal. In the UK study of individual budgets, there were anecdotes of financial abuse of direct payments (Glendinning et al. 2008, pp. 173–4). The study reported that:

> … examples were cited of financial abuse, financial irregularities, concerns about the criminal record of the carer (fraud), deception regarding levels of need, allegations of rape and personal assistants ignoring court injunctions preventing family visits. (p. 175)

For example, one team manager of disability services indicated three or four cases of financial abuse by attendant carers within a four-month period.

However, while anecdotes indicate that abuse occurs, the systematic evidence suggests that the levels of abuse are low. If anything, the evidence suggests that while people with disabilities are vulnerable, if anything, they are less vulnerable under consumer-directed care arrangements than through those organised by specialised services.

Carmel Laragy (sub. 84, p. 5) noted that in the (Australian) individual funding models she had studied, there 'was always a high degree of review and no instances of abuse reported'. A Queensland service provider reiterated this point, indicating that of the 165 families getting access to cash payments, there was just one instance where a family did not meet the accountability requirements (Ward, Mamre Association, trans., p. 402). Perth Home Care Services observed that in Western Australia the evidence suggested fewer risks with self-directed funding than traditional agency approaches (sub. 520, p. 7).

Evidence from annual audits of direct payments over a three year period in one council area in the United Kingdom identified one minor case of misuse of funds (relating to taxi receipts). The audit costs to detect this instance were around £165 000 (Poll et al. 2006, p. 85). The third evaluation of self-directed funding in the United Kingdom found a significant improvement in the capacity of professionals to manage risks (around 40 per cent of professionals sampled), while less than 5 per cent considered that risks had worsened (Tyson et al. 2010, p. 143).

A more detailed empirical examination of rates and types of abuse experienced by people with disabilities under self-directed and traditional funding arrangements in the United Kingdom found that the rates of any form of financial abuse was 5 per cent under self-directed funding and 9 per cent under traditional care models. The comparable rates of psychological, physical and sexual abuse for the two different forms were 6 and 13 per cent, 1 and 3 per cent, and 0 and 2 per cent (with

the first number of each set being for self-directed funding) (Adams and Godwin 2008, p. 34).[26]

Other evidence more generally points to the considerable problems of abuse in specialised institutions compared with informal settings, notwithstanding the quality controls that governments put in place in the former.[27] For example, in the United Kingdom, a relatively significant number of complaints of abuse (for the elderly disabled) relate to nursing homes and hospitals, and there are similar concerns about abuse in specialised residences for those with an intellectual disability (Poll et al. 2006, pp. 94–95).

In the United States, there was likewise little evidence of any systematic exploitation, neglect or fraud associated with self-directed funding, even though the target populations tended to have lower than average incomes. There were very few instances of reported fraud or abuse (of consumers or workers) in the large US *Cash and Counseling* trials of self-directed funding (Schore et al. 2007, pp. 461–2). Counsellors periodically contacted consumers and their representatives in person and by telephone, and both counsellors and bookkeepers reviewed consumer spending. Only two of 37 New Jersey counsellors reported any incidents and they related to only two people (one of self-neglect and the other for exploitation). Counsellors considered that any agents chosen by consumers acted in the consumers' best interest in all but a few cases. In this trial, people had the right to enrol in the program without any screening for their suitability, which would tend to increase the risks of abuse. For that reason, the program director in each state had the power to revoke the right to use self-directed funding in the event of abuse or exploitation. Very few consumers had this right revoked (Phillips and Schneider 2007, p. 404).

The trials also revealed that informal carers had far fewer concerns about the safety of the person with a disability where that person was enrolled in self-directed funding (compared with outcomes for a control group without access to self-directed funding). The share of caregivers worrying that:

- a care recipient's safety was at risk 'quite a lot' fell from by between 19 and 14 percentage points (depending on the state)

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[26] A flaw in these statistics is that the questions related to 'ever' experiencing abuse. One reason people may report a higher abuse rate for traditional services is that they had used such services over a longer period than self-directed funding. Nevertheless, survey evidence that asks people to rate their relative vulnerability in the two systems overcomes this bias. That evidence shows that 77 per cent of people with disabilities felt they were *less* vulnerable under self-directed funding than under previous traditional support models (Adams and Godwin 2008, p. 39).

[27] A point made by the Pave the Way Mamre Association (sub. 528, pp. 17–18) and name withheld (sub. 74, p. 11).

- there was a significant risk that someone will take the care recipient's money or other belongings fell by between 5.5 and 7 percentage points

- a care recipient would face a significant risk of inadequate help fell by between 13 and 18 percentage points (Foster et al. 2005, p. 29).

Cash and Counseling had no adverse (and sometimes positive) effects on objective, care-related outcomes for consumers, such as injuries incurred while receiving care. This is again consistent with higher, or no lower, levels of health and wellbeing outcomes for people with disabilities (Carlson et al. 2007 and appendix E). For example, the incidence of bedsores, urinary tract infections and falls were lower among those using self-directed funding than those in the control group.

A further large US study of the risks associated with consumer-directed care compared with traditional agency services (based on the California In-Home Supportive Services Program) found that self-directed funding was associated with a lower or equal level of risk for people than agency-based care (Matthias and Benjamin 2003).

Risks for support workers

There can also be risks for support workers, such as low pay, failure to meet statutory employment standards and abuse. However, there is little consistent evidence of low wages, but reasonably reliable evidence that wellbeing of employees is typically better, or at least no worse (appendix E). For that reason, there are no grounds for blocking people with disabilities from employing support workers directly or of excessively regulating their employment. However, there are grounds for some protections (discussed below).

What do the risks mean for policy?

The trade-off between the risks of self-directed funding and the benefits it brings suggests the need for prudent oversight.[28] People with disabilities also acknowledge the need for safeguards from misuse and abuse of self-directed funding.[29] Risk mitigation should be achieved by:

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[28] Some participants stressed the need for a balance between risks and benefits, for example, the Councils of Social Service in Australia (sub. 369, p. 7); and Scope (sub. 432, p 19).

[29] For example, name withheld (sub. 482, p. 5) and consultations by the Disability Advocacy and Complaints Service of South Australia with up to 50 people with disabilities (sub. 267, p. 11 and attachment).

- assessing the capacity of people to handle their funds before agreeing to direct payments. Scope (sub. 432, p. 19) recommended that the stability of a person's social situation and health needs should be a condition for eligibility to self-directed funding. Brightwater (sub. DR752) observed that people with cognitive or psychosocial disabilities may not be able to make well-informed decisions by themselves (though that would not rule out assisted decision-making). In the United Kingdom, there is a legislative requirement that people be 'willing and able' to manage direct payments (Frontier Economics 2006, p. 55). Some local authorities have explicitly assessed the risks for individuals using Risk Enablement Panels, and these have generally received strong support by care coordinators (Glendinning et al. 2008, p. 177). If a person is perceived as high risk, then management of the funding could be the responsibility of an intermediary, but the person could still determine the decisions about the allocation of funds in accordance with their approved personal plans. DSOs could play such a role in Australia. Local area coordinators would also assess whether a person was coping with self-directed funding[30]

- providing information, training and support to people using self-directed funding where it is needed, and clear guidance on appropriate usage of funds, including an understanding that penalties may be applied for misuse (as suggested by Melissa Ryan, sub. 251, p. 9)

- providing avenues for people using self-directed funding to complain to the NDIA about any inappropriate behaviour by providers and to have these investigated (chapter 9 describes the complaint mechanisms)

- ensuring reasonable accountability for funding, with acquittal periods determined on a risk basis, with less frequent acquittals by those who demonstrate proficiency in managing their funds and initially greater supervision for those inexperienced with self-directed funding. People would have to account for most of their expenditure with proof of purchase, but as discussed in section 8.7, a small amount of the individual budget should not require acquittal

- ensuring that people with a disability and their carers have easy and cheap access to police checks of employees who provide personal services. Such vetting

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[30] The Australian Federation of Disability Organisations (sub. DR982) argued that it would violate the UN Convention of the Rights of Persons with Disabilities were funding only to be available to people who could meet the risk criteria. However, this fails to recognise that poor risk management could easily harm the person with a disability, contrary to the goals of the UN Convention to protect their interests.

would be required for would-be employees working alone with vulnerable people,[31] such as children or adults with intellectual disabilities (chapter 15)

- improving community engagement with people with disabilities (chapter 4). The Disability Advocacy Network Australia pointed out that 'other measures that are known protectors of people with disabilities from abuse and neglect involve ensuring that the person is well connected to a range of people who care about their well-being including people who are willing and capable of advocating in their interest should the need arise' (sub. DR1010, part B, p. 22).

Just as self-directed funding (or any support arrangement) poses risks for people with disabilities, they also pose risks for employees. That suggests provision of information to, and support for, employers to help them meet their obligations to employees, particularly in relation to worker's compensation (where that applies). It also suggests that there should be measures for employees that allow for mediation, lodgement of complaints and advice. These could address employee/employer disputes, inappropriate behaviour by employers, and issues relating to concerns about unreasonable expectations. For example, the latter might be requests to an untrained attendant carer for clinical services, where an issue of quality or safety arose (Attendant Care Industry Association, sub. 268, p. 8). Finally, one of the considerations in removing a person's right for self-directed funding would be whether the person had handled any employer responsibilities inappropriately.

RECOMMENDATION 8.7

Before offering self-directed funding to a person, the NDIA should:

- ***meet with the person with a disability (and if appropriate, others involved in their care and support), and take account of their experience and skill sets***

- ***use that and any information provided during the assessment phase to determine whether the person and/or their support network are likely to be able to:***

  – ***make reasonably informed choices of services***

  – ***manage the administrative and financial aspects of funding if they wish to oversee these aspects by themselves.***

RECOMMENDATION 8.8

In offering self-directed funding, the NDIA should ensure that:

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[31] Such employees would need to be distinguished from one-off employees. That could be determined by any contract period or where the person was covered by the full employment arrangements described in section 8.10.

- *it reduces the risks of neglect or mistreatment of people with a disability by support workers or other service providers hired by users in the informal sector, by:*
  - *ensuring easy and cheap access to police checks*
  - *giving users the capacity to complain to the NDIA about inappropriate behaviour of providers, and to have these investigated*
  - *monitoring by local area coordinators*
- *it reduces the risks to support workers employed under self-directed funding by requiring that they are covered by workers' compensation arrangements and have an avenue for lodging complaints*
- *it adopts a risk-management approach for receipting and other accountability requirements, which:*
  - *requires less accountability for people with low risks or who have demonstrated a capacity to manage their funds well*
  - *takes into account the compliance costs of excessive accountability measures*
  - *allows a small component of the individual budget to be free of any receipting requirements*
- *there is adequate data disclosure, subject to measures to limit unnecessary 'red tape burden'.*

8.14   Implementing individualised funding

The grounds for greater self-directed funding are strong. However, national implementation poses challenges. Western Australia already has a well-developed system and Victoria a rapidly developing one. In other jurisdictions, self-directed funding is still in its infancy. The international experience suggests that it takes time to adapt processes for consumer-directed payments and to build up the capabilities in government, service providers and service users for their adoption (Glasby and Littlechild 2009; University of Minnesota 2009). For example, the United Kingdom Government initiated consumer-directed payments through the Independent Living Fund in the late 1980s and introduced direct payments in early 1997. There was a myriad of changes over the subsequent decade to encourage the adoption of consumer-directed payments and to allow greater flexibility for people. Accordingly, there is a 20 year history of evolving arrangements in the United

Kingdom, and arrangements are still in flux. It was notable that in the pilot programs for individual budgets in the United Kingdom, the evaluators noted:

> The costs and complexities of implementing [individual budgets] alongside traditional resource allocation systems and service provision were major challenges in all sites. Even sites that intended using the [individual budget] pilot to transform the whole of their adult social care provision recognised the need to operate parallel systems for significant transitional periods. Particular concern was expressed about the capacity to offer [individual budgets] while resources were still tied up in relatively long-term block contracts, especially in smaller authorities where overheads were proportionately greater. (Glendinning et al. 2008, p. 23)

Different challenges emerged in the United Kingdom with the Independent Living Fund — the UK's first cash-for-care scheme (which continues to exist alongside new self-directed funding arrangements like Individual Budgets and Direct Payments). While the Independent Living Fund has had beneficial impacts on people with disabilities (for example, Doyle 1995), a recent evaluation found that people did not understand how their cash amounts were calculated, the decision-making processes used in the scheme, or how they could challenge decisions (Henwood and Hudson 2007). These weaknesses reduced the benefits of self-directed funding — suggesting that the administrative processes used in any self-directed funding arrangement should be transparent and carefully explained.

In the United States, the story is much the same, with the same perceived challenges. As one study pointed out:

> … individual budgeting requires a degree of fiscal flexibility, accountability and data management capacity that is unprecedented in developmental disabilities services and present significant challenges to states making the changes from traditional methods of funding and service design. (Moseley et al. 2005, p. 264)

Australia can benefit from the experiences of Western Australia, Victoria, the United Kingdom and other jurisdictions in implementing consumer-directed payments to avoid the same drawn out process.

Nevertheless, it is important not to oversell the capacity for consumer-directed payments to revolutionise care arrangements in the medium run. It is unlikely that take-up will be very high initially:

- people with disabilities and their families will need to become aware that they have scope to be in control of their funding and to understand how the system works. Against an historical background of lack of choice and control, substantial capacity building and support will be required for many people with disabilities and their families. But regardless, many families will never want to undertake these tasks, given their existing workloads, and may well want to exercise choice through the 'choice of provider' model described in section 8.1

- the NDIA overseeing the system would also need to develop accounting systems and other approaches to manage the new system, as would providers. The NDIA would also need to create practical guidance for people to use a system that pushes more administrative costs onto them (for instance, a guide on hiring and firing employees and how to deal with any occupational and health risks). In the early experiences of consumer-directed payments in the United Kingdom, there were cases where recipients faced thousands of pounds of debt because they had unwittingly failed to make the appropriate national insurance contributions for carers they employed (Glasby and Littlechild 2009, p. 16). In a major survey of local authorities in England, the single most important factor aiding direct payments was an effective direct payments support scheme (Davey et al. 2007, p. 100)

- service providers will have to adapt to a system that reduces their certainty of funding (chapter 10). Intermediaries that help people manage consumer-directed payments will need to develop

- service coordinators and local area coordinators will need to take different approaches to decision-making about services for their clients. The evidence from the United Kingdom is that positive staff attitudes and training can encourage take-up, which will take some time to realise (Davey et al. 2007, p. 97). A survey of local authorities in the United Kingdom found that staff training was rated as the second most important factor in implementing direct payments successfully (Vick et al. 2006)

- it will be important to ensure that local area coordinators and disability support organisations provide consistent advice about people's entitlements and obligations under self-directed funding. Significant inconsistencies emerged in the United Kingdom as they implemented self-directed funding. The British Government developed overarching principles and national legislation, and local authorities implemented it in the field, but often at odds with the national rules. Nearly one in five local government policies indicated that people were unable to employ a close relative living in another household when national policy allowed this, and nearly one in ten local government policies stipulated a maximum amount of direct payments when national guidance stipulated no limit (Tobin and Vick 2004)

- the flexibility that underlies many of the benefits of self-directed funding means that people with disabilities will legitimately make purchases (like attending a football match) that the community may sometimes perceive as inappropriate. Accordingly, there will need to be some reassurance and education of the wider public about self-directed funding (a point made by the City of Playford DDA Community Reference group, sub. 308, p. 4)

- there should be certainty that direct payments to people made under self-directed funding are not treated as income for taxation and welfare purposes, since that would have the unintended impact of reducing the available funding and the incentives for uptake of self-directed funding (appendix F). The Commission recommends legislative change to avoid these problems as self-directed funding is rolled out across Australia. In addition, sometimes people may wish to augment direct payments with private funding, including early release of superannuation. There are reasonable restrictions on obtaining early release, but unnecessarily severe tax treatment of the released funds, which the Australian Government should change (a matter discussed in more detail in appendix F).

Accordingly, the 'gradual, step-by-step' approach recommended by the Centre for Cerebral Palsy (sub. 290, p. 5) is appropriate. However, the speed of adoption of self-directed funding should still be as fast as possible, within the constraints of the development of supports, ensuring administrative efficiency, and safeguarding measures. The development of an evidence base from monitoring and evaluation to inform the ultimate form of self-directed funding will be an important component of its long-run effective implementation — a point emphasised by People with Disability Australia (sub. 524, pp. 30–1).

RECOMMENDATION 8.9

The NDIA should undertake ongoing monitoring of self-directed funding arrangements, with a quarterly report to the board of the NDIA on issues arising from self-directed funding. There should be a full evaluation three years after their commencement to assess any desired changes in their design.

RECOMMENDATION 8.10

The Australian Government should amend the Income Tax Assessment Act 1936 and the Social Security Act 1991 so that the following are not treated as income for assessment of taxes or eligibility for income support or other welfare benefits:

- *self-directed funding paid by the NDIA and, in the interim, by state and territory governments*
- *early compassionate release of eligible superannuation amounts for disability expenditures which meet the criteria set down by the Superannuation Industry (Supervision) Act 1993.*

Complementary initiatives

The benefits of self-directed funding can be improved substantially if there are other, complementary policy initiatives to improve the disability system. These are:

- a reasonable number of competing service providers in the local area (or the prospect of their entry), so there is a genuine threat of moving to another supplier (chapter 10)

- information that allows the purchaser to assess the relative quality of competing providers (chapter 10). As one submission noted: 'When you don't know who to turn to or what questions to ask, living across the road from a brilliant service provider would not help' (Kate Evans and Frank Beard, sub. 278, p. 4). A person could also contract with a DSO to help find the best services when assembling a package of supports

- adequate funding so that people receive the budgets determined by their individual assessments. Were funding to be inadequate, a person would be reluctant to move to another supplier for fear of going to the back of a waiting list, and the service variety and infrastructure available under self-directed funding may not meet people's reasonable needs. Several participants made this point (for example, National Foundation for Australian Women, sub. 248, p. 11; Uniting Care Australia, sub. 291, p. 14). Moreover, a highly constrained budget would often mean people could only select the absolute necessities of support (an attendant carer, but no funding for community interaction), and could frustrate innovative aspects of self-directed funding.

9   Governance of the NDIS

Key points

- Measures to underpin good governance will be critical to the ability of the NDIS to provide services to people with disabilities over the long term.
    - a corporate model of governance is needed, with an independent commercial board and independence from day-to-day government control
    - the administrative arrangements for dealings with the relevant minister should be specified in legislation, be on an arm's length basis and clearly defined.

- The board should be supported by an independent advisory council comprising people with disabilities, carers, suppliers of equipment and services, and state and territory service providers.

- An independent agency, the National Disability Insurance Agency (NDIA), would administer the scheme.
    - key functions of the NDIA would be to assess needs, manage claims, support people with disabilities, determine efficient prices, authorise funding proposals and coordinate services
    - NDIA local area coordinators would be the primary point of contact for people with disabilities and their families, and would also play a key role in the administration of the scheme.

- A *national* model for the NDIS is preferred. There would be considerable risks that a *federated* approach to an NDIS would revert to the current dysfunctional, fragmented and unfair system.

- Future development of the disability support sector would be heavily influenced by greater use of individual support packages and self-directed funding (chapter 8):
    - disability support organisations are expected to play a role in providing personal planning services, assembling packages of supports and undertaking administrative tasks.

- Dispute mechanisms must be designed to give people confidence in the integrity of the process but without unintended effects on the viability of the NDIS (for example, through an unanticipated widening of the scope of the scheme).

- Other critical governance issues discussed elsewhere in this report include the central role of data collection and use to manage efficiency and costs and promote good outcomes (chapter 12), measures to support self-directed funding (chapter 8) and to ensure quality of services (chapter 10).

9.1   Introduction

Much of this report is about the best design of a national disability insurance scheme — who it is for, the services it would provide, and the power people would have. Governments would play a very different role in the NDIS than they do now. Supports would be determined on an individual basis, and people would either manage their own funds, with appropriate safeguards, or choose a package of support services from suppliers of their choice, or through intermediaries (disability support organisations — DSOs).

In that sense, the NDIS would be a much more devolved model than the current centralised approach. Indeed, from day to day, a person with a disability and their family would mostly have direct contact with their preferred support providers or a DSO, and much of the complex business of managing the NDIS would (and should) be invisible to them (figure 9.1).

This model is akin to some other insurance products — like Medicare. In that area of insurance, the insurer performs many tasks — negotiating with suppliers, developing billing systems and monitoring fraud — but customers mostly only deal with general practitioners, specialists, hospitals and other service providers funded by the insurer. The wider aspects of the NDIS would be more visible to people than is the case with Medicare because people would be periodically re-assessed, their plans and budgets re-set, they may be given access to new intervention programs, and they would have contacts with their NDIA local area coordinator (LAC), who would be their primary point of contact with the scheme. However, for most people, those events will be infrequent.

9.2   Defining the scope of governance in the NDIS

'Governance' is how an agency or system manages its functions. In the case of the agency overseeing the scheme (hereafter referred to as the National Disability Insurance Agency or NDIA), it includes the processes and internal culture that gives different people power in the organisation; monitors the utilisation of support services and outcomes; creates incentives for its performance; provides information for good decisions and verification of performance; maintains probity and accountability; and manages its finances.

It also includes how an organisation chooses to structure itself: what it chooses to do itself and what it might contract to other parties, and the basis for these boundaries. At the scheme level, it also includes how government might limit the NDIA's choices about what it does. For instance, that might cover whether

government would allow the NDIA to exclude competition in some of its functions or whether government would permit the NDIA to undertake some functions at all.

Figure 9.1   **From a consumer's perspective, supports are mainly provided from outside the National Disability Insurance Agency**
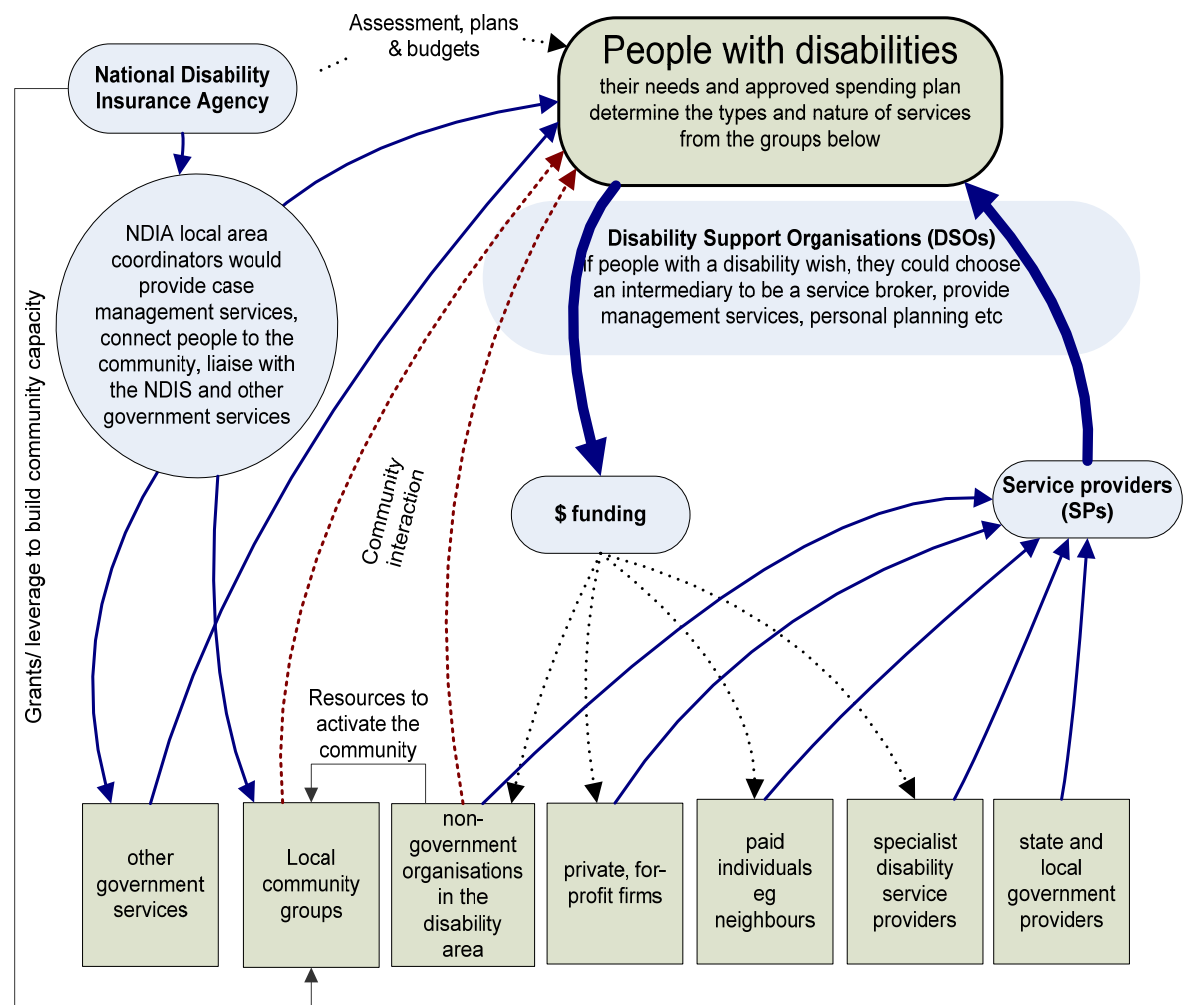
This chapter examines governance from several perspectives, including:

- the roles of the NDIA and of other organisations and parties in the NDIS

- the statutes and guidelines the NDIA would have to meet

- the links between the NDIA and people with disabilities, carers, suppliers and other parts of government, including the relationship between the NDIA as an operational entity and departments that advise governments on policies for the NDIS (or for disability more broadly)

- the processes and structures that would hold the NDIA accountable to the community: the relevant minister, a 'regulator', and appeal mechanisms, external auditing, and open reporting generally

- the processes and structures that would allow the NDIA to operate as an independent manager, free of covert or explicit interference by interest groups (including politicians) that would be inconsistent with its central charter

- incentives for the NDIA to run an efficient and effective scheme, and to manage long-term risks to financial sustainability. For example, these could include the capacity of the board to hire and fire the CEO, a clear culture for high performance; public disclosure of good and bad performance; and the threat of competition from other parties

- any management features and capabilities needed to realise those efficiency and effectiveness goals (such as reliable measures of performance and outcomes for people with disability, financial management systems, data collection and analysis, internal expertise, research functions)

- how it manages funds (delegated or otherwise)

- provide dispute resolution and complaint processes covering the NDIA and suppliers

- monitoring and feedback

- liability estimation and management — the relationship between individual plans and budgets and aggregate funding availability.

The NDIA would have responsibility for billions of dollars of annual expenditure, and process claims from hundreds of thousands of people. It would have to employ a diverse workforce to oversee its key functions (management and strategy, case management, assessment, quality oversight, actuarial services, financial and data management). It would have to coordinate supports for people in all parts of Australia. It would deal with hundreds of specialist providers and with scheme brokers. Any significant failures in governance by the NDIA in any of these areas would rebound on some of the most vulnerable Australians, on taxpayers, and ultimately could threaten the long-term sustainability of the NDIS.

Based on its experiences of governance in insurance and management, the Insurance Council of Australia (ICA) identified four significant sources of managerial risk for a scheme — ignorance, self-interest, ideology and political interference. It drew attention to the failure of some CTP schemes in the 1980s and early 1990s, where poor claims management, inadequate financial discipline, cost blow-outs and the vagaries of government interventions quickly led to a breakdown

in governance and prevented the schemes from operating viably (sub. 238, attachment 2, pp. 10–11).

The overarching goal of the NDIA's internal processes and external rules must be to avoid these risks and, instead, to encourage the hard-nosed, focused pursuit of the sustainable and cost-effective provision of support services for people with disability.

While this chapter covers most of the above issues, some are the subject of other chapters in this report:

- The NDIA would need clear agreements with key government agencies — health, housing, education, employment, transport — so that people with disabilities get a coordinated suite of supports, and to ensure that services are not duplicated or accidentally omitted (chapters 3 and 5). There will also need to be data agreements so that the NDIA can model the broad outcomes for people (for example, getting a job or hospitalisation) and the inputs beyond those provided by the NDIS that might be important in achieving those outcomes. This recognises the value of considering all the 'inputs' that lead to wellbeing and other outcomes for people with disability (and their carers and families), as well as interventions by different parts of government that are complementary to this.

- Without good information and a strong analytical capacity, the NDIA would be an empty shell. As in many insurance schemes, the continual collection and reporting of data, and the analysis of that data, is essential for managing long-term costs, achieving outcomes for people, and in uncovering better intervention and prevention strategies (chapter 12).

- There are governance issues arising for particular topics discussed in this report (for example, concerning how assessments are to be made, how consistency can be obtained across assessors and in the rules that would apply to self-directed funding). In the main, we discuss those issues in the relevant chapters.

9.3   The role of the NDIA and others within the NDIS

The NDIS has many functions (table 9.1), many of which have been discussed in other chapters or in more detail later in this chapter.

What functions should lie outside the NDIA?

Some functions *must* lie outside the NDIA. An example would be the normal right of appeal to the courts when an NDIA decision is disputed.

Table 9.1 Functions of the National Disability Insurance Agency

Relationships with people with disability, their families and the community

(1) Assess needs of people.

(2) Refer people to supports outside the NDIS where needed.

(3) Facilitate personal planning.

(4) Determine a support package, to be discussed in draft form with the person, their NDIA local area coordinator (LAC), the assessor, and where the person elects, a DSO. Authorise people's funding proposals and provide them with individual plans or budgets to self-manage for eligible expenditures. Where people want to use a traditional service model, or appropriate spending items are outside the self-directed funding budget, the individual's preferred supplier/s would be directly reimbursed.

(5) Ensure that people get appropriate supports and services (eg attendant care, aids).

(6) Oversight supports funded by the NDIS, coordinate informal local community supports and facilitate other government services through NDIA LACs. Leverage and support a bigger role for community groups and not-for-profits to connect people with disabilities with the community.

(7) Provide people with a way to complain about suppliers or the NDIA and to have decisions reviewed.

(8) Collect information from people about the performance of funded support providers, and about their NDIA LAC.

(9) Provide people with information (web, publications, call centres, and ratings of suppliers) and provide a single point of contact.

(10) Address the social contributors to disability (such as stereotyping, prejudice and stigma, and inappropriate public infrastructure).

(11) Encourage and inform, but not necessarily undertake, programs that address the physical causes of disability (eg accidents) – noting the link to (10) above.

Arrangements with providers and intermediaries

(12) Oversee regulation of providers (eg ensuring police checks are undertaken and suppliers are solvent) to inform consumers and give them the capacity to move away from poor performers. The quality of suppliers would be rated using consumer feedback, with that information made public.

(13) Use purchasing arrangements for some supports, appliances and aids to get lower prices.

(14) Set up data collection and billing agreements with providers.

(15) Direct reimbursement of services not purchased under self-controlled budgets; set prices payable to suppliers for provision of services of agreed quality on receipt of vouchers from consumers.

(16) Where cost-effective, fund the supply of best practice and cost-effective therapies, aids, appliances and treatment regimes (including early interventions).

(17) Provide complaint investigation and review processes for suppliers.

(18) During the early stages of the scheme, mentor providers in developing person-centred approaches to support, which should lead to a wider offering of services.

(19) Encourage and support the development of DSOs to help build the decision-making capacity of people with a disability and those who support them.

(20) Establish an innovation fund for suppliers.

System functions of the NDIS

(21) Governance structures that ensure the objectives of the NDIS are met efficiently and accountably (regulator, independent auditing, an independent board).

(22) Manage revenue inflows and outflows, and future liabilities. Advise the Future Fund on investment requirements.

(23) Collect and analyse data, including for financial reporting, risk management, evaluation and research, and produce reports which are also made available to government. These reports will include regular monitoring of the scheme's experiences, and will feed into actuarial analysis.

(24) Research and analysis (for example, development of appropriate assessment tools, new developments in therapies, interventions, equipment and service provision; better risk management).

(25) Coordinate NDIS services with complementary services, such as health, education, housing, employment and transport.

(26) Other general operational matters (computing, personnel, contracting, legal, liaison).

Others would *appropriately* belong outside the NDIA. These would include measures to ensure that the NDIA reports are timely, accurate, and provide adequate reporting of the performance of the organisation.

In particular, the Commission does not envisage that the NDIA would be a supplier of services for people with disability and carers. There are several reasons for this.

