

Individual funding systems: What works?

Author:

Helen Dickinson

Associate Professor Public Service
Management, Public Service
Research Group, University of
New South Wales

Author contact:

h.dickinson@adfa.edu.au

Abstract

The introduction of the National Disability Insurance Scheme (NDIS) has the potential to substantially transform care for Australians with disabilities. One of the key components of this system is individual funding – where the person with disability is allocated an amount of resource that they self-direct within a market system. A number of other countries have experimented with individual funding approaches and this review explores this recent experience to identify lessons that will be salient for the Australian context. In doing so, the review analyses evidence relating to the outcomes reported from these systems and sets out lessons concerning their implementation in terms of the further development of the NDIS.

Disability policy has become increasingly internationalized, not least through commitments such as the 2007 UN Convention on the Rights of Persons with Disabilities, which sets out a powerful desire to support people with disability to live active and meaningful lives in the context of their communities. In recent years, we have seen articulations such as this take hold in different nations, broadly tied to a personalization agenda. Australia is currently following this trend and embarking on significant reform of care services through the National Disability Insurance Scheme (NDIS). A key component of this system is self-directed care, based on the idea that giving people with disability control of a budget they can use to purchase services allows individuals to tailor their care to meet specific needs. It is argued these systems of care should empower individuals and their families by expanding choice and control over services. This will help integrate individuals into societal life, restoring people's rights as citizens (Oliver and Sapey 2006).

In making the case for the NDIS reforms, it was argued that disability services were underfunded, inflexible and built around the needs of the system, rather

than of the individual (National People with Disabilities and Carer Council 2009). Traditionally disability services have been the responsibility of state and territory governments, and different models have been developed across the eight jurisdictions (Fisher et al. 2010). Some Australian states had developed individual funding components, but they varied in their particular features (Purcal et al. 2014). The funding and organizing picture for disability services was complex, with splits between state and territory and federal responsibilities. Added to this complexity was the existence of insurance-based funding of disability services, and disability services funded privately as a result of public liability claims. What this meant was that individuals who acquired a disability through no fault of their own (at work or in a road traffic accident) may be entitled to greater levels of service provision through the relevant insurer than someone born with a disability.

In addition to the organizational complexity, people with disability were often reported as being marginalized from mainstream society and having fewer life chances. It has long been recognized that quality of Australian disability services and outcomes for people

with disability are poor, particularly when compared to other developed nations. A study from the OECD found Australians ranked lowest in terms of quality of life for people with disability (OECD 2009). Australians with disabilities have low levels of income and labor force participation (Milner et al. 2014), experience social exclusion (Mithen et al. 2015), and significant levels of violence (Kmjacki et al. 2016). Moreover, longitudinal evidence suggests that inequalities persist, and in fact these trends have become worse over time (Kavanagh et al. 2013).

The Productivity Commission (2011, 2) was charged with investigating the organization and funding of disability services and found it ‘underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports’. The report set out a new approach to funding care services through the NDIS. As well as greater investment in early intervention and community-based support for people with low support needs, individualized packages of funding would be available for people with higher support needs. The economic rationale behind this system is that spending resources in more appropriate ways – tied to early intervention and investment approaches – should ultimately save the public purse money, as individuals with disability are better able to engage with the labor market and mainstream society. Unlike some other countries, the NDIS focuses solely on those who enter the scheme before 65 years of age. The federal government committed to providing \$22 billion to this scheme, funded in part through an increase in the Medicare levy. While Australian disability services have been predominantly block-funded, the NDIS will bring them closer to much of Western Europe and North America, where variants of individualized funding are available (Purcal et al. 2014, 89).

The NDIS began national rollout in July 2016 and recently recruited its 100,000th participant (Probono 2017). Yet the scheme is still developing as it is rolled out across the country, and there remain questions over how this will work in practice. A much-used metaphor for the NDIS has been a ‘plane being built during flight’ (Whalan et al. 2014, 4). Rolling out initiatives ahead of an evidence base is not confined to Australia, with Needham (2010, 136) noting that ‘personalization is an agenda in which policy roll-out is racing ahead of the evidence base – spreading into new services before earlier pilots are concluded’. Given significant domestic and international experience of these schemes, this review explores the evidence base to glean insight into the degree to which they improve outcomes for individuals and provide lessons about the effective implementation of these schemes.