External suppliers often have cost and efficiency advantages over governments

When supplying goods and services, private for-profit and not-for-profit agencies are often less costly and more nimble than government. These agencies are often less bound by the, sometimes rigid, rules that governments require. Over time, Australian governments have divested themselves of directly producing many goods and services, and instead purchased services from external providers. (Australian governments used to directly supply employment services; banking, most utility services, aircraft manufacture, airlines, printing, abattoirs, brickworks and even bakeries.)

That trend does not mean that governments should not run some services — and they continue to play an important role as suppliers in some areas. However, generally, government would have to make the case that they were likely to be more, or at least as, efficient as non-government suppliers, or that social or other goals of services could not be met through contracts or subsidies to non-government agencies.

The case for government supply is weakest where private provision can occur in workably competitive markets. Disability services generally fit into this category (though see chapter 10 for some exceptions). They do not involve complex technologies, and it is relatively easy to set up an agency to provide services. Currently, the main constraint on competition and responsiveness to people with disability and carers is that consumers do not have choice and do not hold the purse strings (chapter 8), with government often a bulk purchaser through block funding (chapter 10). The structure proposed by the Commission would allow for state, territory and local governments to continue to provide services, but in competition with other providers.

Putting the fox in charge of the henhouse — conflicts of interest?

Direct provision of services by the NDIA could create conflicts of interest. Were the NDIA to be a supplier, it could subtly favour its own services over competing

external ones, especially if a key performance indicator for the organisation was its market share and output levels. For instance:

- LACs might advise people to use NDIA services or 'market' them more strongly than alternatives

- payment of external parties for services not covered by self-directed funding might be slower than funding of the competing services provided internally by the NDIA

- the price charged internally by the NDIA might appear lower than external competitors — justifying internal provision — but may not properly reflect the full costs of services (for example, in the treatment of fixed and overhead costs of the NDIA). It can sometimes be quite hard to find out whether a government agency has breached requirements for the neutral treatment of external versus internal provision ('competitive neutrality' principles).

The history of large vertically-integrated agencies that hold a monopoly over functions[1] that are inputs into the supply of services by external providers, is that the agencies often find ways of favouring the arms of their own businesses. This is why governments often insist on separating the arms of such agencies ('structural separation').

Any favouritism would not just risk inefficiency, but would work against the principle of self-determination for people with disability. One of the departures of the NDIS from current practice in most states would be that the NDIS would give people with a disability and carers the ability to control their agreed individual packages or budgets. This would allow them to choose providers and, for those who wish to and are able to, have much greater control over the elements of the package. That can only work fully if the 'market' from which people purchase is a fair one.

Government-owned agencies are often given less freedom and flexibility

There are often strong constraints on the behaviour of government-run enterprises. In part, these reflect the political vulnerability of ministers when a government agency does something that might appear to breach the public's expectations (the 'radio-talk-back' test). It seems that governments are less vulnerable when an external party — even one contracted to it — makes such decisions. For instance, under the Job Network arrangements, some providers occasionally gave job seekers second-hand bicycles or even skateboards for transport to jobs — a strategy that

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[1] In this case, this would include approval of people's funding proposals and case management.

would have been impossible for the former Commonwealth Employment Service (PC 2002, pp. 3.3–3.4).

There might be exceptions

The NDIA might supply services in cases where it found it too difficult to reach efficient purchasing agreements with outside suppliers. That would probably be uncommon, but it might occur where:

- there were large difficulties in verifying that external providers were genuinely achieving good quality and cost-effective outcomes for people with disability and carers[2]

- there were significant economies from combining several services together and where government has advantages in supplying that package of services ('economies of scope'). Such economies might sometimes apply to the provision of Indigenous disability supports, where governments have to deal with multiple levels of disadvantage (housing, health, education, urban amenity, employment, transport *and* disability). In such cases, governments may need to provide 'last resort' supports to assist local communities in instances where adequate supports are not available (see chapter 11)

- government may also need to be a 'last-resort' provider in other cases where it proves impossible at reasonable prices to get non-government provision of some supports. For instance, that might be true for people with very challenging behaviours (chapter 10).

What does this mean for state and territory-owned service providers?

While the NDIA would generally not supply services, that would not prevent current state-owned and run suppliers from competing for business with non-government agencies as service providers. Such state-owned suppliers would

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2 The key to this issue are the difficulties that a purchaser (the 'principal') may sometimes have in ensuring the quality and quantity of services provided under contract by an outside supplier (the 'agent'). For example, in residential support of aged people with disability (aged care), the funder is not readily able to measure the quality of the services, especially for the most vulnerable people, who cannot complain when services fail to meet the appropriate standards (Ergas 2009, p. 29). Similarly, the Australian Government experienced this problem when contracting with Job Network providers. For example, some providers created temporary 'artificial' jobs to secure outcome payments from the government (PC 2002, p. 3.13). That said, such 'principal-agent' problems may not be sufficient to justify government provision, especially as they can persist in different forms in large government organisations anyway, and as there are other problems associated with government supply.

operate at arms' length from the NDIA, which would have no incentives to treat them differently from other providers. People with disabilities would decide which supplier to deal with. The advantage of arms' length arrangements between the NDIA and suppliers, and the capacity for people with disabilities to make their own choices, is that it identifies those suppliers who best meet people's preferences. The issue of their ownership would be irrelevant.

What would the National Disability Insurance Agency do?

Drawing on the analysis in other chapters, the key functions of the NDIA are those of many insurers generally, such as assessing needs, funding, coordinating services at a high level, and collecting and using data to manage efficiency and costs, and it would also recommend to government on the setting of future levies.

The Commission does not assume that the NDIA would necessarily undertake all of these functions internally. Rather it would have responsibility for them, and would decide whether to undertake the functions internally or to contract them out, depending on the relative cost effectiveness and any economies of scope. For instance, while the NDIA would need an internal research capacity, it would also provide grants or contracts for external research and analysis. That is because the NDIA often would not have specialised research and analytical capabilities in many areas. Similarly, various IT, data analysis, auditing, and web design and maintenance functions might well be contracted out. Assessments would often (but not always) be contracted out to independent assessors, but with their accuracy and reliability subject to constant monitoring (see later and chapter 7).

In some cases, the NDIA may choose to contract out a proportion of its activity in specific areas to test its internal efficiency and to pressure those inside the organisation to behave efficiently.

In many instances, the motivation for the NDIA to control a function is obvious (such as collection and use of data; cost controls; monitoring of, and advice to, the funds manager and internal complaints processes). However, some may be less obvious:

- *assessment of needs* (including both the assessment 'toolbox' and the professionals applying that toolbox). There are several major motivations for the NDIA to control this (though not necessarily through direct provision).

    First, systematically high assessments of required supports would pose a risk for the sustainability of the scheme, while systematically low assessments or unreliable ones, would be unfair to people with disability. (It would create another lottery for people with disability since they might get less than they

needed if the assessor was a 'hard marker' or if the assessor was simply sloppy that day.) Therefore, the NDIA must be able to monitor assessors' accuracy and reliability — and advise (or even fire) them if they lie outside the appropriate performance bands.

Second, the NDIA would need to monitor the performance of the assessment tools to ensure that they gave accurate and reliable measures of people's reasonable needs for funded support. Parties other than the NDIA do not have these incentives. Indeed, some parties — such as those also supplying services — would have incentives to overlook soft assessment, and certainly not to zealously suppress it

- *local area coordinators (LACs)*. The Commission envisages that locally-based staff, operating at a 'grass roots' level, would perform many functions in the NDIS (box 9.1). (Many participants pointed to the considerable advantages of having people on the ground in the local area. The Commission also sees this as crucial to the effective delivery of NDIA services.)

  The primary role of LACs would be to oversight the delivery of services to people in the NDIS, and their ongoing interaction with the NDIS, and provide some links to the community. But they would also assist in monitoring other aspects of the scheme — for example, by helping to independently assess the quality of service providers (through feedback from people with disabilities and carers).

  While LACs would generally be employed by the NDIA, some may be employed under contract. To avoid any conflict of interest, they could not be employed by a provider that is also providing supports to the person. And as LACs would serve a regulatory function for the NDIS, concerns about potential conflict of interest suggest that people with disability should not hire LACs.

  There are many issues associated with increasing the disability workforce for all staff levels, including getting sufficient LACs. Those issues, and some strategies and recommendations to address them, are the subject of chapter 15.

- *authorisation of funding proposals*. The arguments about the need for NDIA control in this area are the same as those applying to LACs.

  For many people, funding for assessed needs would be provided by way of entitlements to specific forms of supports, such as a number of hours of attendant care of a particular kind per week, certain aids and appliances, and so on. At least in the initial stages of the scheme, while both people and providers are becoming accustomed to a new way of operating, such entitlements should be given effect by the use of vouchers that people would take to providers of their choice. This would allow consumers scope to try new providers as they

learn about the new system and find ways to take advantage of the new arrangements while operating within a broadly similar and familiar framework.

A voucher model will also give them the certainty, at a time when the implementation path for the NDIS is being bedded down and early problems are being ironed out, that they will get the supports and services they have been allocated. This would be a simpler approach than self-directed funding (chapter 8), where consumers choose to have direct control over their budgets and they, or a DSO, will need to enter into negotiations with providers over price and services. A voucher model therefore involves more certainty but less flexibility and less responsibility. Nevertheless, it should still lead to a reshuffling of service provision arrangements during the early stages of the NDIS.

Well-designed voucher arrangements in the early years might also act to temper the early expectations of both consumers and providers as to what the scheme can and should deliver. Indeed, the early availability of cashable budgets under self-directed funding across the board, while potentially providing many benefits to consumers, might initially create undue expectations about what can be delivered under the scheme, which could undermine its phased implementation and threaten its long-term financial sustainability.

- *determining the 'prices' of the vouchers* that the NDIA would provide to people with disabilities to enable them to obtain services and supports.

An important early task for the NDIA would be to set appropriate 'prices' for each support to be purchasable by voucher. Use of vouchers means that the NDIA needs to determine the 'price' it will pay for each form of supports provided under the NDIS — for example, for an hour of a particular category of attendant care. Once the service had been provided, the provider would cash the vouchers in to the NDIA at the pre-agreed price. This is not the same as block funding, as the consumer would be able to choose which provider to purchase supports from.

The NDIA could negotiate prices with suppliers, or set what it judges to be 'efficient' prices based on a theoretical model of costs (as the ACCC does in respect of telecommunications). In both cases, the NDIA would need to take account of the very wide range of supports of different levels of quality that need to be provided to the population of people with disabilities, all of which would need to be individually priced. Moreover, these prices would need to be amended periodically, as costs and market circumstances changed, and made transparent. This is the same approach as taken in the Commission's parallel inquiry into aged care, which discusses the determination of appropriate prices at length (PC 2011a).

Box 9.1   **Local area coordinators (LACs)**

LACs in the NDIA would play a critical role in the operation of the NDIS. They would:

- provide a point of contact for people with disabilities in their dealings with the NDIS

- operate locally, at a 'grass roots' level (although some would have a regional focus)

- provide advice, and oversight and monitor the interaction between people with disabilities and the NDIS, and the delivery of services to them

- liaise with other government services on their behalf

- assess the capacity of a person to use self-directed funding, help them draw up spending plans or to pay family members under the pilot arrangements

- have a limited pool of funding to address emergency respite and other special circumstances best resolved on a common sense basis at the local level (to be separately accounted for and monitored)

- negotiate, if requested, with service providers in the event of a dispute or complaint

- be the point of contact for people to provide confidential views about the performance of suppliers, for analysis by the NDIA.

LACs would either be directly employed by or contracted to the NDIA.

The importance of terminology

Several participants proposed that the NDIA use the term 'local area coordinators', as used in Western Australia, rather than 'case managers', when identifying staff who would have the front line role of assisting people with disabilities. A common concern was that people not be seen as 'cases':

> The nature of these roles is to shape resources, it's to work with the individual and not necessarily merely to place people into a set of pre-established service options … [it should be] about working with the individual, trying to place the individual within the community, honouring the individual's ambitions and then matching the resources to make the best and most efficient supports assist them towards those ambitions and goals. (People with Disability Australia, trans., p. 342)

It would be important when setting prices administratively to avoid setting prices too high, which would mean over-compensating providers, or too low, which would be a disincentive to providers to supply those supports (and which would reduce the returns from future innovation). Nevertheless, a 'standard' voucher may well prove to be more valuable when used with an efficient provider (for example, one who provides punctual, high quality attendant care), and over time, people's preferences as reflected in the use of vouchers will influence the overall pattern of service provision.

At times, and for specific supports, the NDIA might issue tenders and form contracts for particular providers for the supply of services at a given per-unit price for a given tender period. The NDIA would also have to specify quality for

bids to be clearcut, so there would need to be regulated quality guidelines for all supports. Again, this would not be the same as block funding. The producer would not be given a guaranteed market because consumers might not choose to go to them.

Under either approach, there will be scope for some price competition. For example, an efficient provider may well offer 'deals' to consumers, such as an extra hour of attendant care to what is allowed for by their vouchers if they 'sign up' to that provider for sufficient paid hours (the commonly-observed 'coffee club' approach, whereby the tenth coffee is free). This would effectively lower the average price of that service, directly benefiting the consumer. Equally, consumers may be able to 'trade' vouchers when they need some short-term flexibility additional to that already provided for in their packages. For example, in order to attend a special occasion such as a family wedding held during the evening, they may wish to swap some hours of 'ordinary' day-time attendant care for a smaller number of higher quality hours of active late night or overnight care. And over time, it may be possible to open up price competition in at least the competitive parts of the market, a point also made in the Commission's parallel inquiry into aged care.

The role of DSOs

One important aspect of the NDIS not covered elsewhere is the likely role of intermediaries, which might perform several potential functions. While the primary point of contact for a person interacting with the NDIS for tier 3 supports will be their LAC, they may also receive additional supports from outside bodies, such as service providers and NGOs. But in addition, the Commission envisages a role for a new form of organisation, 'disability support organisations' (DSOs), that would offer people brokering services; management services (such as dealing with the administrative aspects of self-directed funding, were a person to go down that route); assistance in developing the skills and confidence to practically exercise choice; personal planning services; and orientation supports for people who are suddenly faced with the unfamiliar world of severe disability.

Thus, the principal role of a DSO would be to act as an agent for a person with a disability on a range of matters, including in relation to the implementation of that person's package of services from the NDIA. It is a role separate to that of a LAC (boxes 9.1 and 9.2), but complementary to it. For example, once the NDIA has undertaken an assessment and agreed to a funding plan, people with disabilities have several options. They may choose to nominate particular service providers to meet their needs, or they may create and manage their own support services by contracting with a range of different suppliers in a variety of ways. They may

undertake the organisation of this themselves, or they may prefer to employ the services of an intermediary for all or part of this task.

There is a range of tasks that such an intermediary might undertake for people with disabilities. Some are already provided now by some agencies.

Providing brokerage services/ helping resolve disputes

DSOs may advise people with disabilities about the quality and choice of specific support services available, and act as brokers by assembling 'packages' of supports for them. There are several potential benefits from this approach:

- DSOs will face lower 'search costs' (that is, finding services and obtaining information about the availability and quality of products and services will be easier, due to their knowledge and experience) than for some people with a disability, who may have little experience with the sector or may have functional limitations that make research and organisation difficult.

- Their knowledge and experience with the sector will also give DSOs an advantage in negotiating with service providers. DSOs could try to get the best support package for a person from among a variety of providers, given the person's preferences and the constraints of his or her individualised plan, or may try to enlist free community resources for this task (see later). (An example of the sort of question a broker might ask of competing suppliers is 'My client needs someone to take them to church on Sundays at 7 am — can you do that reliably?').

Where a DSO has helped a person obtain particular supports, it may assist that person to resolve any subsequent (minor) disputes with the service provider that subsequently arise, either by acting on the person's behalf, or advising them about how best to do this. More serious disputes would fall within the purview of the NDIA's Office of the Inspector–General (see below).

Providing personal planning services

Service planning for people with disabilities would begin with their early interaction with their LAC, the formal needs assessment, and ongoing informal advice and support from their personal support networks. However, some people will also need ongoing help in 'life skills' areas, such as personal relationships, employment, financial management and succession planning, and for many this will also extend to help in visualising a wider menu of life possibilities, and means of working towards them. Pave the Way said:

… whole of life and succession planning is vastly different from service planning …
Services might play a role in assisting individuals to achieve some goals, for example,
those concerning home, work, recreation, communication and education, but are
unlikely to play a role in many other aspects of the individual's life, such as personal
security, financial security, decision making, relationships and friendships, health,
spirituality and developing individual passions. Services can assist people to have a
good life; they do not constitute a life. (sub. 528, p. 9)

Box 9.2   Disability support organisations (DSOs)

People could choose to use DSOs to:

- provide them with personal planning services over and above what they obtain from the NDIS

- help them get the best value from their self-directed funding, once that has been determined under NDIS procedures

- help them develop the skills and confidence to practically exercise choice

- provide them with information of the quality and choice of support services available from specialist and mainstream providers

- assemble 'packages' of supports from specialist and mainstream providers

- undertake administrative tasks such as record-keeping and tax returns.

Such a role may facilitate greater innovation in the provision and coordination of services to people with disabilities.

When first dealing with the NDIA, people would be informed by their LAC about the services that a DSO might offer them. They could choose a DSO to deal with from a list, or if they preferred, the LAC may recommend one to them.

The need for such assistance is likely to be larger for:

- initially, most people with a disability — for them, the changes implicit in a shift to a model based on personal choice and decision-making are fundamentally different from the current arrangements

- children with a disability, whose life circumstances and needs will change as they grow and develop, and move through the education system and different stages of their lives

- people with degenerative diseases, whose support needs are also expected to change over time (often at an uncertain rate)

- people with an intellectual or psychiatric disability, who may find it difficult to articulate what they want, and who require carefully coordinated or creative solutions to live independently (particularly when family, carers or guardians are no long able to supervise and help with important decisions)

- people in times of crisis and transition, when the normal support package may need reassessment, either for a short or longer timeframe.

While the NDIA assessment process and the ongoing services of the person's LAC can address these matters to some extent, DSOs can play an important ongoing role in providing 'life planning' assistance to people with disabilities. This could be funded by the NDIA where the need has been demonstrated through the assessment process.

Undertaking administrative tasks

This would involve helping people meet such administrative tasks as those associated with self-directed funding — record keeping, and tax and workers compensation matters, for example. Some agencies already undertake this function as an adjunct to their main activities (for example, My Place, sub. 217). It could also include assistance with the paperwork associated with accessing disability supports from education departments, hospitals or Centrelink.

Other roles

The activities of DSOs may help facilitate community capacity building and encourage greater inclusiveness through:

- *community brokerage*. Some DSOs may be able to help people with a disability to find businesses, community groups or social events that match their own interests and which are able to adapt their activities (if necessary) to any particular requirements associated with the person's disability.

- *community capacity building*: Some DSOs may develop expertise in advising mainstream businesses and community groups about how to become more accessible to people with a disability by offering advice on how to upgrade facilities and train staff, as well as how to overcome stereotypes and misconceptions about disability.

- *community awareness*: Some DSOs may be involved in activities that, directly or indirectly, increase awareness about disability issues and that help engage community involvement with people with disability.

Chapter 4 discusses the role of the community in greater detail.

Other possible roles include providing induction-type services to those who want it prior to assessment, informing the NDIA about breaches of service standards by

providers, and assisting people who wish to change from one service provider to another.

Box 9.3   **The roles of LACs, support groups and DSOs**
From the perspective of a person with a disability

If a person with a disability has been judged as likely to be eligible for tier 3 supports, a LAC would be appointed as their ongoing point of contact with the scheme. All people who received tier 3 supports would have their own LAC.

Depending on the person's circumstances, the LAC may visit them in their home, become familiar with their situation, and learn about the extent of their natural supports and needs.

As part of this early interaction, the LAC would advise the person of disability-specific support groups in the community that he or she may benefit from linking up with. (Examples include groups that assist and represent the unique interests of people with multiple sclerosis, autism, Parkinson's disease and those who are blind and/or deaf — many such groups are to be found in the submissions list on the inquiry website.)

Such support groups may, for example, provide auxiliary services that are likely to be less comprehensively provided by the NDIA — for example, specific details on the condition or disability they have, how it feels to be in that circumstance, how the disability might progress, obstacles the person is likely to face, ways of tackling those obstacles, and a clearing house for information on the disability. Importantly, such groups offer the immensely valuable perspective of other people who are in essentially the same situation. The LAC can provide information on what these groups do, how they operate, the sorts of services they offer, and how to get into contact with them in the local area.

The LAC would also explain the role of DSOs, what they might be able to do for the person, over and above what the NDIA would provide or the support groups could offer. The LAC could inform the person about DSOs in the local area, their services and any specialisation or skills they have, which DSO services the NDIS would pay for and which the person would have to pay for themselves out of their NDIS package. People could then, if they wished, choose one or more DSOs to undertake any of the range of activities listed in box 9.2. The LAC would also explain the role that DSOs have in liaising with the LAC on particular matters affecting the person's interaction with the NDIA.

Both the LAC and the DSO would seek to promote the participation and inclusion of people with disabilities into the community, whether by providing information about social or community activities that match their interests, or by helping them connect with particular groups or organisations (chapter 4). This role would also extend to advising businesses and community groups about how to become more accessible to people with a disability.

Conflicts of interest?

The arrangements governing the operation of DSOs will be critical in determining their usefulness. As DSOs will commonly (and helpfully) influence the bundle of services provided to people with a disability, it is particularly important that the interest of such people not be compromised by the financial interests of the DSO.

In general, DSOs should not be permitted to act as disability service providers (although exemptions might be made where it can be shown that no conflict exists — such as for service providers that also offer services that reduce the administrative burden of self-directed funding). For example, it would not be appropriate for a DSO to provide the supports to which they might refer people as part of a brokering role. Similarly, DSOs should not be able to accept commissions (either in the form of direct payment or through brokers 'keeping the change' on any discount they negotiate) from the service providers.

There is also the potential issue of DSOs referring people to other *DSO services* that they themselves provide (for example, a DSO that offers planning services but that also encourages people to purchase the brokerage and administration services that it also offers). Equally, the provision of services by DSOs in one area may limit their contribution in another. For example, Pave The Way said that the service provision focus of a DSO's brokerage role could interfere with the whole-of-life perspective it needed for long-term planning (sub. DR898, p. 7). But in some cases, these services may naturally form part of an integrated planning process (that is, they could potentially be just different aspects of the same basic service). If so, artificially splitting planning, brokerage and administration may not be in the interest of the person with a disability. Consequently, the best approach may be for the NDIA to monitor instances of DSOs fulfilling multiple roles, but not prohibit this in the first instance.

Finally, it is important that access to services such as planning and brokerage do not deter people with a disability (or their carers) from developing the capacity to manage their own package of support, and acting independently to achieve their own goals and aspirations. In some cases, there may be a risk that DSOs have a financial interest in the ongoing provision of services to people with a disability that runs counter to the interest of the individual's personal development. Such risks arise may be minimised by:

- monitoring the effectiveness of DSOs over time and assessing them against clearly specified, person-specific objectives

- ensuring (where possible) that helping people to develop planning and organisation skills are themselves a feature of DSO activity.

Funding DSOs

Some roles and services provided by DSOs would be subsidised by the NDIS, but others would be reflected in charges to people with a disability who choose to use them. Where they:

- undertake administrative tasks, such as dealing with tax and superannuation payments and reporting for paid carers that are hired under self-directed funding, their costs should be met from the person's funded package

- provide brokerage or long-term planning to a person in tier 3 of the scheme, they would be funded by an additional NDIS entitlement allocated to that person, based on assessed need. Such entitlements should be capped at a reasonable level to limit the inefficient use of DSOs, and should include an element of support for capacity-building

  Over the longer run (say, after a person has been in the scheme for five years and has developed a good understanding of the arrangements), it may be appropriate for some entitlements to become part of people's individual packages, which they could trade-off against other supports they may want. Where ongoing assistance was assessed as essential, this would remain a funded element of the person's individualised package.

- undertake activities such as capacity-building or the organisation of emergency attendant care services, DSOs should be funded by the NDIA where it thinks it is getting good value from such an approach

- are used to promote the capacity of the community to include people with disabilities generally, they should be funded through grants and/or block funding, but would need to compete with other bodies in performing this role (for example, with local government).

In addition, the NDIA could, as part of its public education strategy, fund DSOs to provide information for people with disabilities and support providers, to explain how the scheme will operate and the DSO's role in it.

In such cases, DSOs may, for example, run workshops and provide some follow-up guidance for people who request it. This would help build a knowledge base and greater self-support capacity among people with disabilities, by informing them about the options available to them. Such 'capacity building' should be an important focus of the NDIA, particularly in the early years of the scheme.

Table 9.2 **Local area coordinators and DSOs: a comparison of roles**

Role or function	Local area coordinator (NDIA)	DSO
Assessment	As the key NDIA point of contact with the person, their early involvement (visits, learning about the person, providing early guidance and advice) will help inform the draft assessment package.	Helps the person think more broadly about the supports they will need, and their life aspirations (allows the person to approach the NDIA assessment better prepared).
Planning	Immediate service planning, including providing information and advice on available supports; indicators of quality; available local community supports, resources and activities to fulfil needs or aspirations; and how to access other government supports.	Where needed, assist with short and longer-term planning, focusing on life possibilities, succession planning etc. Will tend to be wide ranging, iterative and require creative solutions. (Some not-for-profits do this now.) NDIS-funded where need has been assessed.
Brokerage	No role	Additional funds provided as part of the entitlement may be used for brokerage if the NDIA assesses that need. For others, hire DSOs on fee-for-service basis.
Administration of self-directed funding packages	Provides guidance on suitability for the person, and undertakes compliance checking	If the person wants self-directed funding administration to be done by the DSO, costs should be met from the person's cashed out individual package
Community access and inclusion	Operates on an individual level through planning and assessment as described above	May be block funded to offer community brokerage, community capacity building and community awareness (chapter 4)
Regulatory oversight	Periodic checks on people, (according to degree of vulnerability). Contact point for complaints and breach of standards (as LACs would be the major source of information for NDIS participants about service providers). Able to initiate investigation against service providers, or pass to Office of Inspector–General	Would pass evidence of breach of service standards or other service problems to LAC
Resolution of disputes between service providers and NDIS participants	Would seek to resolve more serious conflicts. Has access to past information on both person and provider and authority to initiate further investigation if necessary (or to involve Office of Inspector–General)	Where needed, may be involved in resolving minor issues concerning services the DSO has helped organise, or in advising people how to take their complaint further, including how to contact advocacy services
Assist in transitioning from one service provider to another	Can provide information, advice and support to people transitioning (if required). Where transitions occur due to quality problems, LAC would advise Office of Inspector-General (see below).	People with a longstanding and positive relationship with a DSO may be most comfortable with their advice and assistance in transitioning. DSO would keep LAC informed.

During the early stages of the NDIS, the NDIA will need to encourage the development of DSOs, including through funding. Such a temporary subsidy would be justified by the fact that many people have become used to being passive in the current system, and that inertia would be likely to persist unless the market changed.

9.4   Creating a National Disability Insurance Agency

The Commission proposes that the Australian Government constitute the NDIA as a new independent Commonwealth statutory authority. While the NDIA would be a new government body, it would replace significant functions in existing state and territory bureaucracies, rather than merely adding to, or attempting to coordinate them. Moreover, as discussed in chapter 19, ultimately the NDIA would replace the existing plethora of agencies that pay for and oversee disability services at the state and territory level. As one participant cautioned, the problem of an unwieldy bureaucratic structure would not be fixed by creating 'yet another box' on that structure (JacksonRyan Partners, sub. 30, p. 7).

The increased Australian Government role reflects its much greater funding commitment and above all, the desire to remove the striking inequities in service entitlements and access to self-determination across different jurisdictions.

A corporate model of governance is needed

While the NDIA would be a government entity, there are strong arguments that it be independent and use a corporate model of governance. This is usual in commercial insurance arrangements and government long-term care schemes such as Victoria's TAC, the NSW LTCS scheme and New Zealand's ACC.

Broadly, the Commission proposes that the NDIA:

- be an independent Commonwealth statutory authority
- be overseen by a governing board that would be skill-based, not representational
- have an advisory panel of key stakeholders to advise the governing board
- be independent from day-to-day government control
- have its own legislation that specifies its roles and objectives.

Figure 9.2 sets out the broad framework — with its main features described in more detail in the remainder of this section.

Figure 9.2   **Accountability arrangements and the NDIA**
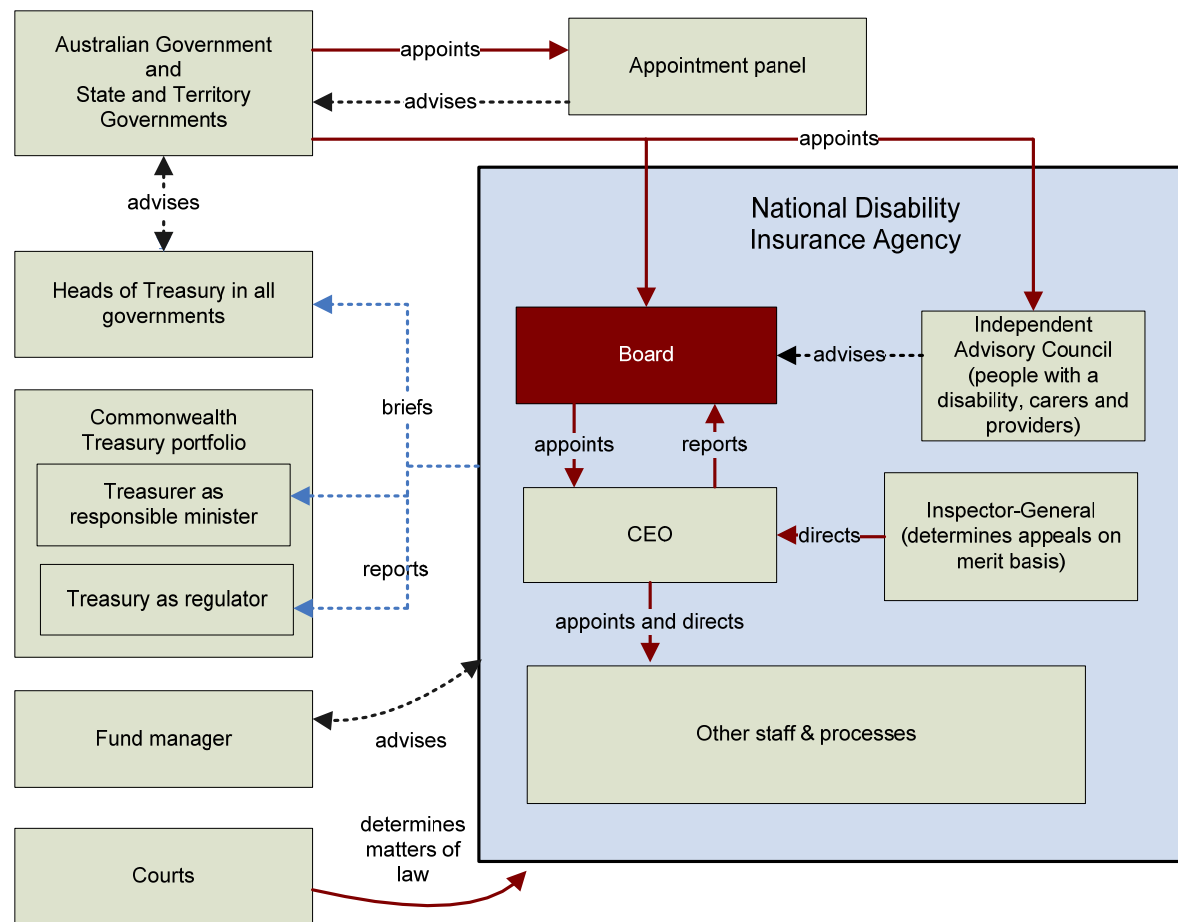
Given these proposed governance arrangements, the NDIA should operate under the Commonwealth Authorities and Companies Act 1997 (CAC Act) and not under the Financial Management and Accountability Act 1997 (FMA Act). The latter would not usually be suitable for agencies that require a governing board. FMA organisations face much more direction from the responsible minister, the Finance Minister has primary control over their financial arrangements (which are in any case not appropriate for an organisation that will need to incur and hold long-term contingent liabilities), and employees would typically be employed under the Public Service Act. The CAC Act is much more suited to 'commercial-like' agencies, such as the NDIA (box 9.4), and would generally not engage staff under the Public Service Act unless there were good reasons to do so (DoFA 2005, p. 39).