The review is structured as follows. Having set out a brief account of the policy context, the next section provides an overview of the methods adopted for the review and a summary of the nature of the evidence base. Although there is a current international trend for individualized funding systems in disability services, the evidence base is far from strong. The review then moves on to the findings, providing an overview of the different types of funding systems, their impact, and lessons regarding implementation. There is a lack of high quality evidence and much is still unknown about the efficacy of these mechanisms. There are, however, a number of important lessons about what factors seem to be important when implementing these schemes.

Methods

This review set out to explore evidence relevant to the NDIS in terms of the processes and outcomes of individual funding schemes. The author previously conducted a rigorous review of the literature relating to individual funding in 2010 as a component of a project exploring the implications of the personalization agenda for the community sector (Dickinson and Glasby 2010). Since this time there have been a number of additions to the literature. Therefore, this review focuses principally on the evidence generated post-2009, building on the previous project.

The following bibliographic databases were searched: CINAHL (EBSCO), EMBASE, Scopus (Elsevier), Social Services Citation Index (Web of Science), Social Services Abstracts (Proquest) and Google Scholar. The key search terms used were:

- ‘Personalization’ AND (‘disability’ OR ‘health’ OR ‘social care’ OR ‘social services’)
- ‘Individual funding’
- ‘Self directed care’
- ‘Market management’ AND (‘disability’ OR ‘health’)

The criterion for inclusion in the review was that papers should include original evidence relating to the use of individual funding schemes and their efficacy in the context of disability services. Items that reviewed the existing evidence base without offering new empirical data were not included. Articles that discussed issues relating to the topic of individual funding in a conceptual sense or speculated on the potential impacts of this agenda, but without the presentation of new data, were not included. Items that focused solely on the implications for particular

professional groups without considering the efficacy or impact of individual budgets were not included. Articles that focused on aged care were not included, as older people are not eligible for entry directly to the NDIS. Inclusions were limited to English language papers. Papers were not included where they focused on a discussion of other policy areas (e.g. health) with little mention of disability-related issues.

The initial search yielded 1031 items. All papers identified were assessed using a three-step process. First, the title of each article was scanned to develop a list of articles that potentially met the review criteria, and to remove any duplicate items. This yielded 151 articles. Abstracts for these articles were then reviewed and 80 broadly met inclusion criteria. Narrower criteria were then used to ensure that items were only included if they met the inclusion criteria outlined above. In total 25 articles met the inclusion criteria. As these full articles were read, note was taken of any relevant 'grey literature', and four more items were identified as a result of this process. Appendix 1 provides an overview of all the items included in the review.

Nature of the evidence base

When seeking to extract lessons from different national contexts it is crucial that we take care, given that these settings are informed by the various national, historical, institutional and cultural contexts in which they operate (Williams 2009). In this case we also need to take care because the quality of the evidence base is limited. As described above, a number of papers were excluded from the review as they did not include empirical data and were largely normative discussions concerning the design and delivery of disability services. Even where papers did include empirical data, there are questions as to the methodological robustness of these explorations and the quality of those data. For example, in a systematic review of personal budgets for people with disability, Webber et al. (2014) found that studies often lacked detail about funding mechanisms, and in some cases found it difficult to distinguish between processes and outcomes. Along with a number of 'methodological shortcomings', the team found they were limited in the extent to which they could interpret findings. Manthorpe et al. (2015, 44) concur, describing studies found in their scoping review as 'often small-scale and/or characterized by small sample sizes; they may be reliant on pilot activities, with little or no long-term follow up'. This team concluded that there are some

critical gaps in our knowledge, particularly in relation to implications for consumers and carers. Webber et al. (2014) further note there are greater gaps around some service areas than others (e.g. mental health).