The approach summarised above has several advantages. The agency's roles and responsibilities would be clearly defined, including mandatory performance reporting. It would avoid the risks of political interference in operational matters (ICA, sub. 238, attachment, p. 14). It will require a long-term funding agreement so

that its finances would be quarantined from the uncertainties of the annual budget process, which would otherwise undermine the goal of the NDIS to provide future surety of services (South Australian Government, sub. 496, p. 19). Finally, it would recognise that the body would have long-term commitments and complex financial dynamics (Victorian Government, sub. 537, p. 24).

The Victorian Government further noted that:

> The governance model adopted must enable strong management of all aspects of the scheme. An understanding of the very long-term nature of the liabilities and the financial implications of strategies and decisions are essential if the scheme is to be sustainable. (sub. 537, p. 24)

The Victorian Government, citing TAC as a model, proposed that the NDIS be constituted as a statutory authority, to operate in a corporate manner with a commercial board.

RECOMMENDATION 9.1

The Australian Government should establish a new independent Commonwealth statutory authority, the National Disability Insurance Agency (NDIA), to administer the National Disability Insurance Scheme.

The NDIA should be subject to the requirements of the Commonwealth Authorities and Companies Act 1997 (CAC Act), not the Financial Management and Accountability Act 1997.

An independent commercial board

As noted by the ICA, an essential aspect of a corporate governance model for the NDIA would be an independent commercial board, which is given genuine responsibility for actively managing the balance of costs and benefits of the NDIS over time (sub. 238, attachment, p. 11). The New South Wales LTCSA, the TAC in Victoria and the ACC of New Zealand all have independent boards.

Primary roles of the board would be to appoint the CEO, provide strategic direction and oversight of the scheme's success in meeting the objectives laid down in its Act, to ensure financial sustainability and to manage the relationship with governments. The board would need to ensure that the scheme, and the NDIA, was run professionally and efficiently, and that structures and procedures were in place to ensure that costs and the associated future liabilities were monitored and controlled. The board would seek external advice, such as regular actuarial assessments, as it saw fit.

Box 9.4 Aspects of CAC Act supervision of government agencies

While there is 'a policy preference' not to create new government agencies, where new agencies are created, they need to be made subject to the *Financial Management and Accountability Act 1997* (FMA) or the *Commonwealth Authorities and Companies Act 1997* (CAC Act).

Broadly, the FMA applies to budget-funded bodies, regulators and bodies that raise public money under a Commonwealth law — examples include government departments, APRA, Comsuper and the courts.

But for agencies for which a governing board will be essential for its effective governance, the appropriate supervisory structure is the CAC Act. The Reserve Bank and CSIRO are CAC Act bodies.

In discussing governance arrangements for CAC Act bodies, the Department of Finance and Administration noted:

- where the CAC Act is appropriate, it is preferable to establish the body as a Commonwealth authority, rather than a Commonwealth company
- the governing board sets strategy and oversights management:
  - board appointments should be skills-based, rather than representational
  - directors and officers must exercise their powers and duties in the best interests of the body and for a proper purpose
- the CAC Act allows the Government to rely on the directors to properly govern the relevant body, in line with their directors' duties
  - directors have legal duties under the CAC Act and Corporations Act 2001, with penalties attached to breaches of these duties
- a CAC Act body could also have an advisory board to advise the governing board
- the CAC Act does not give Ministers a general power of direction in relation to a body's functions (this is left to the enabling legislation if required)
- but it does give the responsible Minister and the Finance Minister broad powers to require the authority to provide information about its activities.

Source: DoFA (2005).

As with these and corporate boards generally, NDIA board members would need to be chosen for their commercial skills and experience. The scheme would also benefit from having some board members who have experience with long-term care or insurance schemes. Maurice Blackburn et al. said board members should be chosen based on their expertise and skills in managing large insurance funds (sub. 392, p. 74). The DIG report emphasised the need for:

> … acumen and experience in a range of disciplines necessary in managing a personal disability care and support service delivery system operated within a prudential insurance framework (DIG 2009a, p. 166).

The Commission sees a highly skilled and genuinely independent board as essential to the successful operation of the NDIS. While the CAC Act quite clearly provides for this, the issue of independence — and the public perception of the board's independence — is so important that it raises the question of *how* board members would be selected, especially given the importance of guarding against 'politically friendly' appointments' as one participant noted (ICA, sub. 238, attachment, p. 10). Historically, some have criticised the processes used to appoint the boards of Australian public sector agencies (Edwards 2006).

One avenue would be to:

- set up clear merit-based criteria for the appointment of board members in the legislation. These could include the requirement that, across the board, there was a mix of skills and commercial expertise in areas such as finance; management; insurance; and knowledge about the prudential management of a large and complex commercial corporation with long-term liabilities of the kind envisaged here. The board should include some people with these skills who also have experience and understanding of disability. There should be board members from a variety of locations around Australia (that is, not just Sydney and Melbourne).

- establish an independent appointment panel,[3] with agreement by all Australian governments that this group has their confidence. The panel would comprise people with skills and experience in the same areas, including people with a clear interest in disability policy issues. It would provide a recommendation about the appointment of the chair of the board, which would need to be agreed by the majority of Australian governments (similar to the process used for appointing the chairman of the ACCC). The panel would nominate at least two candidates per vacancy for other board positions, reflecting the broad range of skill sets and experience required. The final appointments would be based on the majority decision of all jurisdictions, with a responsible minister in the Australian Government (the Treasurer, in the Commission's view — see later) making the ultimate decision if the votes were tied. Appointment for a five-year term may well be appropriate.

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[3] A somewhat similar approach was taken to make additional appointments to the ABC and SBS boards in 2009, with the panel nominating at least three candidates per vacancy, with the Australian Government making the final choice. It may be necessary to nominate a smaller number of candidates per board member for a full board. Governments in the United Kingdom and some Canadian provinces (like British Columbia) and have also reformed appointment processes for all public sector boards so that independent appointment panels/agencies make recommendations to the relevant minister (Edwards 2006).

This sharing of the responsibility for the initial nomination process and appointment of the board chair highlights that the NDIA would be a cooperative federal venture. The goal is to create a new federal social and economic institution that would be independent from all governments in operational matters.

Were the board or its chair to perform badly, the Australian Government could dissolve the board, or seek to replace its chair, re-triggering the appointment process described above. (The Government would not be able to sack the CEO, as this would be a matter for the board.)

Once put in place, the board would appoint a CEO, who would appoint a senior management team to help implement the scheme. On good governance principles it would be preferred that the board alone appoints the CEO, without the need for additional authorisation from a relevant minister (shareholders usually do not authorise the appointment of CEOs in commercial entities). As the Department of Finance and Administration noted:

> Boards of directors are an effective governance structure where they have been delegated the full power to act … Such powers would usefully include the appointment and removal of the CEO (2005, p. 36)

What about the decision-making power of people with disability?

Several advocacy groups argued that the board of the NDIS should comprise 'a majority of people with disabilities' (Disability Advocacy Network Australia, sub. 490, p. 18), or be representative of peak disability groups (see also People with Disability Australia, sub. 524, p. 43). The Julia Farr Association said:

> … our view (based on the principle of 'nothing about us without us') is that the membership of the body of governance for the scheme should include people living with disability. This should not be limited to advisory functions but should extend to authentic participation in the formal leadership of the scheme, including the range of decisions that any board of directors might be expected to consider. (sub. 494, p. 59)

Some participants quoted the United Nations Convention on the Rights of Persons with Disabilities to the effect that people with disabilities and their representatives should be involved in and participate fully in 'the monitoring process'. (Article 33.3 of the UN Convention states that '... persons with disabilities and their representative organisations shall be involved and participate fully in the monitoring process' (In Control Australia, sub. 570, p. 110).) People with Disabilities ACT argued that this should extend to:

> The making of higher policy level funding distribution decisions and the resourcing of local/regional disability resource centres that would play a key role in providing

independent advice and could support development of initiatives at the local level that would enhance effectiveness of individualised funding allocation. (sub. 488, p. 7)

In Control Australia took the same view (sub. 570, p. 110), emphasising the importance of people with disabilities being at the centre of decision-making about their lives. Several participants reiterated this point in their submissions made in response to the draft report.

The Commission strongly agrees that any new disability system must give people much more power over their lives, and the design of the NDIS intends to do that. However, the issue of who governs the scheme is not just about who uses its services. The responsibility for the operation of the scheme needs to be at arm's length from the main users, in the same way that Medicare is independent of the chronically ill and medical practitioners who are the biggest users and producers of its services. Equally, the board would not be constituted to represent the interests of the Australian and state and territory governments, disability service providers or other interested parties. As the DIG report put it, the NDIS needs 'a business board rather than a stakeholder board' (DIG 2009a, p. 166). Nevertheless, where consistent with this stipulation, the Commission agrees that the board would benefit from having some members with understanding and experience of disability.

Keeping the scheme on track and within funding limits needs a single-minded commercial focus to avoid loss of strategic direction, indecision, and cost overruns — a particular risk for schemes such as this — and to keep sight of the scheme's main objectives. The risk otherwise is that decisions about assessment tools, local resourcing and many other aspects of the NDIS would be determined without a mind to the financial sustainability of the scheme and without the objectivity needed for fair and efficient allocation of services.

This approach is not peculiar to disability, but are principles generally adopted in corporate governance. Notably, in its directions on governance arrangements for Australian Government bodies, the Department of Finance and Administration indicates that for government entities under the CAC Act, 'appointees to governing boards should not be there in a representational capacity' (2005, p. xv).

An independent advisory group

However, while the governing board should be an expert board, there are very strong grounds for mechanisms that give stakeholders the capacity to advise the board. The South Australian Government said that stakeholders should have input into decisions:

An Advisory Board for key stakeholders would be one option to enable ongoing stakeholder engagement — representing interests of clients, service providers, taxpayers/premium payers, Federal and State governments and disability specialists. (sub. 496, p. 20)

Ros Madden and others saw an 'essential' role for an advisory body that included people with disabilities, their families and NGOs, noting that such groups:

… have been significant drivers of innovation and expansion in the field … National management structures should draw more formally on this well of expertise' (sub. 493, p. 21).

In their view, such a body could advise on the early development of the scheme, and promote integration with other services, better outcomes for people with disabilities and carers, adequate, equitable and consistent access to services across the country, and the development and sharing of data for use in improving outcomes for people and services (pp. 21–22).

In light of these points, the Commission considers that there are strong grounds for an independent disability advisory council to advise the board on the scope and activities of the NDIS, from the perspectives of people with disabilities, carers, suppliers of equipment and services, and state and territory service providers. The council should comprise representatives of each of these groups. Such an approach has proven successful in other areas such as consumer policy administration and development. For example, the Consumer Consultative Committee advises the Australian Competition and Consumer Commission on issues or market developments affecting consumers, and emerging issues that may be of concern to particular groups of consumers. Similarly, the Consumer Advisory Panel provides advice to the Australian Securities & Investments Commission.

An advisory council would help identify problems at the coal face on how the NDIS was operating. As hypothetical examples, it might reveal faults in the way self-directed funding was working, inadequate training of LACs, excessive compliance burdens, or poor IT links between suppliers and the NDIA. The board and the CEO would then consider this advice when determining how they ran the NDIA. The advisory council would provide an annual public report on their principal advice.

RECOMMENDATION 9.2

An independent skill-based board should oversee the NDIA. The board should comprise people chosen for their commercial and strategic skills, and expertise in insurance, finance and management, and should include some people with these skills who also have experience and understanding of disability.

- *As specified in the CAC Act, the board should not be constituted to be representative of particular interest groups, including governments, disability client or service provider groups.*

State and territory governments and the Australian Government should together establish an appointment panel comprising people with skills and experience in these areas, including people with a clear interest in disability policy issues.

- *The panel should nominate multiple candidates for each board vacancy against tightly specified selection criteria set down in the Act governing the NDIA. Appointments should be based on the majority decision of governments.*

With the agreement of the majority of state and territory governments, the Australian Government should have the power to remove the chair or dissolve the board as a whole.

The board would have the sole power to appoint the CEO and to dismiss him or her if necessary, without authorisation from governments.

RECOMMENDATION 9.3

State and territory governments together with the Australian Government, should establish an advisory council. The council should provide the board of the NDIA with ongoing advice on its activities and effectiveness in meeting its objectives, from the perspectives of people with disabilities, carers, suppliers of equipment and services, and state and territory service providers.

- *The council should comprise representatives of each of these groups.*

In addition, the board or the CEO may find it helpful to seek formalised advice from others in the community, and may establish further advisory councils or committees to advise it on specific issues, on a short-term or standing basis, as it sees fit. This may be useful to obtain information or advice on such matters as voucher pricing, the availability and characteristics of aids and equipment, and particular service standards.

Many participants were concerned about the large and ongoing compliance burdens of current arrangements. This matter is discussed in various places in this report, where examples are given, and where proposals, such as electronic patient records, are put forward with the objective of reducing unnecessary burdens. But the Commission also sees merit in a formal advisory group that would monitor all aspects of compliance costs, and advise the NDIA on ways to keep this to a minimum.

There should be a red-tape advisory group for the NDIA that includes key stakeholders — people with disabilities, carers, service providers and disability support organisations. It should advise the NDIA on ways of controlling compliance burdens on providers, people with disabilities and carers, and to ensure plain English forms, letters and emails.

Independence from day-to-day government control

Governments (as agents of taxpayers) are the implicit shareholders of the NDIA and, consequently, the NDIA would ultimately be accountable to government, and thereby to the community. However, unlike line departments and existing disability services, the NDIA would be a more commercially-oriented body, with a need for long run stable funding and independence in its operational decisions. Consistent with the CAC Act, this implies a more limited role for government in the management of the NDIS. The ICA also took this view, noting that, while a level of government scrutiny is a necessary and helpful part of the governance framework, 'micro decision making' by responsible ministers and 'micro management' by a government department should be minimised (sub. 238, attachment, p. 11). The DIG report also made this point. For example, it would be problematic were governments to interfere in particular cases — such as the assessed amount of services, whether the NDIA might contest an appeal, or decisions about what would constitute 'reasonable' goods or services. New Zealand's experiences provides a warning. The ACC has made decisions — led by directives and subtle persuasion by the government — that have at times undermined the scheme's sustainability.

For these reasons, the Commission considers that the administrative arrangements for the dealings by the board and the CEO with the relevant minister should be specified in legislation, be on an arm's length basis and clearly defined. The provisions would stipulate the:

- frequency of meetings (for example, monthly meetings might be appropriate) The key concern would be to avoid a close day-to-day relationship with the minister or the government of the day, while providing appropriate reporting about the performance of the scheme

- transparency of requests made by the minister or his/her advisors for action by the NDIA (for example, the need for an 'extraordinary' meeting or encouragement for investment in a given measure). These should be in writing and recorded in the annual report

- requirement that the minister receive copies of any significant reports made to the board

- requirement that government should seek in writing the advice of the board on policy changes that would substantially affect the NDIA, given that such changes may have unexpected impacts on solvency. However, in general, policy would be determined by the government and be achieved through statutory changes, rather than through 'advice' to the board.

The Commission also recommends that the Australian Government minister with responsibility for the NDIS should be the Treasurer, reflecting the commercial focus of the NDIA and the critical need to ensure strong cost controls, its insurance characteristics, long-run sustainability and appropriate management of funds set aside for the NDIA. Other ministers — such as in health, community care, disability or social services — would play a prominent role in developing new disability policies, which might affect the precise specification of the various requirements of the Act governing the NDIA.

RECOMMENDATION 9.5

The arrangements between the NDIA and governments should be at arm's length, and subject to strict transparency arrangements.

The federal Treasurer should have responsibility for the NDIA.

The NDIS should have its own legislation

The NDIS legislation should specify the roles, objectives and powers of NDIA and the NDIS, and the critical features that would affect the costs and operation of the scheme. It is important that the legislation be tightly specified to provide a clear indication to the community about issues such as entitlements, coverage and service provision, and to permit the management team and board to plan with assurance.

As there is a need for a single, overarching national Act, and the funding is intended to come from the Australian Government, it should be Commonwealth legislation, but constructed with the agreement of the states and territories. Its design should also take into account advice from experts, including existing state government injury insurance schemes (such as the Victorian TAC, NSW LTCS scheme and the Tasmanian MAIB), New Zealand's ACC, actuaries and commercial insurers.

The legislation should include a list of functions of the scheme, one of which should be financial sustainability, to be made an obligation on the NDIA, its board and the Australian Government, through the responsible Commonwealth minister (as the

South Australian Government said, 'a fiduciary duty to maintain a viable scheme' sub. 496, p. 20). The legislation should also specify that recipients are eligible for benefits only as nominated in that legislation. Both of these inclusions may also allow the NDIA to more readily deflect claims that in effect 'widen' the scope of the scheme. As Yooralla observed, managing expectations will be an issue for the scheme (discussed elsewhere in this chapter), while National Disability Services argued that:

> A stable scheme requires stable rules — projecting costs into the future is difficult without these. (sub. 454, p. 20)

And in the case of the NSW LTCSA:

> … the Authority has had a number of internal audits … which have stressed the risk to the Scheme of over-servicing and participants receiving inappropriate or unnecessary services. … The Authority must … ensure that the Scheme is affordable (LTCSA NSW 2009, p. 9)

There would also be merit in specifying 'entitlement to support' as an objective that should be enshrined in this legislation. As JacksonRyan Partners observed:

> Unless service entitlement is included in Disability legislation, the current rationing of services based on a nebulous relative needs approach will continue to promulgate the existing broken system (sub. 30, p. 12)

However, that should be tempered by a statutory provision that support services provided by the NDIS should be 'reasonable' (an issue discussed further in section 9.8 and in chapter 5).

Future changes to the scheme should be made transparently

Future changes to the legislation should be implemented in accordance with a protocol to ensure good governance and transparency, in consultation with the states and territories, and with full parliamentary scrutiny. Such changes would be independently assessed and audited for their financial implications. Periodical widening and narrowing of eligibility and generosity, such as happened in New Zealand with successive changes of government, exemplifies the problems that can happen. In that case, the financial sustainability of the ACC was put at risk.

The legislation should also enshrine the requirement for independent external reviews of the NDIS to be undertaken at regular intervals (recommendation 9.9).

RECOMMENDATION 9.6

With the agreement of, and input from, state and territory governments, the Australian Government should provide the NDIA with its own legislation that specifies its objectives and functions, and its governance arrangements.

- *Financial sustainability should be a specific obligation of the board, the management and the minister, and this obligation should be enshrined in legislation. It should specifically guide any external review (recommendation 9.9).*

- *An entitlement to reasonable support should be enshrined in legislation, together with details about people's eligibility for services and the range of services to be offered.*

Future changes to the key features of the scheme should be undertaken only by explicit changes to the Act itself, be subject to the usual processes of community and Parliamentary scrutiny, and require consultation with all state and territory governments.

- *Such proposed legislative changes should be accompanied by an independent assessment of the impact of the changes on the sustainability of the scheme, which should be made publicly available.*

9.5   Measures to encourage high performance

Markets provide some disciplines for private corporations to manage efficiently and prudently. Such pressures include risks of reduced market share, takeover or insolvency and visible performance indicators (like dividends, share prices, debt/equity ratios and credit ratings). While in recent years, there have been massive failures in corporate governance and reporting that have not provided proper commercial disciplines (Enron, HIH, Freddie Mac), markets generally provide strong incentives for efficient management when combined with appropriate regulatory oversights.

The NDIA would not be subject to these competitive forces, so other means are needed to ensure good management and cost control.

The Commission proposes several approaches, under several broad banners.

External ongoing monitoring and prudential requirements

Auditing

Accurate, timely and public reporting provides a major discipline. New Zealand provides a lesson in the problems of timely and complete disclosure. In the 2009 Annual Report of the ACC, the responsible minister made the following comments:

> My first glimpse of ACC's financial difficulties came from an urgent briefing before I received my Ministerial warrant last November. I was advised that the Non-Earners' Account required an immediate injection from the new Government of $300 million and similar amounts for future years. These requirements caused considerable angst as the new Government in opposition prudently budgeted commitments to the electorate and this single item exceeded the sum of our new spending. A subsequent Ministerial Inquiry found that this problem should have been disclosed in the Pre-Election Fiscal Update … under the Public Finance Act. Nor was it acceptable that this problem was not disclosed in the Briefing to the Incoming Minister. This annual report discloses similar problems in all six of ACC's accounts. These financial problems have been driven by years of significant increases in costs, increasing numbers of claims, Scheme extensions and declining rehabilitation rates. The underlying cause has been a shift from ACC being a public insurance scheme to it becoming an extension of the welfare state. (ACC 2009, p. 3)

The Chair of the ACC gave a similar picture indicating that the 'Scheme's very existence could be under threat' unless its financial position improved (ibid., p. 4).

The reporting and monitoring arrangements for the NDIA must ensure against similar difficulties.

The Commission considers that, as is usual, the annual financial statements of the NDIA would be audited annually for accuracy and compliance with appropriate accounting standards.

In addition, given the insurance nature of the NDIA, there should be tiered levels of actuarial monitoring. This would include regular (monthly) reporting of trends in usage and costs — and 'red flags' for significant departures from expected outcomes.

More importantly, it would also involve independent professional actuarial assessment of the NDIA on a quarterly and annual basis, with the obligations of the assessments defined in the NDIA Act. While it would not be feasible to fully fund the NDIS, the reporting framework for the NDIA and its independent actuary should cover both its quarterly/annual costs and its notional future liabilities (acting *as if* it were fully-funded). Among other things, the actuarial assessments would:

- monitor and report on outcomes for scheme participants

- identify the likely capacity of NDIA funding arrangements (chapter 14) to meet the future expected liabilities of the scheme

- identify the main factors leading to the costs of the scheme and service utilisation, with that analysis undertaken for different groups of people with disability, by location and by support type

- consider the magnitude and sources of any emerging risks for the scheme, including risks to solvency. A major objective of the report would be to separately consider the impacts on long term liabilities of:

  - internal factors under the control of the NDIA, such as: improving or declining rehabilitation rates; changes in key transition rates (including outcomes); changes in the patterns of assessment of eligibility and entitlements to supports; trends in service use; and over-servicing in allied professional services

  - external factors, such as the impacts of changes in input costs (like wage increases) on overall costs, and the effects of asset rates of return on the NDIA reserve

- examine the quality of the strategies being used by the management of the NDIA to address those risks, and any recommendations for improved processes

- make recommendations about the suitability of data collected to monitor the scheme

- recommend any additional (or changes to) performance measures that could usefully indicate the performance of the NDIA. Notably, the Victorian Auditor-General found that performance reporting by public financial corporations was flawed, 'with the result that the effort and cost of producing performance indicator data [was] therefore largely wasted' (VAGO 2008a, p. 2). It made specific criticisms of the reporting by the Transport Accident Commission (p. 38).

These actuarial reports would be provided to the board, the minister and the external 'regulator' (see later), and in line with agreed standards, highlight any emerging difficulties. The Secretary of the federal Treasury would report regularly to Heads of Treasury meetings on the actuarial performance of the scheme.

The Australian National Audit Office could also conduct periodic performance audits of the processes used by the NDIA, including its reporting functions, but with a clear focus on appropriate, cost effective risk management, scheme accountability and sustainability.

An external monitor

A small specialist unit in Treasury should provide external monitoring of the activities of the NDIS.[4] It would receive the NDIA reports made to the board. As well as covering the matters addressed in the independent actuarial report, the unit would:

- consider the performance of the NDIA across a range of other indicators (for example, client satisfaction and benchmarked performance against other insurers in areas such as claims processing efficiency and overheads)

- analyse the reports made to the board and the annual actuarial report (seeking the advice of the Government Actuary if necessary), seek clarification if needed and provide advice to the relevant minister if the scheme's performance was falling below expectations

- assess whether the NDIA was managing costs and claims efficiently, and had the right processes for doing so.

The Treasury should be required to prepare an annual statement on the performance of the NDIS and the NDIA, to be provided to all governments and made public.

The Treasury would advise the Australian Government of any necessary legislative changes that, if agreed, would then be put to state and territory governments as part of the consultation process.

RECOMMENDATION 9.7

An independent actuarial report on the NDIA's management of the NDIS should be prepared quarterly and annually, and provided to the board, the regulator (the Australian Treasury), the federal Treasurer, and to all state and territory governments. It should assess risks, particularly in regards to the capacity of the expected funding stream to meet expected liabilities within its funding framework, the source of the risks and the adequacy of strategies to address those risks.

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4 APRA adopts a supervisory role for private insurers, but as noted by the ICA, the nature of the NDIA is different, and alternative approaches would be justified for that reason (sub. 238, attachment, p. 9). (Notably, the NDIA would have far less control over its financial assets, and government is its funder.)

RECOMMENDATION 9.8

A specialist unit should be established within the federal Treasury to monitor the performance of the NDIA against a range of cost and performance indicators, to report its findings annually to its minister, state and territory governments and the public, and to provide policy advice to the Australian Government on the scheme.

Periodic independent reviews

Periodic evaluation is required for large government-funded programs (and this need should be reflected in the enabling legislation for the NDIS). Accordingly, the NDIS and NDIA should be independently reviewed after its first three years of operation, and every five years thereafter, with the outcomes publicly and promptly released. A key focus should be on the performance of the scheme in assisting people with disabilities and their carers.

RECOMMENDATION 9.9

The NDIA should be independently reviewed, initially after its first three years of operation, and every five years thereafter, with the outcomes publicly and promptly released.

Other incentives for efficiency

The transparency and reporting requirements discussed above provide the government, the public and the media with information to hold the NDIA accountable. In itself, these are quite powerful forces for performance. An embarrassed government can sack a poorly performing board or an embarrassed board can fire a CEO.

An important measure that can encourage greater performance is benchmarking against comparable agencies. The NDIA will undertake activities similar to many other corporations and insurers in Australia and elsewhere — claims processing, research, IT and data management, accounts and personnel departments and so on.

Figure 9.3 Who does what?
Long-run structure of the NDIS

Functions controlled by the NDIA

Governing board

- Appoints CEO
- Sets corporate plan
- Oversees the performance of the NDIA
- Ensures financial sustainability and good governance
- Seeks advice from Independent Advisory Council as to how well the NDIA meets the needs of its stakeholders
- Reports to Minister and the community

National Disability Insurance Agency

- Assesses needs and determines individual plans and budgets
- Authorises funding of services and supports
- NDIA local area coordinators oversee system at local level
- Web and information services for people with disability, carers and Australians generally
- Assists people in contacting other government service providers
- Helps build capacity among participants and providers to work within the scheme
- Helps build local community capacity for inclusiveness, including encouraging not-for-profits to take on this role, and through small grants to local community groups
- Determines efficient prices for supports provided
- Central purchasing of some goods & services
- Manages costs and future liabilities
- Collects and analyses data about services used, outcomes, efficacy of interventions and provider performance
- Research function
- Provides advice to and monitors fund holder
- Innovation fund
- Interacts with and reports to the board
- Creates a stakeholder group that advises the NDIA on ways of controlling compliance burdens on services providers and people with disabilities, and to ensure plain English forms

Internal but independent review process overseen by Inspector-General to:

- Manages complaints about suppliers
- Reviews NDIA decisions where a person appeals
- Provides mediation services
- Oversees quality assurance of service providers

Functions controlled outside the NDIA

Functions focused on people with disabilities

Government disability & mainstream services outside the NDIS
- Provides other government-funded services to people with disability
- Provides income support
- Agreements with NDIA about respective responsibilities
- Referral of clients to the NDIA
- Provides data to NDIA

DSOs (intermediaries)
- Provides personal planning services & individual guidance
- Links people to the community
- Assembles 'packages' of supports from specialist and mainstream providers
- Undertakes administrative tasks for people using self-directed funding
- Provides data to NDIA
- Innovation in coordinating services

Disability service providers
- Supplies & promotes services to people
- Coordination of a specific provider's services
- Internal complaint mechanisms
- Provides data to NDIA
- Innovation in service delivery

Private mainstream providers
- Supplies services to people

The wider community (not-for-profit organisations, local councils, businesses)
- Community awareness of disability issues
- Economic and social inclusion of people with disability
- A compact with the NDIA to improve outcomes

NDIA-focused functions

Governments
- Form policies
- Appoint Board
- Monitor sustainability
- Guarantees collection of funds (Australian Government)

Courts
- Hears appeals on matters of law

Treasury
- Assesses scheme performance
- Reports to governments about problems with performance

Fund manager
- Manages funds on behalf of the NDIA
- Provides advice to NDIA
- Responds within constraints to advice from the NDIA

Auditing
- Provides professionally independent audits and accounting reports on the NDIA to the government and public

There are several metrics that could be used to assess whether the NDIA was performing adequately. For example, are its administrative costs to be significantly higher than New Zealand's ACC, or its case management cost for complex cases greater than the TAC? If other agencies outsource certain functions, and appear to reap gains from doing so, why is the NDIA not doing so? (There may be good reasons, but the point is to place pressure on management to look for more efficient solutions, as the ACC was required to after disclosure of its recent financial difficulties.) Over time, the NDIA could also be benchmarked against aspects of the National Injury Insurance Scheme (NIIS — chapter 18). The external monitor would periodically fund benchmarking studies for these purposes.

RECOMMENDATION 9.10

The NDIA should be subject to benchmarking with other comparable corporate entities to assess its relative efficiency in its various functions, with the federal Treasury initiating benchmarking studies.

9.6   Why have just one agency?

Currently nine governments fund, organise and, to a varying extent, directly supply supports to people with disability and their carers. The Commission is proposing a simpler approach with one national organising agency. Legislation would define the roles of the NDIA and some of its processes. All Australian Governments would have a role in appointing its board, which would be a commercial rather than a representative board, independent from day-to-day supervision by governments (see below). Individual jurisdictions would still decide whether they wanted to retain a role in directly providing services and supports to people with disability. In addition, the Commission proposes that governments of all levels would still provide many broader supports — education, public housing, public transport, most employment services and income support — through their existing agencies. No scheme could efficiently encompass all functions. The NDIA and NDIS would draw on the existing federal model for disability services, but into a more coherent national framework and with a clear single organising agency.

The differing views of the states and territories

While some state and territory governments were generally supportive of the Commission's draft report proposals, others indicated a preference for a more federated model in which state and territory governments would largely determine the direction of policy and details of service delivery, with the role of the Australian Government limited to providing funding and setting some basic standards.

Box 9.5   State and territory views on the NDIS as a national body

The NSW Government (sub. DR922) said it is unconvinced that a NDIA is preferable to a federated model. It expressed concern that the proposal limits the involvement of, and accountability to, the states and territories. It would like to see more consideration of a federated model. It agreed that the Australian Government is best placed to provide the required funding base for the NDIS.

The Victorian Government (sub. DR996) said it would like a balance between Australian Government and state and territory government responsibilities for a NDIS. It noted that the Commission's preferred model seems to significantly reduce the state's governance role. It would like to explore a range of governance options (rather than just the model with the NDIA and the Australian Government having legislative control). Any proposed governance model should take into account state and territory expertise in the provision of disability services. It added that in other areas of service delivery (such as health, education and housing) where there is significant Commonwealth funding, services are still primarily delivered by the states.

The Queensland Government (sub. 1031) is supportive of and optimistic about the Commission's proposed scheme for disability care and support and proposed funding increases. However, it said it required more details on the costings of the NDIS and NIIS before it could say the proposals were acceptable.

The South Australian Government (sub. 861) supports the proposed NDIS as a nationally funded disability care and support scheme that is entitlement based. It sees its policy role to be working with the Australian Government in the design of the new scheme, and in helping develop an effective interface between its mainstream services and the NDIS.

The Western Australian Government (sub. DR683) does not agree that the WA system is broken. It believes that new arrangements should build upon high-quality state arrangements where they already exist. It does not want a centralised scheme managed and funded by an Australian Government agency, and does not want the Australian Government to have policy control over its system. Additional national funding would allow it to improve and expand its services, but it wants its disability system to remain state-managed, its agencies to retain control over the allocation of funding and for the state government to control policy. It argued for a federated model based on agreed standards of service delivery and consistent data collection.

The Tasmanian Government (sub. DR1032) supports the NDIS and would like to see it fully funded and operated by the Commonwealth. It said that Tasmania needs additional funding to be able to provide enough services for its people with disabilities.

The ACT Government (sub. DR1012) said it was generally favourable, but wants clarification of the roles and responsibilities of the states and territories. It sees the states and territories continuing to play an important role in the maintenance of viable and appropriate community services. It noted that the transition to the new scheme will present logistical challenges, and urged careful consideration of the impacts on disability systems of moving funding to the Commonwealth.

The strongest proponent of this viewpoint was the Western Australian Government, which said it would oppose any scheme that provided the Commonwealth with funding and policy control over the state's disability sector (sub. DR683, pp. 1–2). In its view, changes to the disability system should build on current state-based service systems and compensation schemes, with state control of funding and administration. It said that the most critical issue is under-resourcing, and the Western Australian system would be improved through the provision of additional resources and an agreed national policy framework to improve consistency of services within and between jurisdictions.

Other governments were more supportive of the Commission's proposals. For example, the South Australian Government saw the proposed NDIS as providing 'unequivocal benefits' to people with disability:

> The proposed arrangements (and the principles which sit behind these arrangements) will provide much greater certainty and equity for people with disability and their carers than the current State administered arrangements. (sub. DR861, p. 2)

Some drew attention to matters where they thought further clarity was required before they could reach a final position on the scheme. For example, the Queensland Government, while supportive in principle, said:

> There are a number of issues which are key to deciding whether an NDIS could be supported … Clarity is required in relation to who would receive services under an NDIS; how many people this would be; what services they would receive; how much this would cost; and how this cost would be met. (sub. DR1031, p. 10)

The New South Wales Government, while welcoming the proposal for an NDIS, and describing it as a 'once-in-a-lifetime opportunity' that was 'essential to ensuring that people with a disability have access to appropriate supports and certainty into the future', remained unconvinced that an NDIA model was preferable to a federated model. In addition, it sought greater clarity on:

> … governance arrangements; funding mechanisms; the detail of the coverage; and the role of the non-government service sector in building community capability to support people with a disability (sub. DR922, p. 1)

Several jurisdictions saw the proposed NDIS as broadly aligning with the direction of reforms they themselves are currently undertaking (for example, the *Stronger Together 2* program in New South Wales, sub. DR922, p. 2; and the *Growing Stronger* program in Queensland Government, sub. DR1031, p. 3).

A federal model for the NDIS?

Under a federated model, the Australian Government would provide additional disability funding to state and territory governments and stipulate some common national features (as specified in box 9.6), but would otherwise leave state and territory governments in control of their own systems. It could be achieved by way of agreement between all parties on these common features, with funding then allocated to each jurisdiction — based on summing people's individual budgets following the assessment.

Within the confines of these overarching rules, state and territory governments could then have some latitude about how their system ran. For example, jurisdictions could choose:

- different approaches to acceptable expenditures under self-directed funding. Some might accept paying family members under self-directed funding or be more open about what would be an 'appropriate' choice (for example, some might say yes to the use of the funding to allow an uncle to take a child with an intellectual disability to a football match as family respite; others not)

- whether to employ assessors directly or to contract out this function

- what were permissible or non-permissible therapies under the NDIS (such as acupuncture)

- what boundaries to set around the use of personal plans

- whether to supplement the funding provided under the NDIS to improve supports further, depending on state budgets and on the preferences of the community. (Given a common assessment tool and an entitlement to the budget determined by the assessment process, they could not *reduce* funding.) Augmented funding might be directed to areas like more dwellings for independent living; rates relief; cheaper or greater access to transport

- the extent to which the role of the LAC extended to helping people administer self-directed funding or in trying to engage the community to support people with disability

- how to measure and regulate the performance of providers. Some might maintain highly detailed regulatory approaches — others more light-handed ones

- different ways of informing people with disability about how the system works and their opportunities

- the way in which various supports outside the NDIS would interact with other government services — like education, housing or transport. For instance, some

might closely tie access to public housing to the NDIS assessment of needs; others might use separate processes.

Would this approach be appropriate? It depends on why different jurisdictions would adopt different positions on the micro-design of the disability system. The differences could reflect:

(i) the underlying preferences of citizens in each jurisdiction. If true, that would be both more democratic and more efficient

(ii) differences in the capacity of lobbying groups to achieve outcomes. For example, in one state, lobby groups might strongly resist paying anyone other than workers employed by an agency through self-directed funding because of concerns that broadening the labour market might reduce workplace bargaining. In another state, regulation of service providers may be much more onerous because of embarrassing media-highlighted abuse by one provider

(iii) leadership and circumstance — some states will forge ahead undertaking experiments in policy which, whether they fail or succeed, are useful for other states to learn from. For example, Western Australia has been a leader in self-directed funding and NSW is a leader in transition to work programs

(iv) whimsical variations that arise from 'accidents' of politics, history, fads, the desire to differentiate, or the style of policy making in each jurisdiction, rather than variations that are carefully thought-out matters of design.

If interstate differences mainly reflected (i), then that would be an important balancing consideration in deciding how much national uniformity would be appropriate. But it is hard to see the current differences in jurisdictions' design and funding of disability as genuinely reflecting intrinsic differences in the attitudes of Australians in different states. For example, is the historically lower funding of disability supports in Queensland really a reflection of a lesser need than in other states? Moreover, neither the political process nor mobility really give people a nuanced way of achieving their preferences in any given state. Variations between states in disability service offerings can make relocating difficult. People living near state borders often find such variations illogical and inequitable. And there are so many tradeoffs when voting for a particular political party that means that the package of policies that emerges will often not best match people's preferences.

Consideration (ii) might reflect some of the differences that we see now or that could arise in a system in which the NDIS was implemented in this way. However, would such variations be a good thing?

All other things being equal, consideration (iii) is a virtue of a federal system. However, Australia is a small player in a large world — and there are many more and bolder experiments conducted all around the world all the time. For example, elaborate models of self-directed funding have been in place for years in the United States and the United Kingdom. And meta-studies of programs that attempt to help carers show that most occur overseas. Accordingly, the gains from federal experimentation should not be overstated.

This is all the more so since experiments do not always have to have a federal flavour, but can involve regional or community experiments by national governments (for example, as in Indigenous policy or the Disability Support Pension employment trial). In particular, the strong motivation for the NDIS and NDIA to control future liabilities and to measure outcomes — and associated with this, the much more structured use of data — suggest that a single NDIA may increase *considered* experimentation.

In many, but not all cases, (iv) is likely to be the major source of jurisdictional variations. It is hard to see these as the virtuous outcomes of the revealed preferences of different states.

In that context, it is far from certain that this approach to governance of the NDIA would be appropriate. This is especially so as the Commission's proposed arrangements gives a voice to all governments, and preserves their roles in many important areas.

Moreover, it ignores one of the central benefits of the proposed NDIS. The capacity of people with disability to choose their service providers or to manage their own supports leapfrogs the controls exerted by *all* levels of governments. Under such an approach, governments would not be irrelevant, but their relevance would be much less than is currently the case. Consequently, any additional gains could not be large.

Were the above federated model for the NDIS to be used, it should involve the common elements specified in box 9.6. If this were not done, it is doubtful that the way the disability 'system' worked for people would be much improved, apart from having more money. That would leave intact many of its flaws.

A well-funded federal model developed along these lines would be better than current arrangements. However, there are many deficits in this approach. Moreover, it is unlikely that a coherent model incorporating the above essential features would materialise over the next decade. The system would remain fragmented, and the support received would retain features of the postcode 'lottery'. The opportunity for an insurance approach that provided certainty for people with disabilities would be

forgone. In particular, such an arrangement would expose Australians to the significant risk of:

- divergence rather than convergence in the essential aspects of a coherent system (such as jurisdictions over time adopting their own unique assessment tools or processes, eligibility criteria and levels of service standards)

- undermining the core requirement that funding be sufficient to meet people's entitlements for their assessed needs This would occur, for example, if state and territory governments' funding contributions started to again reflect the vagaries of their budget cycles or were based on arbitrary criteria (such as maintaining real per capita spending levels, despite growing needs).

In the Commission's view, a federated scheme would not offer people the assurance of high-quality long-term care and support.

Importantly, a model along the lines recommended in this report can emulate the apparent advantages of a federated approach. Some participants said they preferred a federated model, in part to ensure a close relationship between service providers and people with disabilities, and to maintain local management and decision-making. But as noted in this chapter, the Commission is recommending that the NDIA would be fundamentally local in character, with a strong regional presence, local decision-making that is responsive to local needs, and independence from governments (and eight bureaucracies).

Local area coordinators would be based in, and have close connections to, the local community, with knowledge of local providers and NGOs, and with some scope to respond flexibly to people's needs. While the Commission sees the scheme as being based on national standards and funding, it would be locally executed, with power over such features as service delivery and capacity building at the local level. The NDIA should be about local solutions to local circumstances.

What if all jurisdictions do not agree?

If some states and/or territories were unwilling to sign up to a full national NDIS, a fallback position would be to roll out the NDIS (and the associated Commonwealth funding) to those states and territories that were agreeable, with other jurisdictions joining later if they wished to gain the advantages of that system.

The advantages of such an arrangement would be that the reforms would not be delayed for those people in need in the supporting jurisdictions, and the logistical exercise would be made easier. However, the clear downsides would be the

continuation of fragmented and inadequate arrangements in those jurisdictions that did not join the NDIS.

Such a partial rollout of the NDIS is clearly workable, and would represent a major step forward. The Commission recommends it as its second option.

Box 9.6   Core features of any national approach

Whichever model is chosen — national or federal — the NDIS should be structured so as to have several core features that would give it the character of a national system. State governments generally supported this view, irrespective of their positions on the respective merits of national or federal structures for the NDIS. Those core features must include:

- the same national eligibility criteria, assessment toolbox, arrangements for assessors, and access to the full range of necessary supports. That would mean that regardless of location, people with equal disability status and traits/natural supports would receive the same entitlements based on need

- certainty of future resourcing

- the model and management of an insurance scheme, including the sophisticated collection and analysis of data to measure the outcomes and performance of the system, and a national research capacity. That would maximise efficiency and underpin a framework for decision-making that considers the whole-of-life costs of support for a person, with the capacity to make early investments that save future costs

- a shift from block funding and a service centred model to one in which people with disabilities and their carers would wield the greatest control, whether that be to cash out their package, or to have it met in flexible ways by providers. Under any arrangement, people could choose their providers, which would have to conform to common quality standards, compete on a competitively neutral basis and be remunerated using efficient prices. Informed choice would be supported by providing nationally consistent and publicly available measures of the performance of service providers

- a focus on individual needs and outcomes, allowing people with disabilities to reach their potential through funded supports and/or active interaction with the community. In many cases, this will include supporting individuals in understanding how to take advantage of choice and options.

- the inclusion of local area coordinators, disability support organisations and a wider community role for current not-for-profit specialised providers

- a national service provider and workforce development strategy.

The Commission's strong view is that these core features would be best organised and delivered using the NDIA to oversee a coherent system for all Australians, regardless of their jurisdiction.

For reasons given above, the Commission remains of the view that a 'federated' NDIS would be the most inferior option, one that in all likelihood would not be able to deliver much-needed reform. Its strong view about the desirability of a single national agency model does not stem from any inherent hostility to federalism (hence our recommendation for a federated injury scheme — see chapter 18). But the Commission sees considerable risks that a *federated* NDIS could easily revert to the current dysfunctional, fragmented and unfair system, with 'agreements' breaking down into disputes about relative contributions, special variations and carve-outs.

RECOMMENDATION 9.11

The NDIS and the NDIA should cover all Australian jurisdictions.

In the event that all jurisdictions do not agree to the establishment of a single national scheme then, as a second-best option, it should still be established, but with its funding and scheme design only applying to participating jurisdictions.

In the event that this second-best option is not adopted, a third-best option would be greater Australian Government funding of state and territory disability systems, but matched by the requirement that to receive that funding, any jurisdiction would need to:

- ***adopt the same national eligibility criteria, assessment tools and arrangements for assessors***
- ***ensure entitlements to the full range of necessary individually tailored supports are based on the national assessment process***
- ***provide certainty of funding based on need***
- ***give genuine choice over how people's individual packages were met, including choice of provider and portability of entitlements across borders***
- ***shift from block funding to individualised funding in the forms spelt out in recommendation 8.1***
- ***use the model and management of an insurance scheme, including the sophisticated collection and analysis of data to measure the outcomes and performance of the system, and a national research capacity***
- ***require providers to conform to common quality standards, compete on a competitively neutral basis and be remunerated using efficient prices determined by the NDIA and taking account of regional and other variations***
- ***adopt nationally consistent and publicly available measures of the performance of service providers***
- ***include local area coordinators and disability support organisations in their schemes***

- *adopt service provider and workforce development strategies.*

9.7   Managing the funding pool

The NDIS will be largely structured as a 'pay as you go' scheme. That is, unlike the NSW LTCS scheme or the Victorian TAC it is not 'fully funded' for its future expected liabilities. Nevertheless, the NDIA would need to have a funding reserve because the pattern of claims and their costs are not fully predictable. A reserve acts as a buffer against this unpredictability, and avoids the situation in which the Australian Government would need to inject additional funds from general revenue when there were higher than expected claim costs in any given period (or worse still, if they did not supplement funding, to avoid rationing each time there was a shortfall).

In view of the expected size of the NDIS, the reserve of investment funds would be significant. The management of the NDIA will be most familiar with the patterns of claims and their likely risk profile. Given this, they would need to play an ongoing role in managing the scheme's cash flows and reserves to reduce the likelihood of threats to the sustainability of the scheme.

The way the reserve funds are managed and invested, including the level of acceptable portfolio risk and the net rate of return, will affect the capacity to avoid increases in, or volatility of, funding. Such funds management is a specialised activity and careful investment management over time will be crucial. Also crucial will be the governance arrangements that permit this activity to be pursued efficiently without changes of direction being imposed externally. The ICA, referring to the adverse impact of 'WA Inc.' on the assets of that state's State Government Insurance Commission in the early 1990s, cautioned that:

> Investment risk is material, and government funds are not immune from it. (sub. 238, attachment, p. 12)[5]

Possible ways of handling this include the use of a dedicated investment department within the NDIA, or by outsourcing investment management, which could be done on a competitive tendering basis, to a single or multiple managers from the private or public sectors, perhaps with conditions such as incentives based on a benchmark rate of return (DIG 2009a, p. 159). The DIG report noted that all of these approaches have precedents in Australian accident compensation schemes. For example, South Australia's Motor Accident Commission manages its own funds,

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[5]   The ICA cited National Competition Policy Legislative Reviews, *Understanding Scheme Failures*, 1998.

while a government agency, the Victorian Funds Management Corporation, manages the TAC's reserves.

As the NDIS would be established under Commonwealth legislation, one possibility would be for funds management to be integrated with existing Australian Government arrangements for investing in long-term assets. The Future Fund Board of Guardians, with the support of the Future Fund Management Agency (a Commonwealth agency), is already performing the role of investing the assets of the Future Fund. The fund meets future public sector superannuation liabilities — and holds assets for the three Nation-building Funds — the Building Australia Fund, the Education Investment Fund and the Health and Hospitals Fund. The Board is responsible for the investment decisions of the Future Fund and is accountable to the Government for the safekeeping and performance of the assets of the Future Fund. They see themselves as having a very commercial focus:

> We are a funds management business focused on delivering high, risk-adjusted returns over the long term on contributions to special purpose public funds. Operating independently from the Government, we will tailor the management of each Fund to its unique mandate while delivering efficiency through common infrastructure. (Future Fund 2010, p. 3)

Of the investment options, the Future Fund appears to be the most appropriate. The Future Fund Board of Guardians operates within the constraints of Investment Mandates set for each fund by the Treasurer and the Minister for Finance, which limits the risks to the Australian Government. Since any overspending by the NDIA would represent liabilities for the Australian Government, they would reasonably have a stake in ensuring the prudent management of those funds.

That said, the NDIA Board would still have a role within the broad framework the Australian Government sets for the Future Fund. The board would need to set guidelines for acceptable levels of risk and return on the NDIA's investment funds, and specify such matters as the required mix of investment types (cash, classes of shares and securities). This may well change over time, as the NDIA learns more about the expected pattern of its future expenditures (and therefore likely demands on short-term cash etc, some of which it may have to hold on its own account for day-to-day use). Beyond the need for managing the funds to meet expected liabilities, the involvement of the NDIA board in these matters would have two other desirable effects:

- Since the responsibilities of the board would be greater, the calibre of directors would be higher.

- It would tend to strongly focus the minds of the board on the NDIA's liabilities, while the changing value of the reserve would provide a very clear indication of threats to the scheme's sustainability.

The NDIA would need to establish internal processes and reporting arrangements, including a small investment advisory and monitoring function within the NDIA itself, and reporting arrangements between it and the board.

9.8   Complaints and dispute resolution

The NDIS will require a tiered set of informal and formal complaint and dispute resolution arrangements to hear complaints about the decisions and conduct of the NDIA (Maurice Blackburn et al., sub. 392, p. ii; New South Wales Ombudsman, sub. 596, p. 2) and about service providers (National Disability Services, sub. 454, p. 18). These arrangements will need to take account of the various kinds of problems that people with disability perceive when dealing with the NDIS. The various Australasian accident insurance schemes have detailed complaints and dispute resolution processes, which provide lessons for the NDIS (box 9.7).

Handling complaints and disputes within the NDIS

The primary objective should be to give well-founded confidence to people reliant on the scheme that they will be treated fairly and that reasonable complaints will be investigated.

Service charters are needed

To underpin this, the Commission proposes that the NDIA should establish two charters — one for the NDIA and the other for specialist providers and DSOs. The TAC and MAIB service charters and the ACC code provide good templates.

The design of the charters needs to recognise that formal procedures to handle complaints and disputes are at the tail end of an interaction between people and the scheme, and the nature of that earlier interaction, and how well it is handled by NDIA staff, may be a major determinant of whether an issue ends up as a formal complaint. Transformation Management Services, which has experience in workers compensation and CTP dispute systems, schemes, suggested that many disputes can be avoided early in the piece by having a well-run scheme and such features as readily-available educational material and good lines of communication with the public. In its view, the quality of the claims decision-making process can determine

whether a matter goes to dispute or not. If these day-to-day systems are working well, issues can be resolved early, but in poorly run schemes, disputes will be resolved 'at the back end', not 'at the front end' (trans', pp. 181–183).

The design of the entire NDIA and its procedures needs to reflect such insights. In part it should involve a layered approach to complaints resolution from the level of the individual assessor upwards (see below). But it also reinforces the importance of the internal culture of the organisation and the quality of its day-today interactions with people with disabilities.

RECOMMENDATION 9.12

The NDIA should establish two service charters that specify respectively the appropriate conduct of the (i) NDIA and (ii) specialist service providers and disability support organisations.

Complaints about the NDIA and about service providers

The NDIA would need well-developed and rigorous internal processes for reviewing disputes over its own activities, as they affect people with disabilities. This would encompass:

- complaints about the conduct of the NDIA, its employees and contract staff (that is, breaches of its own charter)

- disputes about such matters as assessments and plan and funding proposals.

There should be layered options within the NDIA for handling such disputes, with the objective of first trying to resolve them quickly and informally, at low cost. Some examples of the approaches that might be taken are given in box 9.7. So, for example, a person would first approach their LAC, and if unhappy with the result, would be offered further layers of complaint or review processes within the NDIA, involving higher level managers and, where relevant, independent assessors who have had no involvement in the matter under dispute. As is the case with many dispute resolution processes, this should be undertaken without legal representation for appellants and not be bound by rules of evidence.

Similarly, people could also complain to the NDIA about any breach of the service charter by a provider (for example, rude staff or erroneous records). The NDIA has strong incentives to act impartially, and would attempt to resolve these matters in a similar way to the TAC. If the NDIA corroborated a complaint against a provider, then the NDIA should make a determination and would reflect the complaint in ratings of provider quality.

Box 9.7   **How do accident schemes structure their complaints arrangements?**

The NSW Lifetime Care & Support scheme uses a independent assessor (a doctor or other health professional unconnected with the matter under appeal) or a panel of assessors to settle disputes that cannot be resolved informally by LTCSA coordinators or assessment managers. Their decisions are binding, with limited recourse to appeals (the next step being the courts).

The Motor Accidents Compensation Tribunal (a division of the Magistrates Court) hears appeals against decisions made the Tasmanian Motor Accidents Insurance Board (MAIB). It also has a customer service charter that sets out MAIB's obligations and which helps guide people about when complaints about MAIB's conduct might be justified.

The New Zealand ACC has a more elaborate system of complaints and appeals processes, reflecting the large size of that scheme.

- It has several informal processes for dealing with initial complaints, initially a manager and then the Customer Support Service.

- It has codified the rights of its clients through the Injury Prevention, Rehabilitation, and Compensation (Code of ACC Claimants' Rights) Notice 2002. The overarching goal of the code 'is to meet the reasonable expectations of claimants (including the highest practicable standard of service and fairness) about how ACC should deal with them'. The code specifies the rights of the ACC's clients and the obligations of the ACC, such as the right to be treated fairly and with dignity and respect and to be communicated with openly, honestly and effectively. The code does not relate to disputes about assessed benefits. A person wanting to complain about a breach of the code can take it up directly with the ACC or refer the matter formally to Office of the Complaints Investigator, who hears formal disputes relating to the code. Decisions by the Office are not appealable.

- A separate body, Dispute Resolution Services Ltd (DRSL), which is funded by the ACC but operates independently of it, offers a specialist review service for people who are unhappy about decisions made by the ACC concerning entitlements to goods and services. It also offers alternative dispute resolution processes, such as mediation and facilitation. It has its own board of directors and a separate management structure. If a person appeals the decision of DRSL, then the matter goes to the New Zealand District Court, which can also conduct a merit review. Where there is a legal point at issue, a person can appeal the District Court's decision in the High Court with the permission of the District Court.

The Victorian Transport Accident Commission has similar processes. Where the complaint relates to a perceived breach of the TAC Service Charter, the person complains initially to the staff member, and if responses are unsatisfactory to the (internal) TAC Complaints Office, and ultimately Ombudsman Victoria.

If the matter relates to a claim (for example, a dispute over an appropriate home modification), a person has several options. They can refer the matter to an 'Informal Review', which involves a thorough review of a decision by the TAC Review Manager (who works independently of the claims area where the original decision was made). If the person is not satisfied, then:

- those that are not legally represented may immediately appeal to the Victorian Civil and Administrative Tribunal (VCAT). There is a small filing fee

- those that are legally represented are (generally) required to attempt to resolve disputes utilising Dispute Resolution Protocols before resorting to the VCAT. This involves the TAC, the claimant and their lawyer adhering to protocols that have been agreed by the TAC and the legal profession, to speed up the resolution of cases and avoid the high costs of legal action. If this process does not lead to agreement, the person can then apply to VCAT.

Of course, a person with a complaint about a service provider would generally complain first to that provider — which would have its own internal complaints processes. The provider would have a reasonable incentive to retain their 'star rating', and this would be weighted in their deliberations. But as noted earlier, where people feel too vulnerable or uncomfortable with this, their LAC or DSO could support them in this process, or act on their behalf.

To support these arrangements, the NDIA should have an internal complaints office that would hear complaints about the NDIA and service providers, or disputes about its decisions (recommendation 9.12). This would operate separately from the other parts of the NDIA. The office would be headed by an Inspector–General, an independent statutory officer appointed by government, who would be responsible for reviewing complaints and appeals made by people with disabilities and support providers. The NDIA legislation should create this role and specify that the Inspector–General would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making.

That leaves two major issues:

- What processes should be required to ensure fair outcomes and a sustainable scheme?

- What institutional arrangements should be used to make merit reviews?

How should a review process be designed?

It is important that appeals processes be carefully designed to resolve disputes in a manner that is fair and transparent, but in ways that also limit any adverse effects on the financial sustainability of the scheme as a whole.

The key concern here is that appeals processes that are unduly 'soft' can create costly precedents, leading to an unplanned and problematical redrawing of the rules and boundaries of the scheme. This can lead to additional unanticipated costs, and demands on revenue, over the long-term. Such outcomes may also undermine the motivation for assessors or other NDIA staff to continue to make hard-headed objective decisions.

Moreover, appeals and complaints processes can be very costly to provide, and there is the reality that not all people make well-founded complaints. As noted in the review of the New Zealand code:

There is a small core of claimants who do not like the ACC and whose expectations will never be met. These people can be extremely litigious and openly discuss future complaints they may lodge. (Litmus 2004, p. 4)

All of these factors would have the capacity to threaten the sustainability of the scheme, and undermine public support for it.

Appeals processes can widen the scope of the NDIS and threaten its sustainability

In its visits and submissions, the Commission heard strong concerns about the risks to the scheme from excessive expectations about the scope of the NDIS. For example, Yooralla cautioned that there would be a serious risk in managing the expectations of some people (and providers) under a well-funded scheme that was no longer subject to tight rationing. It expressed concern that, were unusual expectations from a few people to be upheld at review and appeal, this could compromise scheme viability for everyone:

> … schemes such as the ACC and TAC have experience of some people coming to expect that the insurer will pay for ordinary life expenses and supports that go well beyond what is needed to respond to the disability, provide support and facilitate participation. In some instances, these views have been upheld by review authorities and in court. … explicit boundaries on what can be funded and review/appeal mechanisms must require that review bodies cannot make a decision that would result in the scheme funding ordinary life expenses or compromise the viability of the scheme via flow on effects. (sub. 433, pp. 24–25)

More broadly, the NDIA has to clearly define what it might mean by 'entitlement' to support. The Commission envisages that entitlement means that people get the supports determined by an objective independent assessment (after considering a person's natural supports). But Yooralla warned that some people see entitlement in more ambitious terms:

> Requests for in ground swimming pools, home gymnasiums, ordinary transport costs, computer systems not related to the disability, GPS systems and funding for ordinary child care are sadly common. The notion of an 'entitlement' scheme also becomes problematic when entitlement is taken to mean 'person A' had a computer/gym program/new bathroom funded so I am entitled to have that computer/gym program/new bathroom. (sub. 433, pp. 24–25)

An area of clear risk is in relation to tailored supports, including self-directed funding. The intention of this model of delivery is for people to fashion funding proposals suited to their own specific circumstances. However, once the NDIA accepts a particular purchase in one plan, there would be a need to avoid that creating a precedent for its acceptability in plans for other people in quite different circumstances.

Particular decisions create precedents that widen the scope of the scheme, and that once entrenched, could only be restrained through new legislation. Such ripple effects could damage the sustainability of the scheme.

Given the experiences of the TAC and the ACC, these concerns are not contrived. Yooralla cited a decision on appeal in Victoria that found the TAC liable for ordinary living expenses, such as rent. The Victorian Government needed to make a legislative amendment so that the ruling did not extend to all people living in shared supported accommodation.[6] Another case illustrating the difficulties is from New Zealand about what might be a reasonable home modification (box 9.8).

The impact of such judgments on the public perception of the scheme is an equally serious concern. The scheme's public support (and therefore its political sustainability) is underpinned by the need for benefits to be reasonable.

An additional concern is the cost of contesting claims and their slowness. For example, it appears that the median time to finalise a case concerning the TAC before the VCAT is around six months (VCAT 2010, p. 42).[7]

In what ways can these risks be limited?

The question is how to address these concerns. There are several complementary approaches.

It will be important for review mechanisms to have not only a broad 'reasonable person' criterion, but to be supported by legislative requirements to:

• have thorough and robust formal initial assessments and processes for calibrating them

• assess reasonableness by balancing the costs of some support against the benefits that these supports have for the person

• assess the appropriateness of the service and of its provider

• take account of any threats to the long run sustainability of the scheme from the review outcome and

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6 Among other changes introduced at the time, this resulted in amendment of s. 60 of the Act (*Transport Accident and Accident Compensation Acts Amendment Act 2007, No. 60 of 2007).* The amendment allowed limits to be set in respect of contributions to be made by a person towards the cost of supported accommodation.

7 This is the median period for the 'general list'. While TAC disputes form the majority of such cases, there are several other types, like FOI cases. It is likely that the median would be higher were these other types of cases removed from the statistics.

- take into account the obligation of people with disability or their families to avoid decisions that unreasonably impose costs on the scheme (such as moving to a dwelling that is very costly to modify).

Notably, the Hon. Justice O'Connor, President of the AAT at the time, referred to the need:

> … to exercise discretionary power in accordance with the terms and purpose of the relevant legislation and with due regard for government policy. In some jurisdictions, this obligation is made clearer by the imposition of a legislative requirement to have regard to ministerial or departmental directions or guidelines. (O'Connor 2000)

The scheme's legislation, as much as possible, should attempt to provide clarity about specific entitlements. For instance, in one appeal, a woman claimed that she should have her childcare costs paid while she attended various health care appointments.[8] The VCAT found for the TAC because of the clarity of the legislation on this matter. Chapter 5 sets out how 'reasonable' services might be defined.

There will also be a need to amend the legislation defensively, as loopholes and problems emerge and also, in some cases because more not less supports should be provided. However, it is not always possible to pass amendments to legislation, or to do so quickly.

Scheme design should seek to avoid large increases in benefits that are associated with small changes in context or circumstances, especially where there is ambiguity about the severity of a person's functional limitation. For instance, one reason why there are concerns about the Disability Support Pension is that someone just passing the threshold work test gets paid significantly more than unemployment benefits and is not required to look for a job, fill in a job search diary or meet other commitments. People face strong incentives to get across the threshold. Similarly, the receipt of ongoing loss of earnings capacity benefits under the TAC's no-fault motor vehicle accident scheme in Victoria is dependent on a person having a 50 per cent impairment rating. Many appeals to VCAT relate to whether a person falls over this decisive threshold.[9]

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[8] Dawson v Transport Accident Commission (General) [2010] VCAT 644 (13 May 2010).

[9] For example: Hexter v Transport Accident Commission (General) [2007] VCAT 674 (3 May 2007); Moldovan v Transport Accident Commission (General) [2005] VCAT 1436 (19 July 2005); Kennedy v Transport Accident Commission [2003] VCAT 2035 (19 December 2003); Zagar v Transport Accident Commission (General) [2005] VCAT 820 (4 May 2005).

| Box 9.8 | **What is reasonable?** |

The case of *Witten-Evans v Accident Compensation Corporation [2003] NZACC 5 (22 January 2003)* has acquired the status of a cause célèbre among those concerned about what might be a person's reasonable expectations. The Commission heard about the case from several participants in meetings and it was cited by Yooralla (sub. 433). The circumstances were as follows.

A child had suffered from cerebral palsy and spastic quadriplegia because of medical misadventure. After the breakdown of the marriage of his parents, the original family home (which the ACC had modified) was sold and the proceeds split. The mother purchased and moved to an old two-story villa, which required installation of a lift and other modifications. The historical significance of the building meant that the costs of modifications would be high.

The ACC was advised of the impending purchase, undertook inspections, and according to the District Court, while the ACC's nominated occupational therapist expressed certain misgivings, the mother 'went ahead with the purchase, possibly in the belief of having [the therapist's] tacit approval.'

The ACC agreed to make home modifications, initially up to $25 000, a figure it subsequently amended to $60 000. This figure would fully meet the costs of modifying the building up to the ground floor (including a lift from the carport level to the ground floor), but would not cover additional modifications wanted by the mother, including a lift to the first floor of the dwelling. An original appeal for more money by the mother through the ACC review process found in favour of the ACC. However, the ACC lost its case in the District Court. The Court argued:

> The responsibility on the [ACC] is to pay for the modifications necessary and [so] I find that it is not appropriate for the [ACC] to simply pick on a sum which it may consider to represent an appropriate or reasonable contribution to the cost of those necessary and appropriate modifications. In that regard I find that it is not appropriate for the [ACC] to include any supposed discount factors [in relation to the extra costs of modifying a building of historical significance], particularly when such discount factors are outside the control of the appellant. … the [ACC] cannot expect any contribution from the appellant to his own rehabilitation, such as to the choice of residence or type of residence. … This Court is not in a position to indicate what it finds to be the proper costs of modifications, but as I have noted, it is the [ACC's] obligation to provide for the modifications which are deemed to be necessary and I have found what is deemed to be necessary.

The determination is revealing in that it seems to weaken the importance of 'appropriate or reasonable' as the basis for providing supports, that it disregards that the higher costs of modifying a heritage building were the result of a choice by the boy's mother, and that it is possible to be unclear regarding the proper costs of modifications, but certain about their appropriateness.

Similar benefits should be provided, regardless of the cause of a disability. Without this, the inevitable ambiguities about causes of disability and injury lead to complex judgments and the likelihood of appeal. This dilemma particularly affects accident schemes. For example, in the TAC scheme, they arise when there is doubt about whether an accident is a transport accident, when there are pre-existing injuries, and when a person acquires an additional injury that might be linked to the original accident. For example, in one case, a woman had a transport accident that left her dizzy, light-headed and uncertain on her feet. The next day she fell while changing the sheets on a bed, and struck her head on the wall of her bedroom, suffering catastrophic injuries resulting in quadriplegia. On appeal to the VCAT, the TAC provided compensation.[10] In other cases, decisions about coverage have gone the other way. Either way, these cases are the reflection of the fact that people get significant supports under one system of insurance and poor supports under the alternative. However, because of its general coverage, the NDIS will tend to reduce such disputed cases.

RECOMMENDATION 9.13

The wording of the NDIA Act should limit the capacity of merits review processes to widen eligibility or entitlement. It should require that any claims by NDIA participants would need to:

- ***meet a 'reasonable person' test***

- ***balance the benefits to the person with a disability against the costs to the scheme, including any adverse implications for the long run sustainability of the scheme from the review outcome***

- ***take into account the obligation of people with disabilities or their families to avoid decisions that unreasonably impose costs on the scheme.***

Who should hear the merits-based review?

A difficult question is whether an internal or external review process should review the merits of particular disputes.

There are already legal obligations on the original decision-maker, and the affected party has the right to seek judicial review on the matters of law raised by an administrative decision. However, there is no legal requirement for external *merit-based* review.

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[10] Ng v Transport Accident Commission (General) [2006] VCAT 9 (19 January 2006).

But despite this, there are some arguments for such an external mechanism to promote impartial judgments where a person disputes the NDIA's decision, given that the consequences may have large impacts on the person (for example, about whether they get what they perceive to be an adequate home modification). It would also reflect public perceptions about natural justice.

This approach is the norm for many other government functions, and is true for MAIB, TAC and the ACC. Many participants argued for the same arrangements for the NDIA (see, for example, the ACT Disability and Community Services Commissioner, trans., p. 369; Valued Independent People, sub. DR932, p. 15). Commonly expressed arguments include that external review is a standard approach in many areas of government administration, that having review mechanisms within the NDIA will raise concerns about potential bias, and a perception of a lack of independence. Capricorn Community Development Association put it thus:

> The integrity of any system, and that includes the NDIS, must be protected by a conflict resolution system that people trust. … People with disabilities have suffered internally administered conflict resolution systems for many decades, and are deeply suspicious of them. People understand conflict of interest, and they understand that whistle blowers are seen as a threat, rather than an avenue to address misuse of power, unfairness or other failings in the system. (sub. DR643, p. 5)

On this point, the Victorian Disability Service Commissioner saw an important role for education and capacity building to help overcome people's reluctance and fears about making a complaint, and to help disability service providers respond to complaints. It added that:

> … particular skills are required to work with people with a disability, their families and service providers where there are disputed claims as to whose interests are serviced in the complaint. (sub. DR820, p. 4)

It saw as critical the independence of the process and a commitment to the rights of people with a disability and to improving the quality of the services they use, together with flexible assessment and complaints resolution processes that are adapted to the needs of people with a disability and circumstances of the complaint. It saw an independent complaints body as the best way to achieve this (sub. DR820, pp. 3, 11).

The Commission agrees that these features should form part of an effective and independent dispute resolution process. It also sees them as being consistent with the proposed design features of the NDIS, which include a person-centred approach to funding and delivery, a significant emphasis on education and capacity building among all parties, and internal processes that support the scheme's objectives and underpin its sustainability. The Commission is confident that these features can

form part of its proposed independent complaints and appeals mechanism (see below).

Some participants, such as the NSW Government supported the proposal in the draft report for internal review. It argued on the grounds that a complex appeals process may place additional burden on specialist service providers, if they were required to repeatedly defend their decisions or actions (sub. DR922, p. 31). Suncorp suggested that:

> … the internal review process, similar to that successfully used by the [NSW LTCS] be adopted at least in the initial stages of NDIS implementation. The efficiency and cost of this review process can be considered after a period of operation, say three years (sub. DR991, p. 8)

The Commission has reviewed all of these arguments very carefully. It strongly supports the importance of well-developed, layered procedures for dealing with disputes that are robust, reliable and independent. But it is also very mindful of the importance to people with disabilities and their families of the NDIS being financially sustainable over the long term, and of the considerable difficulties of achieving this even in ideal conditions. It remains concerned at the capacity of *external* complaints-handling mechanisms to undermine the financial integrity of the NDIA, and considers that the financial risks to the scheme that could arise from external review should be constrained to the maximum extent possible.

It sees this as posing a much greater threat to the interests of people with disability than having dispute-handling mechanisms handled within the NDIA by the independent statutory officer — the Inspector–General.

The experience of successful long-term care and support agencies such as the NSW LTCSA have shown that internal appeals processes can work very effectively. They would still be subject to appeals to the courts in the usual way. And there are ways in which the integrity of internal dispute-handling processes can be buttressed to provide a robust appeals mechanism that would merit the trust and support of people with disabilities. While some might fear that such an approach could deny people natural justice, it would provide a genuine avenue for merit review, and would help safeguard the scheme as a whole.

An Office of the Inspector–General

The Commission proposes that there be a separate office within the NDIA, headed by an Inspector–General, who would be separately appointed by the Australian Government, according to criteria set down in the NDIA's legislation, and whose role would be constituted as an independent statutory officer under that Act.

The NDIA Act should place specific legal obligations on the Inspector–General to independently review appeals against decisions of the NDIA (where they had been through internal NDIA review processes but a dispute remained), and provide him or her with the power to undertake its own investigations and, if need be, direct the NDIA to alter contested decisions.

The Act should also oblige the Inspector–General to independently review disputes and complaints about the quality of services provided, and breaches of service standards, including auditing and appeals (as discussed in chapter 10).

The Inspector–General would also be required to report to Parliament, and publicly, on the number and nature of complaints and appeals, the reasons for its decisions, and on the activities of the office more generally.

In the Commission's view, such an approach would be less costly, while still providing strong protection for people using the NDIS, and would leave the scheme (and people who participate in it) less exposed to the risks that a single decision would create a precedent that affected scheme costs and sustainability.

The Office of the Inspector–General would also be the central point within the NDIA for providing advice about how to resolve complaints.

RECOMMENDATION 9.14

The legislation establishing the NDIA should create an Office of the Inspector–General as an independent body within the NDIA. The Office should be headed by an independent statutory officer (the Inspector–General), to be appointed by the Australian Government.

The Inspector–General should:

- *hear complaints about breaches of the service charters (recommendation 9.11)*
- *review contested NDIA decisions on a merit basis (but with appeals on matters of law being heard by courts in the usual way)*
- *have the power to direct the NDIA to alter contested decisions*
- *oversee quality assurance of service providers*
- *be separate from the other parts of the NDIA dealing with people with disabilities and service providers.*

The legislation should specify that the Inspector–General would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making. The Inspector–General should report to the public and to Parliament on the number, types and outcomes of complaints and appeals (subject to privacy protections), and regularly advise the NDIA board on issues arising from its independent investigations.

Alternative approaches

Were governments not to accept this recommendation and instead prefer to establish an external merits-based review process, this could take several forms (boxes 9.9 and 9.10).

Merit reviews of decisions made by the NDIA would need to involve some detailed specialist knowledge about the assessment tools used and their accuracy, past determinations and their precedent value; the guidelines issued by the NDIA; and detailed familiarity with the NDIA Act, which is likely to be a complex and long statute. (The *Transport Accident Act 1986*, which governs Victoria's transport accident scheme, is 333 pages long.)

For such reasons, an arrangement that permitted the building up over time of specialist subject matter knowledge within the appeal body would be an important consideration. This could be achieved by establishing:

- a specialist division of the Administrative Appeals Tribunal (AAT) relating to reviews of NDIA decisions, along the lines of its taxation appeals division

- an entirely new independent tribunal along the lines of the Migration Review Tribunal and the Refugee Review.

In general, Australian governments have tended to amalgamate tribunals. For instance, the Victorian and NSW Governments amalgamated several smaller specialist tribunals into larger, more generalist bodies, creating the VTAC and the Administrative Decisions Tribunal respectively. Given the tendency to avoid further review bodies, this suggests that the AAT could be used as the external merit review body, were the Commission's recommendation of a statutory complaints and appeals officer within the NDIA not to be accepted. But it is important to note that the AAT, through its decisions, can problematically redraw the rules and boundaries of the scheme.

There would remain the capacity to appeal a decision by the AAT to a court on judicial grounds in the usual way. But as is normal practice, a judicial review would look at whether the merit review body used the correct legal reasoning and followed the proper legal processes, but generally would not review the merits of the case.

Box 9.9   **Appeals processes (Commonwealth)**

Federal tribunals and other bodies have been established to review administrative decisions and actions taken by government officials. The states and territories also have bodies that review decisions made by their officials. Some are specialised and deal with a limited range of decisions, while others have a more general jurisdiction.

There are several major Commonwealth merits review tribunals:

- The Administrative Appeals Tribunal (AAT) has a broad jurisdiction to review decisions made under about 400 federal laws. Family assistance and social security, taxation, veterans affairs and workers compensation constitute the largest part of its workload. (The AAT is unique in the world for the breadth of its jurisdiction and the comprehensive nature of its powers (Walker 2009, p. 5).)

- The Migration Review Tribunal and the Refugee Review Tribunal review decisions made under the *Migration Act 1958*, particularly decisions to refuse or cancel visas or refuse applications for refugee status.

- The Social Security Appeals Tribunal reviews decisions made by Centrelink under social security and similar laws and decisions made by the Child Support Agency.

- The Veterans Review Board reviews certain decisions made by the Repatriation Commission under veterans' entitlements legislation

While the latter two tribunals are independent bodies, their decisions may be appealed to the AAT, albeit not in respect of all matters. This is not generally the case for the decisions of the Migration Review Tribunal and the Refugee Review Tribunal.

It is also possible to appeal decisions made by administrative tribunals to the *Federal Court*, but only in respect of whether a decision was made lawfully within the statutory powers of the decision-maker.

The *Commonwealth Ombudsman* has a different role again — it will seek to resolve disputes through consultation and negotiation but cannot override an agency's decision.

A person may also complain to the federal *Privacy Commissioner* if they are concerned about how the government collects and handles their personal information. Information privacy principles set out how government is to treat this information and the circumstances in which agencies can pass it to someone else.

Source: Attorney-General's Department (2006) and ARC (2006).

At the Australian Government level, the AAT is the most common avenue for undertaking merit reviews. In reviewing a decision, the AAT stands 'in the shoes' of the original decision-maker (Downes 2007), has the same powers as that party, and may substitute its own decision for the original decision. The AAT can also refer parties to alternative dispute resolution, and conferencing to try to achieve settlements prior to proceeding to tribunal.

An important aspect of the AAT's process is that it has some discretion in its judgments. While there are many instances where the law clearly points to only one legally available option, the AAT has the power to make a 'preferred' decision when it is able to choose from a range of equally acceptable outcomes (Walker 2009, pp. 4–5). The quality of those decisions is critical to the financial sustainability of the NDIS because they create 'new rules' that act as precedents for other decisions. As noted by the Hon. Justice Garry Downes (2006), while no formal doctrine of precedent exists in administrative law, members of the Administrative Appeals Tribunal will follow earlier decisions of the Tribunal unless they are satisfied that the earlier decision is manifestly wrong.

A different perspective was put by the National People with Disabilities and Carer Council, which comprises people with disability and their families, carers, industry and union representatives and academics and which advises the Minister for Families, Housing, Community Services and Indigenous Affairs and the Parliamentary Secretary for Disabilities and Carers on the development and implementation of the National Disability Strategy. The Council endorsed the Commission's proposal for an independent statutory officer to review appeals against the decisions of the NDIA, but it was not convinced that the AAT was the most appropriate alternative to hear merit-based reviews. It recommended instead that further consideration be given to alternative appeal systems, including an Office of the Disability Ombudsman (sub. DR1026, p. 6).

A common role of an Ombudsman is to seek to resolve disputes through consultation and negotiation, but without the power to force an agency to comply with its recommendation.[11] However, agencies usually do accept such recommendations. There might be merit in use of an Ombudsman in this instance if this would provide strong independent review and at the same time avoid the financial risks discussed in this chapter. But even if this were the case, the Commission remains convinced that the model it has recommended can meet both of these objectives more directly and more effectively, particularly in view of the *legal obligation* of the Inspector–General to *direct* the NDIA to overturn what it

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[11] There are exceptions to this — for example, in the case of Ombudsmen that have responsibilities in the financial sector.

judges to be erroneous decisions. Moreover, under its proposal, the Inspector–General would supervise all internal NDIA appeals mechanisms, adding an extra degree of surety in the layered approach to addressing complaints and appeals, as recommended in this chapter.

A different route again would be to implement recommendation 9.14 on an interim basis only. That is, the NDIA could use the proposed Office of the Inspector–General as an interim arrangement during the setup and establishment years of the NDIS. This would provide a strong complaints-handling regime over the period during which the full NDIA will be implemented (chapter 19) and as its procedures are being bedded down and refined. It would also provide greater protection against cost blowouts. The Government could then revisit the question of the appropriateness of external administrative tribunals, drawing on the experience of the Inspector–General and any other relevant material, including the views of users of the NDIA.

RECOMMENDATION 9.15

If the Australian Government does not accept the Commission's proposed appeals process (recommendation 9.14), two other less preferred options would be that:

- *the NDIA should use the Inspector–General as an interim arrangement during the setup and establishment years of the NDIS, and then revisit the appropriateness of external administrative tribunals*

- *the Australian Government should create a specialist arm of the Administrative Appeals Tribunal to hear appeals on merit about the NDIA's decisions subject to the constraints of recommendation 9.13. In this instance, the Australian Government should set aside significant additional resources to fund this specialist arm and should include a larger reserve for the NDIS, calculated to take account of the higher risks of this approach.*

Costs of an external appeal body

The costs of these arrangements is uncertain, depending on the number of reviews and their complexity. Many VCAT decisions regarding TAC matters involve the testimony of many doctors, the examination of past records, as well as oral evidence from the TAC and others. Judgments can run for 30 pages. The TAC estimates that the external costs of handling appeals heard by VCAT typically range between $5000 and $10 000.

Appeals to VCAT about TAC's decisions provide one source of evidence about possible overall costs. There were 661 appeals to VCAT about decisions by the TAC in 2008-09 (TAC 2009a, p. 30). To put that in context, there were around

40 400 people receiving benefits from TAC in that year and 19 200 new claims lodged (p. 12). Appeals can be in relation to claims or to TAC's decisions about existing clients (for example, eligibility for a specific service, or about how impairment may have changed over time).

Data from existing Australian Government tribunals suggest a range of unit costs (table 9.3).

Table 9.3 **Costs of tribunals**

Size, approximate cost[a] and workload as at 30 June 2010

	Members	Staff	Expenses	Reviews finalised	Cost per case finalised
Administrative Appeals Tribunal	91	162	$35m	7 447	4700
Migration Review Tribunal & Refugee Review Tribunal	94	272	$40m	9 737	4100
Social Security Appeals Tribunal	211	113	$27m	14 706	1858
Veterans Review Board	39	31	$5.5m	3 742	1450

a The estimates of costs per case finalised are very approximate and not strictly comparable. Only a rough estimate of total expenses has been used, without, for example, taking into account how the agency is structured (for example, if it pays lease/rent costs) or the extent of fees charged to the applicant. Similarly, a measure of cases finalised in a particular year does not give a clearcut indication of a tribunal's workload, as considerable work may go into cases in progress but not finalised in the same year. Also, some tribunals hold public hearings in a wide range of locations, or require extensive use of interpreters, thereby raising costs. But for the purposes of planning a new appeals body, having a rough indication of aggregate and per case costs can shed some light on the quantum of funds that would be needed to provide an external appeals mechanism.

Source: Annual Reports for 2009-10, websites.

Supposing, for illustrative purposes only, that in any given year, the NDIS had to assess around 500 000 people, then using the TAC appeal rate as a guide would imply around 8000 appeals to the external review body per year. Were each finalised cost to be $4700 — roughly the current average for cases before the AAT — then that implies appeal costs of about $40 million (roughly doubling the cost of the AAT). In fact, the number of appeals would be likely to be lower, as many of the sources of disputes for the TAC would not be present for the NDIS (for example, in relation to matters affecting income replacement or disputes about the source of a disability/injury). The rate of appeals in the Tasmanian motor vehicle scheme are less than half that of the TAC, further suggesting lower likely appeal costs.[12]

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12 While the Commission did not get data on the number of people receiving benefits through MAIB, there were 3367 new claims received for the Tasmanian scheme (MAIB 2009) and 45 appeals made to the Motor Accidents Compensation Tribunal (Magistrates Courts, Annual

The way forward

As noted above, the Commission is very mindful of the risks to scheme sustainability and the wider injustice to people with disability that this would involve. It favours an internal review process that explicitly avoids that risk. A statutory officer (the Inspector–General) would guarantee impartiality, be an efficient means of reviewing complaints and appeals, and would still leave people the scope to appeal to the courts in the usual way. However, in the event that governments prefer external merits review, this could be undertaken by a specialist division of the AAT. Either way, the risks of review processes should be curtailed through clear legislative guidance.

9.9   Other functions

The NDIA will have several other functions critical to the success of the NDIS:

Quality assessment

The question of how to ensure the quality of support services provided to people with disabilities and their families is a fundamental issue for this inquiry, and a key responsibility of the NDIA. Chapter 10 canvasses this issue in detail, and proposes a range of measures by which this might be achieved.

In view of the greater role that the NDIS would give people with disabilities to make most choices about support services themselves, a major discipline on the performance of disability service suppliers and any intermediaries would be competition. People with disability could:

- assemble their own supports, including through mainstream services

- shift from one specialist supplier to another if they were unhappy with their services. Clearly such mobility would need to balance the reasonable commercial certainty for suppliers writing any longer-term contracts with people with disability and the need to avoid onerous exit terms if services were inadequate (noting that the Australian Government has introduced unfair contract legislation that would address this risk — *Trade Practices Amendment (Australian Consumer Law) Act (No. 2) 2010*))

Reports 2008-2009, Tasmania). This is 1.3 per cent of new claims. Calculated on the same basis, the comparable rate in Victoria is 3.4 per cent of new claims. (This measure is not necessarily the best measure of the incidence of appeals since people can make complaints without lodging a new claim, but it provides a picture of the relative appeal risks of MAIB and TAC.)

In addition, LACs would collect assessments from consumers on a confidential basis about the performance of suppliers, and the NDIA would also have information on direct outcomes achieved from its own data management systems (chapter 12). This would allow consumers to make more informed choices when selecting providers — and would penalise poor providers. This would lead to a publicly disclosed rating for all specialist disability providers akin to the 'star rating' systems used in the Job Network. As in the Job Network system, the ratings could be adapted for the difficulty of achieving outcomes for people with different characteristics. If a supplier was rated consistently poorly, the NDIA could remove them from a list of registered specialist providers.

Chapter 10 addresses these issues.

Data functions

Data collection and management is essential for managing day to day cost pressures and long-term liabilities, testing the efficacy of interventions for people with disability, putting pressure on suppliers to be efficient, adapting assessment processes, and generally assessing risks to the scheme.

As the Insurance Council of Australia observed:

> Commercial insurance by its very nature focuses on "total cost" over the life of the claim and not just individual cost elements. As such it promotes the use of measures which aid the recovery of injured persons to reduce those costs. … To best manage total costs and achieve optimal health outcomes, insurers utilise various strategies including: early medical and rehabilitation intervention; management of external service providers; continually scanning the medical and allied health environment for the latest evidence based programs. (sub. 553, p. 10)

We discuss data collection and management functions separately in chapter 12.

The implication of this data handling and management feature is that the NDIA will need very significant competencies in IT, data management and analysis — encompassing hardware, software and people — with many more resources than currently allocated to this function among the current disability system. The disability sector will also need to have complementary IT and software. The experience with the Job Network was that IT issues dealing with the employment department were a major source of dissatisfaction among providers (PC 2002). Developing the above capabilities will take some time, and would be one of the important initial steps in the implementation of the NDIS. Existing large scale schemes, such as the New Zealand ACC, the TAC, some workers' compensation

schemes (and for that matter, Centrelink, Medicare and the Job Network) would provide practical guidance.

The Commission does not presume that the NDIA would necessarily undertake all of these functions in-house. It would be up to management to determine whether it was more efficient to outsource some of these functions.

Research

The NDIA would need to have research capabilities to, among other things:

- use the data described above to achieve the goals of the scheme
- to assess innovative therapies or new aids and appliances proposed by suppliers
- develop new preventative, early intervention and any other approaches improving outcomes for people with disability and their families.

Chapter 13 discusses this issue in detail.

10   Delivering disability services

Key points

- Consumers experience profound difficulties in finding out what disability services are available and how to access them. Features of the NDIS — specifically, a single point of entry and assessment, increased resourcing and consumer choice — would ameliorate many of these problems. However, there are further steps that should be taken in order to assist consumers by minimising transaction costs. These include:
  - a national internet database featuring information about service providers and indicators of service quality
  - a strong role for local area coordinators to assist decision-making and to monitor clients' wellbeing. Their role should be graduated in terms of the needs of the client and concentrated at key transitions, such as when people first enter the disability system or between school and work
  - assistance with planning, administration and brokerage by Disability Support Organisations
  - a confidential and longitudinal database containing client information, for the purposes of: reducing administrative requirements for both service providers, government and consumers; monitoring the quality of service provision; evaluating the effectiveness of different types of services, rehabilitation, appliances etc; and monitoring the costs and utilisation of support services.

- The use of individualised packages and greater consumer choice will increase competition in the provision of high quality services. Nevertheless, there is a strong argument for a continued role for regulatory oversight in protecting vulnerable consumers from harm and ensuring providers adhere to a basic standard of service. In addition, both consumer decision-making and the market incentives for providers to deliver quality service products can be bolstered by making performance information (such as outcomes of audits or annual reports by community visitors) and other standardised indicators available to the public.

- While consumer payments to providers (or through DSOs) should become the industry norm over time, there may still be a role for some block funding where markets would otherwise not support key services. Specific areas where block funding may be required are: crisis care; rural areas; community capacity building; some individual capacity building; to support disadvantaged groups (such as indigenous Australians) and as a tool to promote innovation, experimentation and research.

- Individual and systemic advocacy should continue to play an important role in the disability sector under the NDIS, and should be sufficiently funded to do so. In order to ensure its independence (from the NDIA) and effective provision, advocacy should be funded by FaHCSIA and from state and territory governments.

- Government-run service providers would be funded by the NDIA on the same basis, and with the same conditions, as not-for-profit and private service providers.

There is a large and specialised market for providing disability support services and equipment to people with a disability in Australia with more than 2200 disability support agencies (AIHW 2011a). The current market gives prominence to relationships between government agencies and service providers and less to those between people with a disability and providers. Government agencies contract providers directly through 'block funding' to deliver services and undertake quality assurance. The person with a disability is often a passive recipient of (rationed) supports from a local block-funded provider, and has little input into the services they get. The providers themselves are given funds well short of the needs of the groups they serve and have little freedom to adopt innovative practices.

The performance of this market has major effects on the lives of people with disability and on governments' purse strings. Under a NDIS, the sector will face significant structural changes over the medium run — in particular, increased funding, changes in the design of disability system, the adoption of consumer choice (including self-directed funding) and new governance arrangements.

Change itself is not new to the disability sector — over the last 30 years the disability system and social attitudes to disability have changed considerably (box 10.1), in many instances for the better (Clear 2000, p. 68; Ward 2006, p. 254). Governments have closed most institutions, and expectations of social and economic participation have risen. Through this period of change, the basic themes of social inclusion and citizenship, empowerment and the need for diverse, responsive and personalised support services, have increasingly been emphasised. However, these themes have not been reflected in adequate resourcing and actual service delivery. Clear (2000) observed:

> … the discourse of state policy pronouncements does not match up with their personal experiences, and community care has not presented a reliable and secure opportunity for citizenship for many parents or their sons and daughters.(p. 71)

In short, the broad aspiration of creating a disability system centred around people with disability themselves, and equipped to meet their needs through the provision of high quality services, is very much an unfinished project. In addition to increasing the resources available to people with a disability, the proposed NDIS will provide people with a disability much greater power about how their needs are met.

Box 10.1　Changes in the disability system in Australia

The disability system in Australia has changed considerably over the last 30 years. Historically, supports for people with a disability were limited (beyond that provided by their families) and tended to be charity based and reliant on large scale institutions. This began to change in the mid 1970s with the movement towards 'de-institutionalisation', whereby residents of large scale institutions were gradually relocated into the community (Ashman 1989). In turn this was accompanied by a growing recognition of the social responsibility to build a more inclusive society through offering greater (and more appropriate) support to people with a disability, as exemplified by the International Year of Disabled People in 1981 and the growth in capacity and variety of disability services throughout the 1980s (Clear 2000).

This culminated in the Commonwealth *Disability Services Act 1986*, which recognised the broad range of services needed to facilitate community (rather than institutional) care and provided a legislative basis for funding disability services. This Act changed the dynamic between government and service providers and set out a framework aimed at linking funding with specific outcomes (such as independence, employment opportunities and integration in the community). The development of Disability Service Standards in 1992, and the increasingly explicit contractual obligations and greater reporting requirements that emerged throughout the 1990s were both geared towards facilitating this in practice.

In 1991, Australian governments entered into the Commonwealth and State Disability Agreement. This agreement demarcated responsibility for the provision of disability services by different levels of government. Its intent (if not its actual achievement) was to address the overlap, duplication, gaps and lack of coordination that had previously been a feature of the sector.

Three subsequent agreements have been entered into:

- 1998 CSDA – aimed at more flexible service delivery models, improved accountability and performance reporting and increased use of technology

- 2003 CSTDA – aimed at strengthening support for families and carers and improving cross government linkages and access to generic services

- 2009 National Disability Agreement – aimed at improving early intervention, lifelong planning and person centred approaches. This agreement identified ten priority areas required to underpin the policy direction and achieve these reforms. (AIHW 2011a).

In 2008, the Australian Government ratified the United Nations Convention on the Rights of Persons with Disabilities. The convention entails certain obligations on parties ratifying it, such as adopting legislation and administrative measures to promote the human rights of persons with disabilities, eliminating discrimination in workplaces and society; providing information to people with disabilities, undertaking disability-relevant research and development and appropriate consultation with people with disabilities in developing and implementing legislation and policies and in decision-making processes that concern them.

This chapter briefly describes the disability service sector (section 10.1) and examines how the provision of support services and equipment can become more responsive, efficient and more adept at meeting the needs of people with a disability.

Given the magnitude of the proposed changes, it will be important for the NDIA to provide adequate support to both people with disability, and to specialist providers, as they adjust to the new system. A central aspect of this is understanding how historical problems in the disability sector may persist under the proposed system, and how best to address them. Prominent amongst these is the complexity of the disability system and the difficulties experienced navigating the disability system — for both consumers and service providers. Section 10.2 discusses how this can be reduced under the proposed NDIS.

Ensuring that support services are of adequate quality is another ongoing challenge for the sector. Under the proposed scheme, consumers would play a much greater role in this than they currently do. In addition, a system of regulatory oversight would be required to deliver high quality services. This should take account of the need to protect vulnerable consumers, and the costs and efficacy of regulation and monitoring. These issues are considered in section 10.3.

Finally, there are specific areas where traditional approaches, such as block funding or government provision of services, may deliver better outcomes for consumers than market-based solutions. This is examined in section 10.4, with a particular focus on the difficulty of providing services in rural areas.

10.1   Disability support services

People with disabilities and their families rely on a range of goods and services in order to fulfil their care needs and to maintain the quality of their lives. Comprehensive data on the government-funded specialist disability services is gathered as part of the Commonwealth State and Territory Agreement, and published annually in the Disability Support Services report (AIHW 2011a). This data collection categorises disability support services into five main groups: accommodation support, community support, community access, respite and employment services (box 10.2 describes these groups in more detail).

Box 10.2   Types of disability services

Accommodation support: Services that provide accommodation to people with a disability, and services that provide the support needed to enable a person with a disability to remain in his or her existing accommodation or to move to more suitable or appropriate accommodation. This includes attendant care and in-home accommodation support, as well as group homes and other residential facilities.

Community support: Services that provide the support needed for a person with a disability to live in a non-institutional setting. This includes therapy, early childhood intervention, behaviour specialists, counselling and case management.

Community access: Services designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence. This includes learning and life skills development, recreation and holiday programs and other community access programs.

Respite: Services providing a short-term and time-limited break for families and other voluntary caregivers of people with a disability, to assist in supporting and maintaining the primary care-giving relationship, while providing a positive experience for the person with a disability. This includes own-home respite, centre-based respite and host family/peer support respite.

Employment: There are three types of employment services which provide employment assistance to people with a disability. *Open employment* provides assistance in obtaining and/or retaining paid employment in the open labour market. *Supported employment* provides employment opportunities and assistance to people with a disability to work in specialised and supported work environments. *Targeted support* provides people with a disability structured training and support to work towards social and community participation, or opportunities to develop skills, or retrain, for paid employment.

Advocacy, information and alternative forms of communication. Services that represent the interest of individuals or groups, campaign for systemic change, and provide accessible information to people with a disability, their carers and families, as well as related professionals.

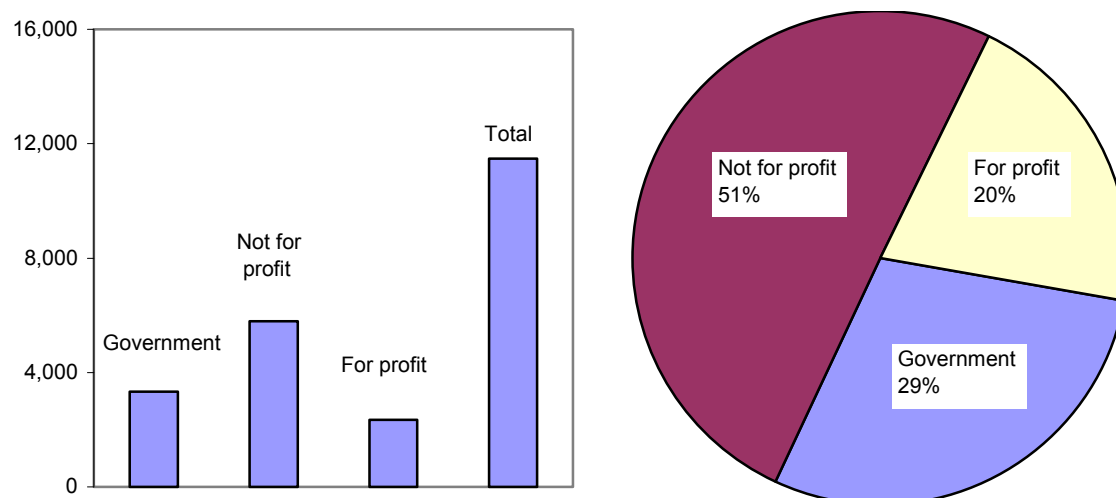*Other support.* Includes research and evaluation, training and development and peak bodies.

Source: AIHW (2011a).

While this comprises the majority of the sector, it does not account for services privately purchased by people with a disability. In addition, it does not provide information on aids and appliances or home and car modification. These physical goods play a vital role in the wellbeing of people with a disability, but are a relatively small part of the sector. For example, attendant care alone (itself a sub-category of accommodation support) can comprise up to 80 per cent of the individual funding package offered in the NSW LTCSS. Similarly, around $1.56

billion was spent on disability services in NSW in 2008-09, dwarfing the $54 million budgeted for aids and appliances, prosthetic limbs and the home respiratory program in that state for 2010-11 (sub. 536, p. 24).
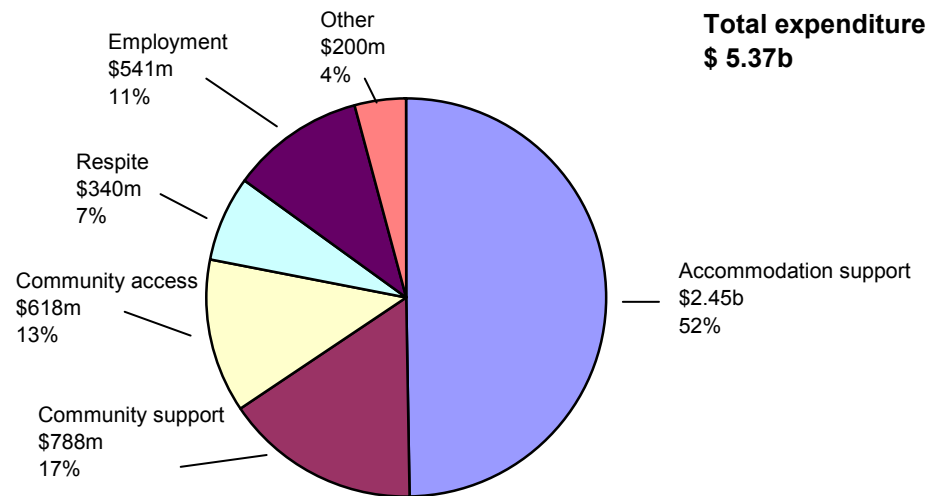
In 2008-09, almost $5.4 billion was spent on CSTDA services, which was delivered by 2200 agencies through around 11 500 service outlets. Of these, around 51 per cent were not-for-profit, 20 per cent were for-profit and 29 per cent were government run (figure 10.1). Accommodation support — mainly in-home support (50 per cent of users of this category) and group home facilities (34 per cent) — is a central feature of CSTDA-funded services, with around 46 per cent of all government expenditure spent in this area (figure 10.2). There were more accommodation support outlets than any other type (figure 10.3), and providers tended to be smaller, servicing fewer clients (8.5 on average) but spending considerably more per client ($63 000) (figure 10.4). Conversely community support and employment services providers tended to be larger, servicing greater numbers of lower cost clients.

Figure 10.1 **Number of funded service outlets, 2008-09**

Data source: AIHW (2011a, table 2.2).

Figure 10.2 **Expenditure share, 2008-09 [a, b]**

Other
$200m
4%

Employment
$541m
11%

Respite
$340m
7%

Community access
$618m
13%

Community support
$788m
17%

Accommodation support
$2.45b
52%
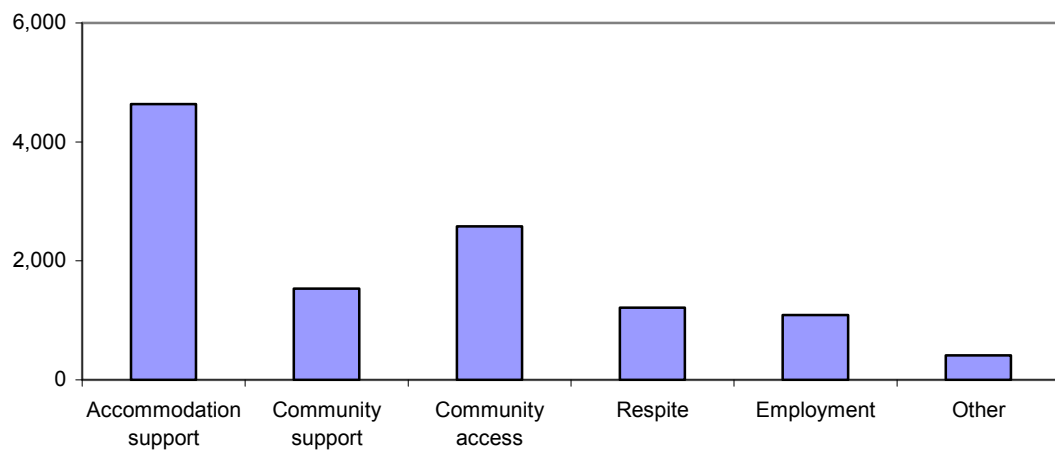
**Total expenditure
$ 5.37b**

a The category 'Other' includes advocacy and information services, administration and other services.

b Individual items exclude expenditure on administration and capital grants. However, administration and capital grants are included in the total expenditure figure.

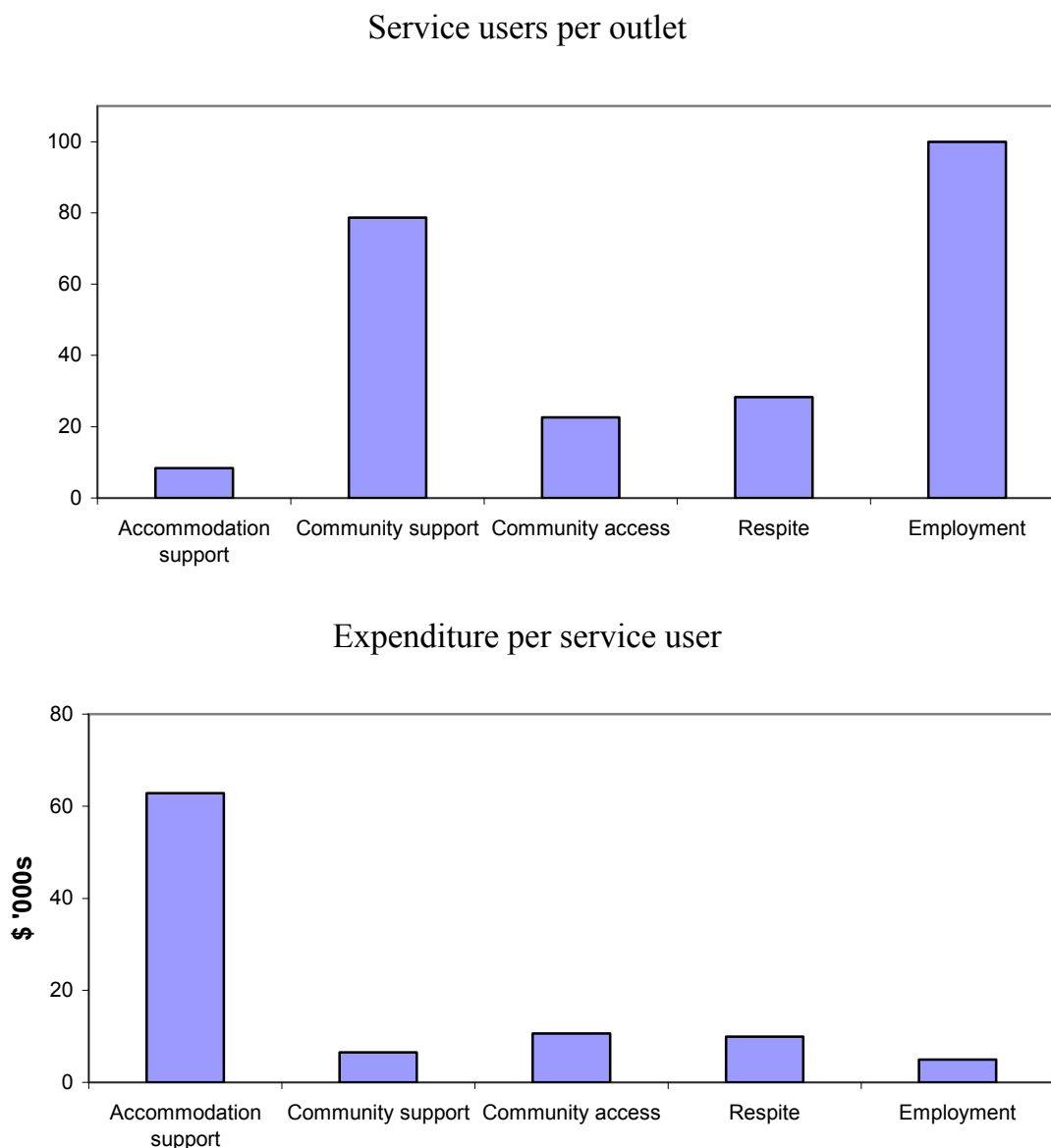*Data source:* AIHW (2011a, table 2.8).

Figure 10.3 **Number of service outlets by type, 2008-09**

a The category 'Other' includes advocacy and information services, administration and other services.

Data source: AIHW (2011a, table 2.2).

Figure 10.4 **Average number of users per service outlet, 2008-09**

Service users per outlet

Expenditure per service user

Data source: AIHW (2011a, tables 2.4 and 2.8).

10.2 Navigating the disability system

People often see the costs of a service in terms of the dollar prices they pay. However, there are many other costs people experience in using the disability system: trying to find out what is available, assessing the quality of alternative providers, filling in forms, completing assessments, and waiting. These 'transaction' costs (box 10.3) represent yet another burden on people with disability. In particular, rationing within the disability system compels people to:

- enter long queues in order to receive support

- waste time and energy applying for support that is ultimately denied (or only partially granted) for reasons other than relative need

- be forced to periodically re-establish or find new supports when funding is withdrawn or 'runs out'.

While the hardship that people face when trying to access disability goods and services is largely driven by the high degree of rationing in the system, it is not the only source of such 'transaction' costs. A common theme amongst participants in this inquiry is the extraordinary difficulties they have encountered merely in finding disability services (hence the 'maze'), and the ongoing time, energy and expertise required to fulfil the administrative requirements even after entitlement to services has been established. While transaction costs cannot be eliminated, minimising such costs can lead to significant efficiency gains (better allocation of resources and less leakage through administrative costs) and can be of considerable benefit to consumers.

Box 10.3   **What are transaction costs?**

In all markets, consumers and producers face search, information and other 'transaction' costs when dealing with each other. These include the costs faced by producers and consumers in finding each other, communicating what they need and can offer, and understanding and meeting the laws, regulations and contractual obligations that govern their exchanges. Transaction costs can relate to monetary costs of the transaction (the cost of petrol to drive to a shop or the cost of a lawyer to draw up a contract between two parties) or to time and energy put into finding the right producer or customer. In the broader economy, such costs are pervasive, often unavoidable, and not usually grounds for government involvement. (In private markets where transaction costs are high, firms can invest heavily into advertising, can integrate vertically to avoid the difficulties they face in procuring inputs into production, and intermediary firms often emerge to match products with consumers, such as real estate agents, eBay etc.)

In the case of the disability sector, these transactions costs largely reflect the central role of government in the disability system. Most of these costs are not measured and fall on some of the most vulnerable people in Australia.

In practical terms, where transaction costs are excessive (and administrative burden is disproportionate to the risks to taxpayer funds) people with disabilities receive less assistance than they otherwise would have and experience greater difficulty in accessing it.

Finding out what is out there (and how 'good' it is)

People with disability and their families need to be able to assess whether services exist in their local area, and their quality and suitability. This is a costly process — in terms of time, energy and money — and the costs are highest when a person first

enters the disability system, when they also typically are struggling to adjust to a newly acquired or diagnosed disability. This experience is often repeated at key transitional points in people's lives, such as when they leave the education system or retire. At worst, this type of transaction cost limits peoples' choices in much the same way as shortages — most conspicuously through the unmet need that arises through 'hidden' programs that people would access if they knew of their existence. For example, Carers Australia said:

> A familiar phrase when carers are talking amongst themselves is "why didn't someone tell me about that? Or "why wasn't I told?" Many carers are unaware of the services and support available. There is a strong need for carers to be well informed about any support or services to be funded under the scheme and the operation of the scheme itself. (sub. 406, p. 17)

Similarly, the difficulty of observing quality (prior to delivery) may make people reluctant to try new approaches, given that the application process is time consuming, uncertain in itself and could potentially affect eligibility for existing arrangements (Kate Evans and Frank Beard, sub. 278, p. 3).

Finding out how to get it

Whilst people's experiences vary, it is apparent that many struggle with the ongoing administrative burden of applying for and maintaining disability care and support services (box 10.4). People with disabilities and their families must often simultaneously become managers and advocates, dealing concurrently with multiple disability service providers, government agencies and health professionals. Typically eligibility (and assessment) must be individually established with each body, and often people must periodically reapply even if their situation has not changed, resulting in them retelling their story over and over again.

Those who are educated, articulate, confident, creative and have managerial skills and strong support networks are better placed to cope with the demands of the disability system. Conversely, those who are most isolated, vulnerable and in need, experience the greatest difficulty in finding assistance and, as a result, are less likely to have their needs met. At an extreme, participants have reported that some families 'drop out of service provision because they find it too hard to continue self-referring for services' (Royal Children's Hospital, sub. 405, p. 6).

Even those best placed to deal with the administrative burden still face all the other anxieties and emotional distress of their own or a relative's disability. For example, one participant spoke of the trauma of having to periodically detail all of things their child will never be able to do (Susan Freeme, trans. p. 533).

There has been expressed need in consultations to reduce the need to repeatedly prove eligibility for different forms of support… …The overarching family-centred assessment process suggested in this submission may assist in this challenge, providing a single assessment to access multiple services. (Carers Australia, sub. 406, p. 17)

Paperwork is the bane of both service providers and families. We have been told we need to update our application for funding even though there is no prospect of a success. This process takes quite some time, requires that we paint ourselves as incapable, requires service provider time with no provision for recompense. The application will need to be vetted and entered into a database, thus using bureaucratic time with no direct service provision. (Bill and Alison Semple, sub. 43, p. 1)

… each of the seven organizations I deal with all require much the same paper work and administrators looking after this paper work (personal response)

We deal with over 30 agencies related to Sammy's disability …The transaction costs for us and the agencies are very significant. Many families are deterred from accessing services for this reason. The efficiency losses are large, real and constant. (Greg Mahony, sub. 356, p. 4)

As an agency supporting consumers, we grapple with complications of complex service delivery system — even with our 25 years experience in the industry it is still difficult for us to understand the intricacies and changes that occur. How can we expect clients to understand? (Housing Resources and Support Service Inc, sub. 207, p. 9)

Why are the system navigation costs so high?

The complexity of the disability sector is driven by a combination of structural and historical factors. In large part, it arises from the logistical problem of matching a highly diverse array of services (see box 10.2) with a large group of people with highly diverse needs. That is, the varied and complex combinations of services that people with a disability need do not lend themselves easily to a simple supply model. This has been compounded by the conditions under which the disability sector has emerged, including binding resource constraints and the constant changes to the sector. Lindsay (1996) argues that much of the sector has grown through specific advocacy actions resulting in 'ad hoc programs' that 'respond to specific needs and demands without any consistent policy framework or philosophy'.

Navigating the disability system is also made more difficult due its fragmented nature. As pointed out by Lindsay (1996), this fragmentation is partly a design feature of CSDTA and partly a consequence of the natural division in portfolio responsibility within government.

Fragmentation is not inherently bad, especially for service provision. Indeed, it can drive specialisation, variety and experimentation, as in markets for many

mainstream goods and services. However, fragmentation of departments that fund and determine access to disability services increases the general complexity of the system and can blur the boundaries of responsibility and accountability, resulting in both duplication and holes in service provision. It also increases the number of 'entry points' and 'check points' that people must discover and traverse in order to access services.

Advocacy groups, support groups and other networks have been an important response to this. Among other things, they provide information and advice to people with disabilities, help people engage with the system and contest unfair decisions and highlight gaps or other problems to service providers and government agencies.

How can the transaction costs incurred by individuals be lowered?

The central design features of the NDIS proposed in this report should significantly reduce transaction costs for people accessing the scheme in three key areas:

- increased funding will reduce the search costs caused by rationing
- the consumer choice model (both self-directed funding and choice of package) will make it easier for people to trade off one type of support against another in order to secure the bundle of goods and services most appropriate for them
- the assessment process will provide a single entry point for many of the support services and equipment that people with a disability need and a clear path for determining eligibility and entitlement (chapter 7).

However, it is important to note that the NDIS cannot be a complete 'one-stop-shop' that facilitates the full range of government services that people with a disability are eligible for (for example, income support through Centrelink, the provision of public housing, education etc). While there are no perfect remedies for this, there are several ways of ways of reducing other transaction costs by making information flow more effectively.

Providing information portals to consumers

One way to do this is through the systematic compilation of information about service providers, into a single searchable database. While most state and territory government offer some form of this, their quality and usefulness is varied. There is merit in substantially enhancing these facilities in the short term, and for the NDIA to provide a nation wide facility following implementation of the NDIS. Ideally, a service provider database should:

- be easy to find and use, particularly in terms of searches for type and location of service. It should also include both advocacy and relevant mainstream services in its search results

- be comprehensive, up to date and link to an accurate description of the services offered

- indicate excess capacity or anticipated waiting lists for particular suppliers

- reveal prices

- be compliant with best practice in accessibility

- link to standardised measures of performance and quality (developing such measures is not straightforward and is likely to be an ongoing task. This is discussed in section 10.3)

- provide contact information on advocacy groups and DSOs that can help them get the services they need (discussed further below)

- provide information about community groups and facilities as well as other mainstream businesses that are designed to cater for people with a disability.

The Care Quality Commission and the Shop4support website in the UK provides a useful example of how an online resource can offer the kind of functionality described above. The latter also offers a number of other useful features, like the ability to directly purchase services (similar to E-Bay), and create and manage service plans. As noted by the Community Affairs References Committee (Senate 2011), many people with a disability have difficulty accessing the internet. As internet usage becomes more ubiquitous, and hardware and software technology continues to develop to make it more accessible for people with a disability, the issue should gradually decline. Nevertheless, it will be important for the NDIS to ensure that effective non-web based information service exist in order provide information about the service system (such as call centres and face to face services).

While this would improve the transmission of information about service providers, most people entering the disability system will need personal advice and information at some point in their life. This may be about what services exist, how to put an assessment plan into practice given the local resources, what other programs they may be eligible for (through other government agencies) and what administrative steps are needed to accomplish this. For this reason, a well-resourced and appropriately designed coordination support service will play a key role in lowering the burden on people seeking disability services (box 10.5). To some extent, this already occurs through case managers, though the access and effectiveness of this is uneven. Depending on the jurisdiction, type of disability and how it was acquired, people may be allocated: no case manager despite the need for

one (sub 255, attachment 1, p. 24); several case managers when only one is desired (sub. 251, p. 4), or one case manager but with inadequate access (sub. 11, p. 7).

Box 10.5   Calls for supported decision making

Each family needs a case manager who can guide people through the maze of options available. We are in shock when we are first confronted with disability. We are not thinking clearly. We need clear appropriate guidance to all possible services we may require. (Sandy Findlay, sub. 193, p. 1)

It is the usual experience of children with disability and families that negotiating the service system is fairly random. If they are fortunate, families may access effective case management or come into contact with someone who has a thorough knowledge of the service system. It is commonplace however that families just stumble upon services … how do you a provide a road map to the jungle? (Children with Disability Australia, sub. 532, p. 9)

We believe that there would be little value providing financial support to people to access care without also providing support coordination. (Care Connect, sub. 407, p. 5)

The RCH supports a scheme design that includes. … A community based case manager to help locate, access and coordinate services. Families generally have no experience in navigating the service system and are in urgent need of support and linkage to appropriate services. (Royal Children's Hospital, sub. 405, p. 2)

The scheme should also recognise that the introduction of choice and control requires an investment in information, resources and advocacy to ensure people with a disability, their families and carers are provided with the tools they need to make informed choices. The scheme should recognise that some individuals will require greater support to plan and exercise choice than others … The scheme should provide a range of choices to individuals – from complete self management to a brokerage system in which individuals would be responsible for planning but not direct purchasing. (National Carers Alliance, sub. 413, p. 7)

… supported decision making should be an integral part of the process of identifying support needs and responses to those support needs … The level of decision making support required will be different for each person with a disability. Providing funding for supports on an individualised basis will enable and support greater choice for people with a disability but in some cases, the person will require support to make informed choices. All people with a disability need portability of funding to enable them to exercise choice about and to change support providers and individual disability support workers. (Scope, sub. 432, p. 19)

The proposed NDIS offers the opportunity to implement a better resourced and better focused version of case management. Currently, case managers often dedicate significant amounts of time and energy to determining the eligibility of their clients to different programs and securing funding. As this would be completed in the assessment phase of the proposed NDIS, their role would appropriately be redirected to: providing their clients with the information needed to make informed decisions; assist in planning; see those decisions eventuate in the delivery of a disability goods and services; muster any community supports; and to monitor their effect on the client over time. In that sense, the model of a 'local area coordinator',

as used in Western Australia, may be the best form of case management. Additional key aspects of local care coordination under the proposed scheme include:

- *accountability for the welfare of the client.* While many people may be involved in bringing a support plan into fruition (for example a panel may be involved in arriving at and approving a support package), there should be one clearly defined person with ultimate responsibility to ensure that clients are receiving the supports they are eligible for, that support services are of an adequate quality, and to monitor their wellbeing over time

- *clearly demarcated work responsibilities.* In particular, local area coordinators should be able to lay a clear pathway for clients to acquire the support they need. This includes through the NDIS itself, as well as advising clients on supports available through other government agencies (for example State and Territory education departments), who to contact and how to go about securing them. However, some administrative requirements would still be undertaken by the clients themselves, or they would contract these to DSOs out of their individual budget (DSOs), or seek to buy packages of support from service providers

- *tailored support according to the needs of the client.* The level of involvement by a local area coordinator should take account of the preferences of the person with disability, his or her capabilities, the complexity of services needed, and the risks (both to the person, any carers and to public monies). It will often need to evolve over time, reflecting changes in people's life circumstances and capabilities. Assistance will often need to be most intensive when people first enter the disability system, and at key transition points in their lives.

- *some degree of specialisation*, in particular, knowledge about disability services and community resources within a particular geographical area. Beyond this, there are benefits in specialisation, in terms of the life cycle (such as early childhood, transitions out of school and the family home, and retirement); the nature of the disability (intellectual disability, physical disability and mental health); particular community groups with distinctive needs (such as Indigenous people with disability or people from a non-English speaking background). Such specialisation will only be feasible where the potential population of clients is large enough

- *a capacity to interface between clients, allied health professionals and service providers to ensure effective communication.* Local area coordinators are well placed to assist in the first instance when disputes and misunderstandings arise between clients and service providers

- *the application of knowledge of local government and non-government providers, community resources and family resources to provide flexible and creative ways of meeting clients needs*

- *providing accountability checks where self-directed funding is involved and where people employ family members and other people not attached to a service provider.*

DSOs, acting as a compliment to local area coordinators, are also likely to reduce the strain from assembling and package of supports and improve outcomes for people with a disability who need additional assistance. These intermediaries can assist people by:

- providing brokerage services that contact service providers and construct a package of support on behalf of (and in consultation with) the person with a disability

- providing long-term, whole-of-life personal planning for those who need more wide ranging, intensive or iterative assistance with planning in order to achieve more personal aspects of well-being such as their relationships, aspirations and achievements, employment, financial security as well as succession planning. (Indeed, the Community Affairs References Committee (Senate 2011) highlights in detail the importance and complexity of succession planning for when parents of people with a disability are no longer able assist with care or decision making.)

- providing ad-hoc support and capacity building (such as NDIS information sessions or life-skill workshops)

- undertaking administrative tasks associated with self-directed funding, such as record keeping and tax and worker's compensation matters.

Finally some people may feel daunted by the system generally, not confident to express what they want directly or complain to service providers (when there is an issues with service provision) or local area coordinators (for example when the assessment process has turned out to be inadequate to meet their support needs). For such people, it will be important for individual advocacy services to continue to play a role in conjunction with the NDIS (this is further discussed in section 10. 4).

RECOMMENDATION 10.1

The NDIA should support consumer decision-making by providing:

- ***a centralised internet database of service providers that indicates the ranges of products and services, price, availability and links to measures of performance and quality***

- *well resourced and effective provision of advice and information to clients, as well as monitoring of their wellbeing, through local area coordinators. These services should be graduated in terms of the needs of the client and concentrated at key points, such as when entering the disability system or important transition periods*

- *funding for disability support organisations, on an individual basis according to assessed need, to provide additional assistance with brokerage, planning and administration.*

Easing the burden of providing and sharing necessary information

While assessment will reduce the need for multiple applications to determine eligibility, service providers still need to be provided with details about their clients in order to meet their needs effectively. Similarly, people will still be required to communicate their needs, what they have received and the outcome it has had on them, as well as reveal any changes in their circumstances to multiple different parties. In addition, there will still be instances when paperwork will be required to match people with appropriate goods or services, for example when replacing a major appliance or seeking supported accommodation.

One way to reduce the costs associated with these activities is through allowing for the electronic submission of all forms and applications (although traditional avenues should also still be available). This is already a feature of some schemes[1] and is a low cost way of reducing the impost associated with paperwork, as well as potentially increasing the speed that paperwork is processed.

However, decreasing the current level of administrative duplication requires a greater capacity to share information between different parties, rather than having to provide it to each individually. The idea that the NDIA should create a shared electronic record that service providers (and potentially other government departments) could access — instead of people having to continually fill out forms containing similar information — was widely supported both prior to, and in response to the draft report (for example, sub. 267, p. 4; sub. 181, p. 1; and sub. 9, p. 2; sub. DR968, p. 2; sub. DR932, p. 16; sub. DR800, p. 21). This would substantially reduce the paperwork involved in securing services offered under the NDIS (such as attendant care, respite, transportation etc). Over time, there is also the potential scope to develop linkages with other government agencies (such as

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[1] For example, Australian RehabWorks argued that this has benefited clients of the NSW LTCS scheme, stating that 'unnecessary paperwork and duplication have been reduced by all necessary forms being delivered and submitted electronically …' (sub. 451, p. 4).

Centrelink) whereby required information relating to someone's disability could also be accessed (with the individual's permission).

In addition to the substantial benefits associated with reducing the administrative burden placed on people with a disability and their families, a shared electronic record and central database would also have a number of other broad long-term benefits, including:

- greater continuity of care. For example, when there are staff changes (such as a new attendant carer) or movement from one service provider to another, an electronic record (with appropriate privacy safeguards) is an effective way of communicating essential information about support needs

- portability of entitlements. Barriers to geographical mobility for people with a disability would be greatly reduced if there was an electronic record of each client's assessed need and financial entitlement applicable throughout Australia

- improved communication and collaboration between allied health professionals and service providers, and better coordination of care

- ease of billing. With appropriate IT infrastructure linking service providers to the NDIA, the electronic record could also house information about purchases made by people with a disability and expedite payment to service providers (for example something like HICAPS). It would also be useful to ensure that the services provided by specialist disability agencies and the prices they charged, were appropriate

- aggregate scheme monitoring and facilitating greater understanding of the costs of meeting the needs of people with disability. The ability to interrogate a central database (but still in a way that strictly protects privacy) could provide rich comparative analysis about the costs of different types of disability and the payoff to certain types of interventions (such as early childhood, or home modification rather than attendant care) in terms of future liabilities. It would also greatly improve the ability to anticipate and plan for changes in the overall cost of maintaining a NDIS (chapter 12)

- the ability to evaluate the effectiveness of therapies, treatments and aids and appliances based on systematic statistical data.

Expenditure by people managing their own entitlement under self-directed funding would not be recorded in detail on the record at the point of sale (because that would defeat the purpose of self-directed funding and be practically unfeasible). However, their expenditure would still be monitored through acquittal requirements (Such requirements would probably be more comprehensive as people first took up

self-directed funding and would decline as they demonstrated proficiency in managing their funds).

The benefits of a shared electronic record, and the system required to deliver them, bear a close resemblance to the Personally Controlled Electronic Health Record (PCEHR) in the Australian Government's E-health strategy. The Australian Government committed $466 million to developing PCEHRs in 2010-11, has released a Draft Concept of Operations describing how PCEHRs will work (NEHTA 2011) and begun trials across Australia. As many of the challenges involved in this task are relevant (to varying extents) to establishing a electronic disability record (see box 10.6), the experience garnered will be invaluable to the NDIS.

Box 10.6   Challenges involved in implementing PCEHRs

Many of the challenges involved in implementing PCEHRs will also affect (to varying extents) attempts to establish a electronic disability record. These include:

- *the difficulty involved in finding solutions to some problems*. Foremost amongst these are privacy and security issues, how to standardise the data that is input into the system and how to uniquely identify providers and people within the system

- *the difficulty involved in coming to an agreement*. There has been substantial growth in the use of IT and E-health technologies across Australia. However the technologies employed have not been coordinated between state health departments or within states (between GPs, specialists and hospitals), resulting in discrete, incompatible information systems.[2] Transitioning from this situation to a unified system requires an agreement as to what the platform should look like — either picking a winner from existing platforms or designing a new one. As the transition from existing systems will be difficult, costly and potentially risky to patients, reaching such an agreement is not straightforward

- *high set-up costs*. In addition to the direct costs, such as hardware, software and training, there are also costs in finding solutions to problems and reaching an agreement about how to transition to a coordinated system. These costs involve consultation, research and pilots.

This raises the question as to what level of linkage or interaction there should be between the two records. Clearly, it is essential that the electronic disability record should be designed such that it can easily incorporate information from the PCEHR

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[2] One expert in this field estimates that 'there are probably 200 companies that are all trying to sell different electronic health record systems and none of them can communicate effectively with each other. And it's actually so bad that there are companies for whom their product from 2010 is not compatible and can't talk to the product that they sold in 2008' (ABC 2010).

relevant to care and support (and where consent has also been given by the person with a disability). However, there are a number of differences that suggest it is appropriate for the NDIA to independently develop and house an electronic record

- There are important functional differences.

  – In particular, the electronic record will assist core functions of the NDIA, such as: facilitating the financial sustainability of the scheme; building evidence about the effectiveness and cost effectiveness of different services and interventions (chapter 13); helping local area coordinators to monitor the welfare of their clients; and ensuring that appropriate and high quality services are being delivered (section 10.3).

  – The database would be much smaller and more manageable, as its population would include only those eligible for tier three of the NDIS (as opposed to all Australians) and the disability industry is much smaller than the health sector. Also, the types of information recorded in the electronic disability record would tend to be simpler than the type of technical data required for clinical diagnosis and treatment. This would include things like: simple personal details; assessed need; services required, received and the prices paid; client outcomes and other additional notes.

- As technological legacy issues are likely to be less of a barrier, there is useful opportunity to develop a universal framework for the electronic record that is appropriate for the disability sector and can evolve according to changing needs. One option would be to develop a simple and secure web service accessible from any computer or mobile device (similar to current internet banking practices). The NDIS will be accompanied by an expansion of service provision, which allows new entrants to be given receive consistent advice about technological requirements and processes associated with the record. This is complemented by the relatively low use of E-health type technology in the disability sector, reducing the extent of disruptions caused by changes to IT systems or existing practises.

As with, PCEHR, the electronic disability record will require careful and clearly articulated privacy protocols, which should be developed in consultation with the Australian Privacy Commissioner. One important facet of this would be differing levels of access. For example, service providers would only have access to a specified range of information, with active consent from the client. Similarly, accesses to the record by different services providers could potentially be 'layered' according to needs or preference of the client. In some cases, a person might not want a provider to have access to the record at all, and in that case, the person would have to provide the required information to service providers in the

traditional way. Similarly, protocols will also need to be established for entering data onto the record (privacy issues are discussed further in chapter 12).

The Australian Government should, with privacy safeguards, fund and develop a national system for a shared electronic record of the relevant details of NDIA participants, including assessed need, service entitlements, use and cost of specialist disability services, outcomes and other key data items.

Supply side transaction costs

In an ordinary market, consumers and producers directly communicate what they want, what they can offer and how satisfied they are with each other. However, in the disability market this exchange is largely filtered through government agencies. These agencies tell consumers what they can have and producers what they should offer, and are then tasked with monitoring the output, consumption and satisfaction of both parties. This requires prescription and subsequent monitoring of prices, quantity and quality, through the intensive use of contracts, regulation, standards, self-reporting and audits. As a result, producers face administration costs associated with:

- reaching an agreement about price and quantity and then securing funding (such as forming contracts and applying for grants)

- demonstrating compliance with regulations, standards, quality assurance frameworks and financial reporting.

Several participants have expressed concern at the cost of overheads, administration fees and management fees associated with the current system (Suzanne Sutton, sub. 19, p. 2; Physical Disability Australia, sub. 543, p. 11, National Federation of Parents, Families and Carer, sub. DR656, p. 2). However it is not clear whether this is indicative of regulatory burden, poor administrative practices, inefficiencies arising from contractual arrangements like block funding (see section 10.4), cross subsidisation when individual funding entitlements are pooled by service providers[3], or simply an inherent feature arising from the complexity of service delivery in the sector.

A survey of NSW non-government community service organisations (including disability service providers) suggested several concerns with funding arrangements

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3 For a given individual there may be a substantial gap between their individual entitlement compared to the services they received. In this case the apparent 'administration fee' is actually indicative of the prioritisation of one client (or type of client) over another.

including: short funding cycles, multiple and incompatible reporting requirements for government funding programs and funding body reporting requirements constantly changing (Hilferty et al 2010).

Similarly, several service providers have pointed to inefficiencies arising from inconsistencies in tendering processes, contractual and reporting requirements and acquittals process:

> Each tender is specific and different from every other tender — with different criteria and demands. … every government department, including ADHC has a different funding agreement or contract with different accountability requirements. This creates issues in terms of multiple reporting. … the acquittals process is complex and inconsistent among programs. (Anglicare, sub. 270, p. 20)

> the requirement to report to local, State/Territory and federal government in respect of different programmes and their associated funding schemes is time consuming, administratively burdensome and arguably of limited value. (ACT Community Sector Collaborative Group, sub. DR894, p. 10)

As the proposed NDIS would reduce the role of government in deciding what would be purchased and how much, the nature of these costs would change, though it is not clear by how much. In some instances, they would probably fall. For example, providers could often avoid the onerous reporting conditions and acquittal procedures associated with grant applications and contracts with multiple funding bodies. Instead, providers would bill the client themselves, or the NDIS, on a per service use basis (as is the common practice under Medicare arrangements). Moreover the Australian Government is currently considering the adoption of standard business reporting for the not-for-profit sector to reduce regulatory burden. This should make reporting of any required financial information to the NDIA easier and less costly.

However, some participants have suggested that consumer choice models (such as self-directed funding) may impose additional costs on providers, and generate additional cash flow management issues (NDS, 2009). That would depend on how the NDIS implemented self-directed funding and on adaptations by existing service providers as the supply model moved away from its current centrally coordinated form. Notably, the costs involved in managing customer accounts are both unexceptional and entirely manageable in other sectors of the economy. As many service providers are unfamiliar with this business model, the costs incurred transitioning to the new model are likely to be significant, though the gradual implementation of the proposed scheme should prevent these costs from being overly disruptive.

Compliance with current regulations and requirements about the quality of services can also represent a large cost to service providers, particularly to smaller ones. On

the other hand, such quality assurance measures serve an important role in mitigating the risk of harm to consumers. The following section explores this issue in more detail.

10.3   Safeguarding quality

There are strong grounds for government to play a role in promoting safe and high quality disability support services, due to the vulnerability of some people with a disability. This vulnerability increases the risk of harm (under current arrangements and under the proposed NDIS), and arises in a number of ways:

- important decisions are often made in times of intense stress and it can be difficult to get good information

- there can be a power imbalance between providers and people with a disability, due to their reliance on uninterrupted provision of care and support

- people with an intellectual disability may have a diminished capacity to make informed rational decisions that serve their best interest and may have a limited ability or confidence to express any inadequacy in the services they are receiving

- support is often delivered in private settings, such as people's homes or group homes, where inadequacies are less likely to be detected by others

- bad experiences with service providers or within society more generally may have an adverse impact on the confidence of people with a disability to demand high quality services or complain when their expectations are not met.

This increases the risks that people with a disability could be subject to unscrupulous or criminal behaviour (such as disrespectful or dishonest treatment, or physical, sexual or psychological abuse) or poor service practices (which, among other things, can result in neglect and deprivation, such as inadequate meals, bathing, cleaning, unfulfilling activities and ignoring the wishes of the client themselves). There are two basic strategies to address this:

- the government could set rules that service providers must obey, such as through legislation, standards or funding agreements. Government would then be tasked with monitoring compliance with these rules, and addressing breaches through alerting providers and offering advice on how to achieve compliance, or if that fails, through punitive measures such as the removal of that specialist provider from the approved list (tantamount to withdrawing their funding)

- the NDIA and DSOs could help people to make informed choices and purchases by providing information, advice and support. This effectively empowers people with a disability themselves to both discipline *and reward* service providers

through their consumption decisions. In turn, this facilitates greater responsiveness to consumers amongst service providers and competition to deliver better quality.

A good quality assurance framework should provide a combination of these. However, shortages and lack of consumer choice means that much of the disability sector currently relies almost totally on the first strategy. The following section provides a brief overview of the current approaches to regulation in the disability sector.

Current approaches to quality assurance

Ensuring that suppliers consistently deliver an acceptable standard of quality is relatively straightforward for physical goods, such as aids and appliances. These goods will often be subject to broad industry standards (such as for electrical goods). In addition, products deemed to be 'therapeutic goods'[4] are subject to the quality, safety and performance requirements of the *Therapeutic Goods Act*. Before a therapeutic good can be sold in Australia, it must be assessed against these standards by the Therapeutic Goods Administration and entered into the Australian Register of Therapeutic Goods. This appears to be a reasonably effective regulatory regime, although some participants have called for more vigorous enforcement of TGA requirements (sub. 477, p. 13; sub. 348, p. 3; sub. 265, p. 2).

It is considerably more difficult to observe and enforce quality standards in the provision of disability services, due to their intangible and highly varied and personalised nature.

Service providers are subject to various (Commonwealth, state and territory) regulatory and statutory provisions in areas such as home and community care, occupational health and safety and building codes. However, state and territory governments mainly regulate service delivery through their respective disability laws (with the exception of disability employment services, which are subject to the Commonwealth *Disability Services Act 1986*). The scope of legislation varies widely, with some Acts as short as seven pages (South Australia) and others over 200 (Victoria). Most include requirements for dealing with complaints. Some have more detailed prescriptions relating to the provision of services, such as:

- requirements for criminal history screening (Queensland)

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4 Goods that are intended to prevent, diagnose, cure or alleviate a disease, ailment, defect or injury and that influence, inhibit or modify a physiological process. (http://www.tga.gov.au/docs/html/tga/tgaginfo.htm).

- enactment of certain monitoring bodies (such as community visitors and the office of the senior practitioner in Victoria)

- specific laws relating to service provision (such as the provisions for residential disability services in Victoria).

Most importantly, legislation confers power on the relevant disability authority (a government department in all cases except for Western Australia, where it is a Commission), to implement a quality assurance framework for the disability services industry. Some Acts stipulate this explicitly (Victoria and Queensland). In other jurisdictions, it is implicitly enabled through the power granted to state and territory bodies to fund and regulate service provision, subject to the principles and objectives of the relevant Act.

There is a basic level of consistency in the approach to quality assurance, which is driven by the common origin of the underlying service standards. The first Commonwealth State Disability Agreement outlined eight minimum National Disability Service Standards (box 10.7) aimed at guiding service delivery practices and ensuring a basic level of quality was maintained amongst service providers. (developed in 1992 and implemented in 1993). The National Quality Framework Working Group is currently updating the National Disability Service Standards (NDSS) in order to better reflect contemporary organisational practices, modernise the language and concepts, emphasise outcomes for service users and address gaps identified by the states and territories.

The NDSS forms the basic guide to the standards that are actually implemented at a state and territory level. While some jurisdictions (such as the Australian Capital Territory and Western Australia) have implemented standards closely resembling the NDSS, others have interpreted, elaborated on and supplemented the NDSS in various ways over time. In either case, the standards essentially articulate the objectives of service delivery, while the associated supporting standards (sometimes referred to as performance indictors) tend to reference systems or processes that aspire to certain consumer outcomes or accord with principles of good management and social justice. For example, self-assessment forms commonly direct service providers to demonstrate evidence that their business practices and policies meet objectives such as: tailoring services to individual needs and aspirations; maximising their clients' participation in decision-making processes; and encouraging staff, clients and stakeholders to provide feedback, including complaints.

Box 10.7 National Disability Service Standards

The National Disability Service Standards listed below are each accompanied by detailed supported standards. For example, supporting standards for service access include that agencies have developed written entry and exit policies, that these are accessible by potential and current consumers and are implemented in practice (supporting standards 1.1, 1.2 and 1.3 respectively).

Standard 1 Service access

- Each consumer seeking a service has access to a service on the basis of relative need and available resources.

Standard 2 Individual needs

- Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals.

Standard 3 Decision making and choice

- Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives.

Standard 4 Privacy, dignity and confidentiality

- Each consumer's right to privacy, dignity and confidentiality in all aspects of his or her life is recognised and respected.

Standard 5 Participation and integration

- Each person with a disability is supported and encouraged to participate and be involved in the life of the community.

Standard 6 Valued status

- Each person with a disability has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community.

Standard 7 Complaints and disputes

- Each consumer is free to raise and have resolved, any complaints or disputes he or she may have regarding the agency or the service.

Standard 8 Service management

- Each agency adopts sound management practices which maximise outcomes for consumers.

Compliance regimes typically involve a combination of self-assessment by the providers and external audit. In large part, self-assessment is geared towards compliance with service standards (as articulated by the state or territory

government department). However, some jurisdictions also incorporate other elements, such as compliance with broader legislative obligations (such as in NSW) and plans for continuous improvement (such as in Queensland). There are large variations in the comprehensiveness of self-assessment processes, ranging from around 20 pages (Western Australia) to around 260 pages (Victoria). Self-assessment is required on an annual basis in a number of states (Victoria, Queensland, Western Australia) and every three years in New South Wales[5] and South Australia. This is accompanied by external auditing, which occurs every year in Queensland, every two years in Victoria and every three in New South Wales, Western Australia and South Australia. With the exception of New South Wales, auditing is conducted independently from the disability authority.

Lessons for an NDIS

Current approaches to quality assurance partly reflect the system in which it is embedded, whereby there are few alternatives to government taking a lead role in promoting service quality. This is due to:

- a traditional agency-based model of service provision, in which government and service providers are typically the contracting parties and principal choice makers. Thus, for a large portion of the disability services sector, competition in service quality is primarily expressed through meeting government requirements (self-assessment, auditing, competitive tendering) rather than through directly attracting clients

- the limited capacity for people with disability to discipline poor performing suppliers by taking their business elsewhere. This is partly a function of underfunding, but is also due to poor publicly disclosed information about the existence or quality of alternative service providers as well as the difficulty and uncertainty involved in securing alternative support

- paternalistic assumptions about the capacity for people with disability or their proxies to limit risks themselves and to gauge quality. Many people would have that capacity if given the right information, and while people with severe intellectual disability or profound mental health problems may be unable to make fully informed judgments, that will typically not be true for people acting on their behalf (such as their parents or guardians).

The NDIS will give people with disability the capacity to make most choices themselves (through the various tiers of consumer choice described in chapter 8), and with an additional level of funding and support that will make choice a realistic

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5 Service providers are also required to provide a short annual compliance return in NSW.

option. This provides a powerful driver of quality *in addition to* regulatory measures. Consumers have a strong personal interest in the quality of goods and services they receive, can observe actual quality first hand (rather than through an audit, for example) and are able to change providers if they are dissatisfied. This directly links service provider's viability with their capacity to satisfy consumers' needs, rather than their ability to fulfil the administrative requirements issued by their funding body. In conjunction with measures to promote robust competition and targeted consumer protection mechanisms, this represents a powerful incentive to deliver high value and high quality goods and services.

However, realising the gains from increased consumer choice will neither be automatic, nor immediate. While many participants in this inquiry are clearly well-equipped to make good informed decisions about the support services they wish to use, to demand high quality services and to complain or switch providers when their expectations are not met (if given the opportunity to do so), this will not be the case for all. As discussed above, the vulnerability of many people with a disability increases the risks of harm or poor outcomes, even when consumer choice is greatly enhanced under the NDIS.

As such, both service providers and consumers will require assistance in ensuring that a more market-based system can deliver good outcomes (as well preventing bad outcomes). Many people with a disability have had little choice available to them in the past and will require support in adjusting to the new scheme. As such, a public education campaign should accompany the introduction of the scheme, including how to seek help, people's rights as consumers and how to make complaints. Direct assistance will also be provided to people with a disability through better advice and support from local area coordinators. This will help consumers make well informed choices, as well as better understanding their rights, how to exercise them and be more aware of the standard of support they should expect from service providers. NDIS clients will also be allowed to use their entitlement to purchase additional support from DSOs if they wish (chapter 9) to assist with administrative requirements, as service brokers or for assistance with long-term planning. The national online database of service providers will be a valuable source of information to clients of the NDIS, and to the local area coordinators and the DSOs assisting them.

Exercising choice will also sometimes mean switching providers when clients are not satisfied with them. This can be difficult for people with a disability and can represent a major disruption to their life if the transition is not handled smoothly. Local area coordinators and DSOs will be an important source of support at such times.

As noted by Novita (sub. DR936, p. 10), it will take time for a competitive and responsive market for disability support services to emerge and additional support may be required in order to minimise the disruption to services providers and their client during the transition. In particular, the NDIA should provide assistance to service providers as they transition from a block-funded system to one based on individual payments and consumer choice. This may include:

- assistance establishing payment systems that interface easily with NDIA

- advice on governance structures or expectations about standards and how to best meet them as well as industry best practice in service delivery

- support in implementing software associated with the electronic disability record

- the NDIA should also contribute to innovation in service quality in the disability sector through an innovation fund that service providers could access on a competitive basis (this is discussed further in section 10.4).

In addition to empowering consumers through support and information, it will also be vital to make sure there are adequate protections in place to minimise the risks of things going wrong. This will be an ongoing task, but will be particularly important in their early stages of the scheme as the market grows and changes in structure. As such, quality assurance within the NDIS should include a rigorous provider approval processes, certification against standards, specific regulation in high-risk areas such as restrictive practices, an *effective* monitoring and compliance regime and a continued role for individual and systemic advocacy.

Approving specialist providers

As a pre-requisite to applying for funding, service providers are currently required to seek approval from the government agency overseeing disability services in their state or territory. This is aimed at ensuring that services providers eligible for funding are legitimate enterprises and have the basic corporate and functional capacity to deliver disability services. In concert with state and territory government agencies, and drawing from their experience with this process, the NDIA should develop its own approval process.

This should include ensuring that service providers:

- have appropriate corporate governance structures

- have appropriately experienced management and qualified staff

- have the essential financial capability

- are fully aware of service standards and how to meet them. Where appropriate policies and plans should meet specific standards (for example in relation to privacy and confidentiality, and complaints and disputes)

- are fully aware of any other legislative requirement specific to the type of services they are delivering (such as OH&S and building codes)

- understand their duty of care and have developed appropriate risk management strategies

- have necessary IT and software to access and update (where necessary) the electronic disability record and understand the protocols governing its use.

This should be streamlined for existing service providers approved within the jurisdiction they operate. Where the existing approval process includes all of the above elements, such providers should be automatically approved. The approval process should also be shorter for specific types of applicants — for example, people who are looking after family members, or are freelance attendant carers. It will be important for the NDIA to conduct basic background checks (such as criminal history checks) of such applicants. However, many of the requirements that a large organisation will be subject to, would not be relevant to individuals (for example having an induction policy for the executive officers of the governing body of the organisation), and would pose compliance costs that would frustrate much needed flexibility (chapter 8).

In the early stages of the scheme, significant resources may be required to ensure that approval processes are efficient and effective in order to reduce the risks of bottlenecks or premature approval of service providers.

The role of standards

Well designed standards can provide practical guidance about good management, accountability and customer service, which may be especially useful to smaller operators. Also with an effective monitoring and enforcement regime, standards improve service providers' incentives to provide high quality supports. If standards are known and clear to consumers they can provide a reasonable service expectation for consumers and empower them to complain when this is not met. In short, standards should continue to play a role in promoting the quality of service provision under and NDIS.

However, as highlighted by the recent reports by the Disability Studies and Research Centre (2011) and the Standing Committee on Social Issues NSW (2011), there are a number of shortcomings of the existing standards, including:

- limited awareness or understanding of the standards among people with a disability

- differing interpretations of the standards by consumers, funding bodies and service providers

- inconsistency among jurisdictions

- ineffective monitoring and enforcement of standards.

The design of the standards themselves is central to addressing these issues — in particular, developing standards that are commonly understood and can be objectively observed. Without general agreement among producers and consumers about the interpretation of standards, and a competent third party that can reasonably assess whether a breach has occurred, the capacity for standards to serve a useful regulatory function is significantly weakened. Achieving coherent, well understood and enforceable standards in practice is made more difficult in the disability sector than other areas because:

- many services are highly varied and need to be tailored to the needs and unique circumstances of people with a disability. Standards that are overly prescriptive about process may reduce, rather than increase, how appropriate services are for some people

- some standards (particularly the supporting standards underlying participation and integration, as well as valued status standards[6]) are partly aspirational, rather than describing a minimum benchmark. These aspirations are important. Where possible, they should: feature within the assessment processes; modelling by the NDIA of outcomes and publication of the performance of providers; and be supported by broader community initiatives (chapter 4). However, for there to be useful standards in this area they would have to: (a) clearly identify the threshold for compliance and (b) avoid over-emphasising visible indicators of compliance (such as a membership card to a club) at the expense of more intangible but valuable outcomes (such as developing real social networks). This may be difficult to achieve in practice.

As funding moves towards a national basis, a single set of national standards and an associated accreditation process should be developed to provide greater national consistency in service quality and to facilitate equivalent treatment of service providers across jurisdictions. These standards should be complete rather than augmented on a state-by-state basis — essentially replacing state and territory equivalents for the purposes of the NDIS. A period of mutual recognition of state

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[6] For example, one such service standard reads 'the service provider promotes a belief in the ability of people with a disability to fulfil valued roles in the community'.

and national accreditation would be required to minimise the transitional impact on service providers.

These standards could be developed by the National Quality Framework Working Group. Alternatively, the NDIA could request Standards Australia to design the national standards as well as seek input from other peak bodies such as the Attendant Care Industry Association (sub. DR642). In either case, development of standards should consult with service providers, advocacy groups and consumers, as well as drawing upon the jurisdictional experience from evaluating the effectiveness of existing regimes. To maximise the effectiveness of the disability standards they should:

- define the minimum standard of service quality that forms the basis for ongoing funding under NDIS

- be as simple and concise as possible so that

    - industry actually uses them and to reduce compliance burdens, noting that more onerous compliance burdens for industry will result in fewer services to people with disability. For that reason, it will be important for the broad industry impact of any standards to be factored into their construction and ongoing evaluation. While standards should evolve with changing industry practices and philosophical shifts, this should not mean the accumulation (rather than consolidation) of standards. That would result in an ever increasing burden on service providers in demonstrating their compliance

    - consumers can realistically interpret what compliance with a standard would actually mean for service quality

    - the NDIA can cost effectively assess compliance. Overly complex standards potentially undermine the capacity for effective oversight, and therefore the main objectives of the quality assurance system in first place

- be supported by an effective compliance regime (discussed below).

Developing practical and effective standards is not straightforward, and is likely to be an iterative process as industry structure and practice evolves under the NDIS. For this reason, there is also value is considering international experience with consumer choice based disability systems, such as the UK, which has recently updated the Essential Standards that care providers must maintain in order to be eligible for funding.

Restrictive practices

For a very small proportion of people with severe intellectual disabilities (and often co-morbidity with mental illness) who display challenging behaviours that have a high risk of harm to themselves or others, at times it will be in their best interest (and that of their carers or others around them) for restrictive practices to be used. These practices include containment (preventing free exit from a service provider premises) seclusion (solitary physical confinement), chemical restraint (involving the prescription of a pharmaceutical for reasons other than a medical condition) mechanical restraint (any device that restricts movement – typically used only in very rare occasions, Office of the Public Advocate 2010) and physical restraint. Restrictive practices are used in response to a number of different challenging behaviours ranging from not understanding the risk of injury from traffic (which might require locking the gate to a front yard) to a history of assault (which might require supervision and occasional physical restraint or seclusion).

Restrictive practices raise complex issues about the rights of individuals to basic human freedoms and some participants have raised strong objections to their use on these grounds (Australian Federation of Disability Organisations, sub. DR982). In contrast, the Victorian Office of the Public Advocate argues that under certain circumstances it is 'necessary to limit a person's rights due to competing interests or for the protection of the community' so long as the restriction meets specific criteria within the Charter for Human Rights and Responsibilities in that state (2010, p. 46).

Challenging behaviours with a high risk of harm to others or self in some jurisdictions are currently managed by staff in residential facilities within a limited legal framework (in most cases legal frameworks are applicable only in relation to mental health) and with little clinical guidance or outside scrutiny. This risks improper use, overuse and abuse of restrictive practices and is likely to deliver poorer outcomes than a framework of independent oversight and regulation designed to minimise its use and promote alternatives.

As such, the NDIS should be accompanied by clear legal obligations on service providers regarding the use of restrictive practices in the disability sector. Specific ongoing monitoring measures will also be essential to ensure compliance (discussed below). In doing so, the knowledge and experience of state and territory government agencies should be drawn upon, with particular attention to the approach taken in Victoria. Similarly, drawing on the Victorian model, regulation of restrictive practices should include:

- a national Senior Practitioner within the Inspector General's office with the necessary legal powers to oversee and regulate the use of restrictive practices

- that restrictive practices cannot be used unless a specific criteria is met, and that service providers must apply to the national Senior Practitioner for permission to use restrictive practices (except in an emergency)
- that the type of restrictive practices to be used are specified and are themselves part of a broader behaviour management plan. This plan should be submitted to national Senior Practitioner for review
- mandatory reporting of the use of restrictive practice and serious incidences to the national Senior Practitioner
- that the use of the restrictive practice be explained to the person with a disability and their guardian. Both should have a right to seek a review of the decision to include restrictive practices in a behavioural plan.

In devising regulatory guidelines for the use of restrictive practices, care also needs to be taken to avoid putting services providers in conflict with their duty of care to their own staff and occupational health and safety legislation.

Effective monitoring and oversight

Under the proposed scheme, both of the primary drivers of quality in the disability sector (regulatory oversight and market forces) are dependent on the quality of information available to consumers, services providers and the NDIA.

As welfare of people with disabilities is the primary motivation for industry oversight, consumer outcomes represent the most direct form of observing service quality, and should be a key feature of an NDIS quality assurance framework. Indeed, the trend towards greater emphasis on outcomes for people is increasingly a prominent feature of state and territory frameworks.

Beyond this, oversight of service delivery should reflect the primary (and inter-related) regulatory objectives of protecting people from significant harm, helping people make good decisions and harnessing competitive market forces to promote quality service products. As such, monitoring effort should reflect the needs of the users of the information gathered and should pay particular attention:

- on areas where the risk of harm is highest
- where the value of the information to service providers and the NDIA is highest in terms of
  - identifying and remedying acute problems
  - identifying and remedying systemic problems

- – evaluating the effectiveness of certain types of services or rehabilitation techniques
- where monitoring provides a reliable signal to consumers and improves their ability to make informed decisions, as well as gives providers a strong incentive to compete in terms of service quality.

The extent to which these areas can be targeted effectively depends on the appropriateness of the monitoring system in place. The following sections examine this.

The role of self-assessment and auditing against service standards

Self-assessment requirements and periodic audits are currently a key monitoring strategy. While in some contexts this is a very attractive approach (such as self-assessment of taxable income), it also has several drawbacks that suggest it should not be the only strategy employed.

First, obtaining accurate and credible information about quality from service providers themselves is reliant on the capacity for effective verification. However, verifying self-assessments would often require direct observation of service delivery and frank interviews with service users. This means that the auditing process would tend to be expensive in order to be effective, particularly if standards are complex.

Second, the time used by providers and senior staff to complete self-assessment forms, gather the necessary supporting evidence and participate in any audit could be a source of significant cost burden.

Third, in practice, self-assessment and auditing tends to focus on the existence (or non-existence) of documented policies and procedures, which are a poor proxy for quality of service. Compliant providers may actually deliver lower quality services (for example, nicely completed forms, but unempathic staff), and non-compliant ones may be more responsive and effective at meeting people's actual needs.

Fourth, burdensome self-assessment and auditing regimes may have anti-competitive effects, since they typically involve fixed costs that loom large for smaller providers offering niche service products. This undermines consumer choice and reduces the competitive pressure on providers to deliver high value and quality service products.

For these reasons, once initial certification has been achieved, self assessment requirements should be concise and aimed at informing providers of their

obligations (in terms of standards and other laws and regulation) and the explicit policy or procedures they must have in place to meet them.

Auditing should remain a feature of the NDIS, and this form of monitoring would be particularly important in the early stages of the scheme as the market matures. However, as a competitive market emerges, frequent and intensive auditing will become a less cost-effective way to support service quality. Thus, over time, the NDIA should move towards a graduated auditing regime with a random component as well as a risk based targeted component that takes account of:

• the historical levels of compliance

• new information indicating a serious problem (such as a complaint or report of a serious incident)

• the risk profile of the consumer group or service type

• the size and scope of the operation.

Auditors would report to the Inspector General, whose statutory office would provide a degree of 'arms length' between assessment of service quality and funding pressures (chapter 9). As the NDIA itself would not be a service provider, the actual and perceived conflicts of interest posed by the dual role of government as supplier and regulator in the current disability system, would be largely eliminated.

While organisations should be subject to self-assessment and audits, where people with a disability hire individuals directly (for example within their self-directed funding budget), such measures would not be required (though they would still have to undergo a basic approval process). Nevertheless, local area coordinators would still provider a degree of oversight and regular checks that appropriate care was being delivered.

Other forms of oversight

In addition to self-assessment and auditing, there are numerous others sources of evidence that should be used to observe whether standards are being met, as well as providing other useful information about service quality to the NDIA, consumers and service providers themselves. These monitoring instruments currently have varied levels of implementation and effectiveness among jurisdictions.

Complaints mechanisms

Simply by buying services, consumers of disability services (and their families) can often monitor the quality of providers. However, where standards fall below an acceptable level, making a complaint can be difficult, particularly under current arrangements where consumers are disempowered by scarcity, lack of choice and support as well as insufficient independence in complaint processes in cases where government agencies are also service providers.

Establishing an effective complaints mechanism will be an important feature of the quality assurance under the NDIS. This should be easily accessible and multi-tiered, with a formal process for reporting back to people on the outcome of complaints. Under the disability service standards, providers would continue to be required to demonstrate effective complaints policies and procedures. In addition, clients of NDIS could also make their complaints through their local area coordinator, or directly to the NDIA itself (chapter 9).

Consumers surveys

These are used periodically in a number of states to gauge satisfaction with service delivery (Victoria, Queensland, Western Australia and South Australia). These surveys are designed to deliver 'big picture' levels of satisfaction to different service types, rather than provide direct feedback on the quality of the service delivery of specific providers. Nevertheless, with appropriate sampling, careful targeting of questions, and surveying methods that protect the privacy of respondents, surveys such as these represent a cost effective way of obtaining information about the quality of service provision from those receiving it.[7])

Advocacy

Both independent advocacy and systemic advocacy will continue to play an important role under the proposed NDIS. The independence of individual advocacy organisations will allow them to represent the interests of the most vulnerable people in the disability system, whose concerns may otherwise be overlooked (the issues surround funding and independence are discussed in section 10.4). Part of this role will entail helping people express concern or make a complaint about the quality of service provision, either to service providers themselves, or to local area coordinators as well as the NDIA directly. Beyond this, individual advocacy will

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[7] For example Western Australia has already indicated the potential for these surveys to be used within their Quality Management Framework (Disability Services Commission 2008a).

also play an important role in ensuring that assessment processes properly recognise people's needs, as well as providing a safeguard when dealing with DSOs and local area coordinators.

Similarly, systemic advocacy will play an important role in promoting system wide quality of service provision through: uncovering system failures; petitioning for widespread change; disseminating information of best practice to service providers; promoting public awareness of disability issues; and promoting the interests of particular groups such as CALD, indigenous and women with a disability.

State and territory statutory bodies

A number of other State and Territory statutory bodies offer support for people within the disability system including, Offices of Public Advocates, ombudsmen and disability commissioners. The responsibilities of these bodies are varied and typically extend beyond disability, including aged care, homelessness, the justice system, health as well the complexities of appointing guardians and administrators. Nevertheless, they also assist people with a disability by:

- facilitating communication and helping them understand their rights
- speaking for and negotiating on their behalf
- providing and alternative avenue of complaint
- investigating and seeking to resolve disputes
- making recommendation for operational and legislative change
- monitoring residential facilities through community visitor programs (discussed further below).

In addition to their broader responsibilities, these bodies should continue to play a role in assisting people with a disability (in both tier 2 and tier 3) under the proposed NDIS. As well as being an additional and independent source of support to people with a disability, their expertise and experience with local service provision makes them well placed to advise the NDIA on emerging issues in the disability sector. The extent of their role should evolve with emerging needs of people with a disability under the NDIS and should be determined and funded by the State and Territory Governments (with exception of the community visitor programs which may warrant additional funding under the NDIS).

Community Visitor Schemes

These operate in New South Wales (under the NSW Ombudsman), Victoria and Queensland (under the Office of the Public Advocate). The community visitors have specific legal powers to make unannounced visits to accommodation facilities, talk privately with residents or employees, inspect operational documents and report on the adequacy of services provided. In addition community visitors support the quality provision of service in a number of other ways:

- they can draw issues to the attention of service providers

- when serious issues are detected, they can instigate further investigation by the NSW Ombudsman, the Office of the People's Advocate or police

- in Victoria, the publication of the annual report provides information to consumers about ongoing issues with certain providers and to government about broader industry challenges and trends in service delivery.

Community visitors are a well targeted way of monitoring groups with particular vulnerability who receive care and support in situations where poor practices or outcomes are more likely to go undetected. The capacity for random inspection strengthens industry wide incentives to comply with service standards as well as other laws and regulations. As such, these schemes should be implemented in states where they do not currently exist under the appropriate state and territory statutory bodies, potentially with funding assistance from the NDIS. In doing so it is desirable to replicate features of the Victorian model, including the publication of annual reports and the use of volunteers.

Local area coordinators

As described above, these play a key role in periodically assessing the welfare of their clients (section 10.2). This role will be particularly important for those who choose to pay family members or partners to provide the majority of their attendant care (if this capacity is adopted following the trial proposed in chapter 8), where there would otherwise be little external oversight of their ongoing health and wellbeing.

Contact with other community members

Other members of the community, particularly health professionals, may sometimes become aware of evidence of inadequate care and support (for example repeated admission into hospital for bed sores or infections). In such cases, it will be

important for them to have avenues to express concern to local area coordinators or directly to the NDIA itself.

What should the NDIA do when problems are detected?

The NDIA would have a range of potential responses to complaints or other evidence that there may be a problem with a service provider (that cannot be resolved by the client and service provider themselves, with the assistance of advocates or in mediation with local area coordinators). Initially it would investigate the issue through discussion with clients, their local area coordinator and the service provider, as well as through visiting their facility. If this process revealed non-compliance with service standards, the service provider would be given a time frame to improve their operations, and if necessary, advice on how to do so. Such service providers would be subjected to greater oversight (including more frequent auditing against service standards) for a period afterwards.

Incidents of substantiated non-compliance would also have a commercial consequence for service providers through the information being made available to consumers and DSOs on the database of service providers (discussed further below).

For serious or repeated breaches of service standards, the NDIA could impose sanctions (such as fines) on service providers, or remove them as a registered provider, which would mean that people would no longer be able to use public funds to purchase disability supports from them.

Evidence of criminal wrongdoing, or breaches of other legislation, should be recorded by the NDIA and passed on to the relevant authority.

Developing indicators that are both used and useful

Quality indicators can be qualitative or quantitative (or both – for example, the number of complaints against a service provider is a quantitative indicator, while the complaints themselves are qualitative). Qualitative indicators can give richer, nuanced and qualified information about quality, but are harder to aggregate, standardise and use comparatively. On the other hand, quantitative indicators are easier to aggregate, standardise, simpler to use for comparative and analytical purposes, but have a greater risk of being misleading, misinterpreted and inappropriately emphasising features on the basis of their measurability rather than their actual value. As such, no single measure can definitively describe service quality. Rather, a balanced impression of service quality has to take account of the

limitations, purposes and context of the various indicators and sources of evidence as well as the varying importance they have to different people.

Broadly speaking, indicators serve two basic functions. First, they can be used to detect serious problems ('red flag' indicators), such as a failure to comply with the laws relating to service provision in the disability sector, broader laws and regulations, as well as serious breaches of services standards. Red flag indicators could potentially come from a variety of different sources including health professionals (such as inappropriate presentations to hospitals), service provider reports from community visitors or senior practitioners (for example indicating use of restrictive practices at odds with stated support plans), or through complaints mechanisms. This information is of primary importance to the NDIA. As noted above, evidence of serious non-compliance could involve fines or de-registration.

Red flag indicators are also useful to consumers and producers. For example, consumers may want to know if a large number of complaints have been made against a service provider, or the outcome of the last service audit. For service providers, red flag indicators ensure that those who are compliant with standards and regulation are not disadvantaged relative to those that 'cut corners'. (That is, good providers are advantaged when those who 'cut corners' are identified and penalised.)

Second, quality indicators can be used to convey some kind of ordinal information about the quality of service provision (differentiators). This enhances decision-making and can allow consumers to trade quality against price (and therefore quantity). When changing providers is costly or disruptive, credible indicators of quality will empower consumers to leave lower quality providers.

Information could be sourced from consumer surveys (for example general satisfaction with a provider, indicator about punctuality, reliability, continuity of staff and respite), through publicly available reports on service providers (such as community visitor annual reports, outcomes of intensive audits by NDIA) or from the providers themselves (such as easily verifiable input measures like staff qualifications or staff-to-client ratios, and the percentage of clients who had achieved agreed outcomes within a certain period of time with the service provider).

Quality indicators are also useful to service providers and the NDIA. For service providers, these measures recognise and allow them to capitalise on investments made into improving service quality. For the NDIA, the measures can be summarised in industry trends that give insight into its own performance. The NDIA would also have a particular interest in indicators that can demonstrate the relative efficacy of one type of service or treatment relative to another. Long-term

costs are one obvious (and straight forward) indicator of interest, but so are others, such as health, mobility, employment and life satisfaction, which could be gathered through regular sources (for example through the type of data that is routinely gathered through interaction with the health system or through general consumer surveys) or through indicators specifically designed to measure the success or failure of a particular trial.

The usefulness of these data ultimately depends on the ease of access by users. The most appropriate central access point for consumers would be the national internet database of service providers described in section 10.2. This database could contain information about simple quantitative indicators, could link to more detailed qualitative indicators and, over time a summarising indicator could be developed by some combination of these, as well as from the personal level data contained in the electronic disability record. For example the Quality Care Commission in the United Kingdom is currently working on a voluntary scheme that will allow providers to be assessed for an 'excellence award'. (Similarly Job Network has developed a star rating, however the purely quantitative basis of this may be difficult to apply to disability service providers). Local area coordinators and DSOs would be available to assist consumers in interpreting these measures.

In many cases, the NDIA would receive red flag indicators directly from those who gather them (people with disability themselves or their guardian, local area coordinators and health professionals). However, there is also scope for the NDIA to use the rich personal information contained with the electronic disability record to forensically mine the data to detect problems. This could be proactive or even automated according to rules or triggers. Alternatively, interrogation of the electronic disability record could be used to investigate whether a specific complaint is indicative of more widespread problems with a particular service provider and if intensive auditing is warranted.

The NDIA should develop the indicators in consultation with consumers, service providers and relevant experts. The NDIA should also monitor the indicators for their usefulness, and any unintended impacts they may have. Table 10.1 describes several indicators that may be useful as a starting point.

The NDIA should develop and implement a quality framework for disability providers, which would include:

- *the development of complete, nationally consistent standards that would apply to all funded specialist service providers and disability support organisations. The NDIA should monitor compliance with these standards and other regulations through a range of instruments, including graduated and rolling audits of service providers, community visitors, senior practitioners, independent consumer surveys, complaints, monitoring by local area coordinators and interrogation of the electronic disability record*

- *arrangements that encourage the diffusion of best practice throughout the disability sector*

- *providing consumers with information about the quality and performance of service providers on the national internet database of service providers*

- *establishing an innovation fund that providers would use for developing and/or trialling novel approaches to disability services.*

Table 10.1   **Potential indicators and sources of evidence about service provider quality**

Indicator	Source	Type	Purpose	User notes
• annual reports • specific service provider report • service provider audit	community visitors, National Senior Practitioner, the NDIA	qualitative	quality differentiator	made available on centralised data base for use by consumers
			red flag	used by NDIA to identify instances of breaches of regulations or standard
mandatory reporting requirement about: • use of restraints • adherence to behaviour plans • serious incidents	National Senior Practitioner	qualitative and quantitative	red flag	used by NDIA to identify instances of breaches of regulations or standard
range of medical outcomes: • inappropriate presentation to hospital • infection rates (urinary, bedsores, respiratory etc) • other evidence of harm	health professionals	qualitative and quantitative	red flag and quality differentiator	entered into clients electronic disability record and used by NDIA
satisfaction, with services, health and life as well as other indicators such as: • how often is your service provider late, unable to assist at a certain time etc. • indicators of continuity of service providers staff and access to respite	consumer survey	quantitative	quality differentiator	made available on centralised service provider data base for use by consumers; potentially used by NDIA to evaluate efficacy of different types of services
serious incidences	police, health specialist, teachers, local area coordinators	qualitative	red flag	used by NDIA to identify instances of breaches of regulations or standard
complaints	consumers, local area coordinators	qualitative	red flag	used by NDIA to identify instances of breaches of regulations or standard
staff-to-client ratios staff qualifications	service providers	quantitative	quality differentiator	made available on centralised database for use by consumers; potentially used by NDIA to evaluate efficacy of different types of training, or ways of delivering services

10.4 The implications of consumer choice for block funding, government-run services and rural areas

The dominant direction of change would be much greater choice by people with disability, underpinned by the market-based delivery of disability services. However, are there residual areas where the traditional service models could still be relevant? For example, some have argued that block funding itself redresses certain market failures and should continue to be a part of the NDIS. There is also the question of whether government run services should continue to play a role in the scheme. Finally, there is the issue about the current and anticipated difficulties of delivering services to rural areas. These questions are discussed in the following sections.

Block funding service provision

The move towards a consumer choice model (self directed funding and choice of package) in the proposed NDIS represents a shift in the way service providers are funded. While jurisdictions have already implemented consumer choice to varying extents, service delivery continues to be underpinned, in large part, by some form of block funding. Block funding essentially refers to any agreement whereby a funding agency (rather than a service user) purchases a 'block' of services from an organisation or firm to be delivered to clients who meet a certain criteria, or are referred to the provider as part of an 'individualised plan'.

In practice, this can cover a range of different types of arrangements, from grants and short-term contracts to longer term undertakings. In general, block funding has become more contestable and transparent, with more explicit contractual obligations and greater reporting requirements. For example, providers may be required to competitively tender for the delivery of a particular service. If successful, governments contract them to deliver a certain volume of services (number of clients or client hours) over a given period, with their interim funding being dependant on satisfying a quality assurance framework and meeting reporting requirements to the funding body.[8]

Notwithstanding the measures to promote quality and efficiency of services, as well as the efforts of some service providers to develop more 'personalised approaches' (National Disability Services, sub. 454, p. 16), the block funding model has considerable disadvantages compared to self directed funding or other ways of giving people choice. In particular, it is very difficult to reconcile with the core

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[8] In theory, re-tendering could occur at the end of the contract period, though in practice it is often extended as a matter of course (so long as funding is still available).

principle of maximising peoples' control over their own lives. This is because block funding is the outcome of a negotiation that excludes consumers. As stated by Advocacy Tasmania Inc:

> It is a mechanism whereby funding agencies make an assessment of aggregate consumer needs, make a determination of the service models they (the funding agencies) believe are most appropriate to meet those needs, and choose the service providers they believe are best placed to deliver the identified services. That is, three kinds of decisions (about need, about service model, and about service provider) have been taken on behalf of the consumer, not by the consumer. (sub. 483, p. 13)

Thus, despite the efforts and goodwill of both service providers and funding agencies, by its nature block funding shifts decision-making away from service users and in doing so, limits their choices and opportunities. This undermines the value that people derive from choice in itself and is antithetical to widely held social norms, such as the freedom, equality, rights and dignity of people with a disability (chapter 8). From an economic point view, it:

- impedes consumers from obtaining the bundle of services most appropriate to them

- dilutes consumer signals as to the relative value they place on different services, reducing the capacity for efficient allocation of scarce resources

- diminishes competition between providers by failing to appropriately reward providers those who deliver good value, high quality, responsive services (or punishing those who don't).

As block funding implies that provider viability is critically determined by their relationship with the funding agency (rather than with their customer), it also risks a number of other adverse effects.

- Highly prescriptive contractual arrangement reduces service provider autonomy and can effectively make them a 'branch of government'. This reduces their flexibility, responsiveness to clients and capacity for innovation and experimentation.

- Historical funding relationships can dominate decision-making, making reallocation of public resources difficult (PC 2010a).

- Block funding reduces the financial penalty of under-delivery of services (Scope, sub. 432, p. 22).

- The competitive tendering process that underlies block funding can bias resource allocation towards low cost (rather than high value) service provision (Local Government Association of South Australia, sub. 519, p. 6).

Box 10.8   Participants' views on block funding

Block funding has shielded operators and has not punished underprovision. (Scope, sub. 432, pp. 22–23)

Block funding for shared supported accommodation — funding tied to the service provider rather than the individual reinforces a 'group approach' to service provision rather than a system that services the needs of the individual. (Office for the Public Advocate Victoria sub. 255, attachment 1, p. 19)

Block funding with one organization holding funding and power as landlord and service provider with no individualized package is not in keeping with disability legislation, inhibits choice and is not acceptable to us. (Mary Nolan, sub. 545, p. 11)

Through laziness and partly through confusion, some governments and providers in Australia have tended to collude in short-circuiting this intended process (individualised services), with funders making block grants to providers for a certain number of 'places' or 'clients', and tagging these funds for use by individual 'clients', subject to a consultation exercise with the relevant clients. This process can not be regarded as a genuine process of self-direction or self-determination in disability support. (National Federation of Parents, Families and Carers, sub. 28, p. 4)

The provision of block-funding to service providers, rather than personalised budgets to consumers, has reduced the choices available to consumers, denying them fundamentally important forms of control over their own lives. We assert that this is a form of de facto substitute decision-making, applied in contexts where independent decision-making and forms of supported decision-making are both possible and desirable. (Advocacy Tasmania Inc, sub. 483, p. 9)

This simple market based mechanism would allow users to 'shop around' to find a service provider that best meets their needs and aspirations, and would be likely to have a much greater influence on service quality than any 'feedback' form or 'quality' audit. The increasing granting of block support funding by DoCs to service providers rather than directly to the person with a disability is antithetical to this and fosters the need for such complex and ineffectual reporting systems. Furthermore, it underestimates and stereotypes all people with disabilities as unable to control their own lives or affairs. (Ben Lawson, sub. 103, p. 5)

However, participants have pointed to a number of areas where block funding or government provision of services, may deliver better outcomes for consumers than market-based arrangements, or is required to overcome specific sources of market failure.

Does block funding allow timely responses to crises?

Inevitably, some people with disability experience unforeseen crises, such as medical complications or changes to life circumstance, such as a death of a partner, loss of accommodation or the sudden breakdown of an essential aid or appliance (National Disability and Carer Alliance, sub. 413, p. 7; Northcott Disability Services, sub. 376, p. 14; Melissa Ryan, sub. 251, p. 3). While additional support usually could be obtained with the assistance of local area coordinators and through

reassessment (if necessary), self directed funding may often be inadequate in meeting acute and immediate need. Even if interim provisions could be put in place that allowed people to draw upon an anticipated *future* entitlement, existing providers may be limited by capacity constraints, or may not be equipped to offer the specific type of crisis support required. The maintenance of block funding to specialty disability providers offering crisis care (or for crisis care as service type in its own right) is one way of addressing this.

Does block funding provide certainty to service providers?

Some participants have expressed concern that the wholesale replacement of block funding with direct consumer choice and payment of suppliers would generate high levels of revenue uncertainty and would result in unmanageable volatility in demand. They argue that this could undermine the viability of suppliers and the loss of services valued by consumers:

> … a shift to the funding of the individual would make financial planning and future strategic planning vastly more difficult due to the lack of certainty of incoming funding. Many service providers within disability are not for profit organisations that operate on very tight budgets and this type of financial uncertainty may well be the difference between solvency and insolvency for some and that is certainly not what we would want to see in this sector. (Parents of the Hearing Impaired of South Australia, sub. 222, p. 3)

> Portable, individualised funding could lead to sudden loss of people attending traditional services or specific organisations; some services may no longer be viable, thereby the amount of choices available to people with disabilities may actually be diminished. (Northcott Disability Services, sub. 376, p. 15)

> Without core funding, the proposition of running a service which meets fluctuating and hard-to-predict levels of need, will deter many providers, limit choice for families and impact on quality of provision. (Wesley Mission, sub. 541, p. 14)

> A move away from block funding to individualised funding has administrative and cash-flow implication for organisations. The right of an individual to move easily from one provider to another reduces income predictability. The management of uneven cash flow requires service providers to have sophisticated financial skills and take on increased risk, particularly if the payment for services occurs some weeks, even months, after they are delivered. (NDS 2009)

However, others have suggested that certainty is neither a reasonable nor a beneficial expectation:

> In some cases, these arrangements have arisen in response to claims by service providers that they need 'certainty' in planning business operations from one year to the next. We say that provider organisations should accept that they operate in a market for their services, and that no business in a market environment can expect their

customers to give them a blank cheque. People with disabilities do not owe service providers, or their staff, a living. (National Federation of Parents, Families and Carers, sub. 28, p. 4)

In general, the Commission does not support the proposition that reducing service provider uncertainty is a legitimate justification for block funding. Uncertainty about future levels of demand and revenue is common in other sectors of the economy and has been accepted as a necessary cost of doing business. Indeed, this 'uncertainty' functions as powerful motivation to understand and fulfil customer needs and drives competition between providers — to the benefit of consumers.

Moreover, in reducing uncertainty, block funding also reduces the necessity for service providers to respond efficiently to variations in demand. In contrast, a consumer choice model advantages providers with systems in place to deal with variation in demand, and gives a strong incentive for others to develop them. Thus, rather than 'fixing' the problems of uncertainty, block funding represent an obstacle for the disability services industry to properly account for the inevitable uncertainty and to adapt accordingly.

It is possible that in the transition to a consumer choice model, some consumers will lose access to a service that they are happy with, as other customers who were previously dissatisfied are given the ability to leave it (making the particular service unviable overall). However, this will be offset by the additional funding to disability services after the introduction of the NDIS, which will take place in market conditions where demand already significantly exceeds supply. This means that, in general, services will tend to be expanding rather than contracting and consumers will likely have more service options rather than less. Also, overall revenue uncertainty in the disability services industry will be much lower than other sectors, as it is based on hypothecated income. In this context, it is likely that exits will be concentrated among providers whose services are valued the least.

In any event, much of the costs incurred through increased uncertainty will be transitory, as service providers adjust to the new business environment and adopt practises that have been long accepted in other sectors. As noted above, the NDIA will provide assistance and advice to service providers throughout this transition, and will monitor the ongoing impacts on consumers.

Is block funding required to account for infrastructure, training and administration costs?

Another potential risk of withdrawing block funding in favour of a consumer choice model is that it might undermine providers' ability to service their fixed costs (such

as rent, capital maintenance administration and other overheads) or make capital investments (including human capital such as training) to expand or improve the quality of their services.

> Another major financial risk that individualised funding poses is how fixed costs will be serviced – that is, how to maintain infrastructure and administrative functions within a demand-driven model? (Northcott Disability Services, sub. 376, p. 14)

> Block funding has also enabled the coverage of costs not able to be recovered through individualised packages. (National Disability and Carer Alliance, sub. 413, p. 7)

> A very real concern of service providers is how fixed costs will be serviced — all organisations require resources just to open their doors, prior to the delivery of any services to people with disability. The question of how organisations will maintain infrastructure and administrative functions within a demand-driven model is critical. (NDS 2009, p. 17)

These problems are not unique to disability service providers and have been widely demonstrated to be surmountable in other industries. The core issue is not the method of payment, but the price paid. Failure to properly reflect fixed costs under the proposed price setting model would be problematic for both producers and consumers — but no more so than is the case under current arrangements.

For many disability services, fixed cost are low relative to labour costs (which can be more easily observed), so the required adjustment to price (and the consequences of the NDIA getting this wrong) would be small. However, in some areas, particularly residential services, accurately estimating industry fixed costs and incorporating these estimates into prices, will be critical to maintain service standards (or to prevent excessive profits and poor value to consumers). The Commission's parallel inquiry into aged care has an in-depth discussion about financing residential care, which may also be relevant to this issue in the disability sector (PC 2011a).

The necessity of such price regulation may diminish over time with the development of a mature competitive market. In this case fixed costs would be driven by consumer preferences and reflect a variety of service models. For example, in the broader economy, industry wide trends towards business models with lower fixed costs frequently benefit consumers. Similarly, models of care with inherently lower fixed costs may deliver substantially greater value to people with a disability (for example, by directly employing someone to provide attendant care rather than going through service providers maintaining physical premises and corporate functions).

Conversely, consumers will often be willing to pay more for products requiring substantial capital investment. The higher prices reflect the required contribution to

that investment. Of course, in some situations, there may be a role for governments in setting prices (for example in rural settings or where market competition is inadequate). However, ideally, prices should only be constrained by the pressures of competition and the usual safeguards against the abuse of market power and anticompetitive practices.

Market-based approaches also have the advantage that suppliers can use innovative pricing to efficiently recover fixed costs from different customers. This includes measures such as discounts for regular use of services, or for periods where demand is often lower.

Is block funding a useful tool to support innovation?

Increased competition in the disability sector will enhance the rewards and necessity for service providers to find innovative ways to meet the needs of their customers. However, some innovations also have broader value in enhancing the stock of knowledge available for all service providers. As individual providers will not usually consider these wider benefits, there may be less research and experimentation than is socially desirable — particularly if it is costly or risky. In the case of the disability sector, innovation may take the form of a new assistive technology, a new approach to therapy or rehabilitation, or a new way of engaging with the community in order to deliver services to people who are the most reluctant or unable to otherwise access them (such as Indigenous Australians, people in remote areas, people with sensory disabilities, or people who are not from English speaking backgrounds).

There are grounds for competitive grants to support research and experimentation in areas that are likely to provide broad social benefits. This could be funding a trial, or 'seed capital' to start a new highly innovative service (in a similar fashion to the Job Services Australia Innovation Fund). In some cases, there may also be benefit in funding research on an ongoing basis, for example through supporting research divisions of disability service providers or by funds allocated by the Australian Research Council or National Health and Medical Research Council (Tech4Life, sub. DR876, p. 3). The broader research functions of the NDIA are discussed in chapter 12.

Is block funding necessary to guarantee services in areas where the market would fail to deliver them efficiently?

In some cases, the potential market for disability service may be too small to support the competitive provision of specialist disability support services under a

consumer choice model (in particular under choice of package arrangement where approved service providers must be used). This may occur in rural areas or for people with very complex needs or very challenging behaviours — potentially resulting in under-servicing and unmet need, or in local monopolies overcharging consumers.

The first of these issues can be largely addressed by allowing providers to take the higher costs (arising from diseconomies of scale) into account when determining prices and individual entitlements. However, the later problem would remain, resulting in the ongoing issue of disentangling monopoly rents from diseconomies of scale. Block funding through competitive tender is one way of addressing this.

It is not clear how prevalent such market failures will be in practice. As discussed in chapter 8, the use of self-directed funding appears to operate reasonably well in rural settings, suggesting that the actual need for block-funded rural providers may be low in practice, outside of specialist health support services, therapy and centre based respite. Some alternative approaches for delivering services in rural settings are also considered below.

The market is likely to fail consumer groups that are not willing or able to engage with traditional service providers. In particular, the combination of remoteness and cultural aversion to traditional models of service provision dramatically increases the risks of exclusion and harm for Indigenous Australians. Service providers directly working to redress this should receive continued block funding, in addition to the provision of funding for trialling innovative approaches mentioned above. Issues around providing support for Indigenous Australians with a disability are discussed further in chapter 11.

Finally, the market is unlikely to deliver the 'public good' type of activity necessary for a more inclusive society such as community awareness and capacity building. Block funding is one potential strategy to promote this (this and other strategies are discussed further in chapter 4).

Putting it all together

Despite the challenges implicit in the transformation of a block-funded industry into one based on consumer choice, most service providers involved in this inquiry have recognised both the necessity, and the desirability for change. For example, Yooralla writes:

> There will be uncertainly and instability for disability service providers as individualized funding replaces block funding which has more financial certainty.

However, service providers are having to move toward individualized funding models of support whether the scheme is implemented or not. (sub. 433, p. 40)

The Commission considers that the shortcomings of the block funding model warrant its use only in very specific circumstances. That is, self-directed funding or other avenues for consumer choice (such as choice of supplier) should become the norm for the industry. Some of the rationales for retaining block funding have little merit. In particular, arguments about uncertainty or the need to cover fixed costs are not generally accepted reasons for government intervention in comparable industries and should not be accepted here. However, block funding should continue to play a role:

- to ensure that crisis care needs are met

- to support research, experimentation and innovation in the industry

- as a tool to redress market failure such as:

  - in rural areas where lack of scale and remoteness may result in under-provision or competition issues

  - for groups less willing or able to engage with service providers (such as Indigenous Australians) or who service providers may be reluctant to take on (such as those with very challenging behaviours)

  - inadequate public goods such as community capacity building.

Where block funding is judged to be the preferable funding method, the NDIA should develop standardised tendering, contracting, reporting and acquittal requirements in order to reduce compliance cost. Findings from the recent Productivity Commission report into the not-for-profit sector (PC 2010a) are relevant to the implementation of block-funded services, including:

- a collaborative approach between the NDIA and service providers that: includes both parties in the design of programs; embeds and funds agreed evaluation processes; regularly reviews and revises service delivery approaches in light of finding from evaluations and changing demands or environmental conditions

- the length of service agreements and contracts should reflect the length or the period required to achieve agreed outcomes, rather than having arbitrary or standard contract periods.

Funding for advocacy

Under the current system, advocates play an important and widely varied role in helping people with a disability get the support they need. In some cases there are

similarities between the functions of advocacy organisation and DSOs, as well as local area co-ordinators. For example, advocacy groups, DSOs and LACs (to varying degrees) may all assist people in the scheme with information, advice, planning and resolving conflict with service providers (DANA, sub. 1010). The critically discerning feature of good advocacy is that no interest is countenanced other than the person with the disability themselves. A commonly accepted definition of advocacy is as follows (People with Disabilities (WA), sub. 1011 p. 18, Uniting Care (Qld), sub. 776, p. 21, Family Advocacy, sub. 712, p. 9)

> … advocacy for people with disability can be defined as speaking, acting or writing with minimal conflict of interest on behalf of the interests of a person or group, in order to promote, protect and defend the welfare of and justice for either the person or group by:
>
> 1) being on their side and no one else's;
>
> 2) being primarily concerned with their fundamental needs; and
>
> 3) remaining loyal and accountable to them in a way which is empathic and vigorous.

There are two main types of advocacy – systemic (aimed at bringing about systematic improvement in policy and practice as well as removing discriminatory barriers) and individual advocacy (which is individual and issues specific). However, in practice, the lines between these types of advocacy are blurred, with organisation frequently engaged in both.[9] Moreover, individual advocacy will often draw upon or operate concurrently with a range of other models including: Self Advocacy, Family Advocacy, Legal Advocacy, Citizen Advocacy (FaHCSIA 2009a).

Neither advocacy, nor individual advocacy are well-suited to a user pays system. This is because systemic advocacy has characteristics of a public good (in some ways similar to research and development), meaning it would be under-provided in the absence of dedicated public funding. In the case of individual advocacy, it is problematic attempting to predict individual need for it during assessment processes. Relying on individual's capacity to privately pay for advocacy is likely to render it unobtainable to those who need it most. For these reasons, it is important that advocacy should continue to be block funded.

In doing so, genuine independence from the NDIS will be a critical determinant of the effectiveness of advocacy. As noted by the Disability Advocacy Network Australia (sub. 1010):

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[9] Sometimes simultaneously, for example where individual advocacy sets a precedent that brings about systemic change.

> Departments struggle not to react negatively when their service administration is called into question and advocacy organisations struggle with the need to bite the hand that feeds them. (p. 15)

Thus, the NDIA should not *directly* fund advocacy. The role of allocating funding for advocacy should continue under the National Disability Advocacy Program administered by FaHCSIA as well as from State and Territory governments. However, there may be merit in the NDIA contributing additional funds to this program (though with no associated directive as to how they should be used).

Similarly, advocacy organisation will often need to act on behalf of individuals experiencing problems with service providers and DSOs, as well as highlighting systemic problems when they are detected. In order to do this effectively, advocacy organisations need to maintain the perception and the practice of independence from both service providers and DSOs. Queensland Advocacy Incorporated (sub. DR965) expresses this point as follows:

> …incorporating advocacy services into the entities which are likely to be the subject of their scrutiny creates a glaring conflict of interest, which would jeopardise the principle of strict partiality to the individuals interests… (p. 10)

As such, organisations funded to provide advocacy services (by either FaHCSIA or state and territory governments) should not be eligible for NDIS funding for either disability service provision or intermediary services as a DSO.

This does *not* mean that such service providers and DSOs will never advocate on behalf of their clients. This is likely to occur frequently of their own volition and in some cases as an essential part of their business (for example, a DSO offering brokerage service may act on behalf a person with a disability when a service package they have negotiated is not being effectively implemented). However, funds specifically allocated to providing individual advocacy for people dealing with the service providers or DSOs should go to organisations with no financial interest in these industries.

RECOMMENDATION 10.4

The Australian Government, through the Department of Families, Housing, Community Services and Indigenous Affairs should continue to provide funding for general advocacy by non-government organisations, with no involvement by the National Disability Insurance Agency in this funding role.

State and territory funding of disability advocacy groups should continue.

Government, not-for-profit and for-profit service providers

People with disabilities in Australia receive services from for-profit and not-for-profit (NFP) providers, as well as directly from government themselves. The trend in most jurisdictions has been for increasing reliance on NFP provision. It has been suggested that NFP providers have a number of other benefits compared to government run agencies, such as:

• NFPs are well placed to respond to community needs and are closer to the target group of a particular service.

• some NFPs are able to access resources that are unavailable to the government, such as volunteers and private sponsorship.

• NFPs sometimes have a longer history of involvement in specific service areas than government agencies — leading to considerable expertise and links to the target group.

• NFPs are seen as being more flexible and adaptable to client needs, as well as having the ability to package government-funded services with other services (PC 2010a).

Nevertheless, in most jurisdictions government is the single largest provider and it is likely that government supply will probably continue to play an important role in some areas. In particular, government providers may sometimes be able to exploit economies of scope, such as the ability to integrate with health services. They might also act as a 'last resort' supplier. For example, this might include providing support in very remote areas (and especially those Indigenous communities where no other provider exists), and for clients with very complex needs or challenging behaviours. Under the NDIS, state and territory owned service providers should be subject to the same regulatory oversight and monitoring as other for-profit and not-for-profit providers.

Similarly, moving disability supply away from centralised control to a more market setting is likely to make the disability sector more attractive to for-profit-providers (The Victorian Government noted that increased provision of individual support packages has been associated with the entrance of for-profit agencies in that state (sub. 537, p. 14).)

Ideally, from an efficiency perspective, competitive neutrality would be maintained between these three different types of providers. Competitive neutrality aims to ensure that a provider does not enjoy competitive advantages over a competitor simply by virtue of their ownership. There are several risks to neutrality in the disability sector:

Concessionary taxation arrangements benefit NFP providers — in particular the fringe benefit tax (FBT) concession. The concession allows a NFP provider to pay its workers in-kind rather than in cash, lowering taxes on workers' incomes. This means that a NFP provider can pay a worker at a lower pre-tax wage rate, but at an equivalent post-tax wage rate, compared with government-owned and for-profit providers. The pre-tax wage rate is one of the major determinants of costs in the disability sector. All things being equal, this means that a less efficient NFP provider may displace a more efficient for-profit or government provider.

The Productivity Commission (2010a) argued that the distortionary effects of the FBT are particularly problematic in the hospital sector and, to a lesser extent, in the aged care sector. It is also potentially an issue in the disability sector. Both the Commission and the Henry Tax Review have argued that more transparent and less distortionary forms of support for NFP providers are preferable to input concessions such as FBT. Because the FBT concessions apply across the entire NFP sector, it would not be realistic or desirable to quarantine reforms to the disability part of this sector alone:

- Changing FBT rules for the disability sector alone could introduce further distortions (for example disadvantaging the ability of the disability sector to compete for labour with the aged care sector).

- Beyond changes to FBT, the means available to restore competitive neutrality are limited. In theory, when receiving tenders for block funding, the NDIA could attempt to estimate the *true* cost of service delivery by NFP organisation (on a provider by provider basis) by estimating the income tax revenue foregone to the Commonwealth. However, the complexity and additional cost involved in doing this are likely to be considerable. While, accounting for these costs are not currently required under Commonwealth Procurement Guidelines, the Productivity Commission (2010a) has recommended that 'the Departments of the Treasury and Finance and Deregulation should jointly conduct a review into the feasibility, the costs and the benefits of requiring value for money assessments for government procurement to consider significant input tax concessions'. The outcome of such a review would usefully inform the approach taken by the NDIA.

Two other sources of competitive non-neutrality are sometimes raised, but neither are likely to be a significant concern.

- NFP providers can often use volunteers to provide services, putting themselves at an advantage to other enterprises that have little scope to use volunteers. However, the policy application of competitive neutrality is always subject to the proviso that the benefits outweigh the associated costs. There are clear benefits

from attracting volunteers to the disability sector, and it would not be in the public interest to penalise those providers who are good at doing this.

- Government providers could, in theory, have competitive advantages over other providers as their activities can be cross-subsidised by government and because they may allocate joint costs (like a personnel or IT function) to the non-competing parts of their activities. However, all Australian governments have agreed to implement competitive neutrality policies as part of the National Competition Policy reform package. Moreover, in practice, determining whether there are genuine breaches of neutrality is often not straightforward.

These issues aside, as a funding and purchasing agency, NDIA should give no preferences to suppliers based on their ownership (whether that be government, for profit or NFP), giving consumers the ultimate power about where to buy the services and supports they want.

Rural issues

Numerous participants have expressed concern about the quality of, and access to, services in rural areas. The remoteness of these areas, and the small size of their markets, present considerable challenges for service provider viability, effective competition, consumer choice, infrastructure adequacy and availability of specialists.

The flexibility of self-directed funding would be likely to ameliorate some of these issues (chapter 8). In particular, by allowing the use of mainstream services and other community assets, as well as letting family and community members take on paid caring roles, self-directed funding is likely to increase competition and choice, as well easing shortages. Local area coordinators will play a key role in taking full advantage of these local resources.

In some areas, the increase in funding associated with the NDIS would be particularly effective in a rural setting. For example, the land, (and in some country towns buildings also) required for accommodation and other services would often cheaper and more freely available. Similarly, higher unemployment and lower labour force participation rates in rural areas mean that, for services where training requirements are minimal, labour supply constraints would be less binding.

However, these solutions are unlikely to be adequate in all situations, resulting in shortages in some types of services, and excessive market power for others. As indicated above, competitively tendering for block funding, (open to NFP, private and government service providers on an equal basis) is a potential response to this.

A key area of concern is the lack of access to specialists (such as occupational therapists, speech therapists, physiotherapist or even GPs), which will continue to be an acute issue under the NDIS. Appropriately pricing the cost of private specialists (including travel time) when determining individualised budgets should improve access to some degree, particularly to regional centres (as opposed to very remote areas). Another way to alleviate the bottleneck is through coordinated and periodic visitation of remote towns with teams of specialists, such as the 'assist teams' in South Australia (Australian Federation of Disability Organisations, sub. 495, p. 41).[10] This would improve access for people who require multiple specialists and could potentially allow travel costs to be split between specialists travelling together, and the patients commuting to see them. Similarly, Anglicare suggested the development of 'the equivalent of a flying doctor service for specialist intervention and support services' that would follow a published circuit through remote areas (sub. 270, p. 23).

The greater use of information technology is also likely to be viable in rural areas where access to specialists and health professional is limited. For example, some have pointed to the potential for telehealth technology to monitor health conditions remotely and telerehabilitation to deliver specialist advice remotely (Medical Technology Association of Australia, sub. 479, p. 15). In some situations, the simple ability to 'skype' with a GP or allied health professional may be an adequate method for advice or referral (Sydney Hills Autism Support Network, sub. 212, p. 5; Parents of the Hearing Impaired of South Australia, sub. 222, p. 5). Deaf Australia also highlighted the potential for remote interpreting services (sub. 374, p. 12). The feasibility of these technologies is primarily limited by the speed and level of internet access in rural areas. As this constraint should lessen over time, the NDIS should actively promote the use of these technologies by conducting research into their efficacy and, where demonstrable benefits arise, funding them (for example, by providing a laptop and satellite broadband connection).

While improving disability services in rural Australia would be a key objective for the NDIS, ultimately, like most other services, it will not always be possible to match the range and quality of services provided in major cities. For people with very complex needs, relocation may be necessary to take advantage of highly specialised services. In such cases, the scheme would also assist with relocation. Nevertheless, the proposed NDIS should represent a considerable improvement for disability care and support in rural areas.

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[10] Similarly, Australian Hearing specialists also visit remote communities to test hearing.