A note concerning the quality of this evidence is important because the majority of literature concerning individual funding systems has an intrinsically positive hue. Alakeson (2010, 3), for example, concludes that 'despite significant differences in programs across countries, evaluations reveal a consistently positive picture'. Yet a more recent review found 'the quality of the studies...was moderate at best... which is rather worrying given the significant investment in research and evaluation on personal budgets over the last 10 years. Many personal budget evaluations had a high risk of bias ...There is a need for large high quality experimental studies in this key policy area to inform...policy and practice' (Webber et al. 2014, 153). There are few examples of the kinds of studies that Webber and colleagues call for. A notable exception is the evaluation of English individual budget pilots (the so-called IBSEN review), which is responsible for ten of the articles included in this review (see Jones et al. 2014; Mitchell et al. 2015; Forder et al. 2012; Glendinning et al. 2008; Jones et al. 2012; Moran et al. 2011b; Moran et al. 2011a; Netten et al. 2012). The reality is that careful and detailed explorations of the impact of individual funding systems are few.

It may not be entirely surprising that we lack quality data concerning reforms around disability services. Studies find that disability research often lacks visibility, is poorly coordinated, and lacks methodological rigor. A study from the Institute of Medicine Committee on Disability in America (2007, 288) concluded that, despite some progress, disability research is 'still substantially underfunded'. These findings have been echoed in Australia, where an audit of disability research (Llewellyn 2014, 43) found:

there were no policy studies identified that provide a thorough evaluation of current or past policy. Policy is critiqued theoretically or practically but this falls short of evaluation and does not provide an effective basis from which to reform policy. There is very little research examining the practice implications of policy innovations. This is a significant gap because the effectiveness of the policy will be measured in how effectively practitioners are able to implement it to meet the needs of their clients. Evaluation is often conducted internally to government, but this is rarely shared publicly as governments and services are reluctant to advertise policy problems. This limits policy learning and encourages the repetition of policy mistakes. There is little cost-effectiveness research in any of these studies.

The introduction noted that disability services in Australia have traditionally been described as underfunded. As we will see in the discussion below, this is not unusual in an international context, where many people with disability remain socioeconomically disadvantaged. At a time when there is insufficient funding for disability services, and concerns over levels of government spending more generally (New Zealand Productivity Commission 2015), it is perhaps difficult to make the argument that more should be spent on disability research in order to ensure a sound evidence base. However, in a context where significant funds are being invested in the rollout of the NDIS, it is important to note the limitations of the evidence base. The next section moves on to outline the individual funding initiatives that have been implemented in different jurisdictions, the evidence concerning the impact of these systems, and lessons learned about what is important in driving these systems.

Different models of funding systems

The key difference between traditional approaches to disability services and individual funding schemes is that the former are designed to offer individuals more choice and control over their lives. Beyond this, there is variety in how these systems operate. First, there are different names for schemes, which is to be expected – although there are some important differences in programs that have the same name. Some systems allow funds to be paid directly to the individual and some allow payment to a host provider to administer on behalf of the individual. In the latter case there are many different agencies that might function as a financial intermediary – in some systems this will be a public institution and in others a community organization or other variation. Typically, programs involve some form of needs assessment and the development of outcomes or goals that are to be achieved, but how this operates varies significantly.

Table 1 provides an overview of some of the different programs available and their key features. As this illustrates, models differ in what individuals are allowed to spend money on, who holds resources, and scrutiny over spending of these funds. In managing what individuals can spend on, Alakeson (2010) makes a distinction between two models of individual funding. The first is described as an ‘open’ model where a cash payment is provided to individuals meeting certain eligibility criteria and they can choose how they spend this money with few restrictions. Care is reviewed to assess whether it is ‘adequate’, and if not this can be removed (Gibson and Redfoot

2007). This model has tended to be used in countries such as Germany and Austria. The second model is a more planned approach, where there is a direct link between the needs of the participant and the goods and services purchased to meet them. This has been the type of approach adopted initially in the Netherlands, the US, and England, and the model that underpins Australia’s NDIS. New Zealand also has a planned individualized funding system that enables people with disability to directly manage the support they are allocated from Home and Community Support Services. The individual funding scheme can be used to purchase services provided by support workers and meet costs relating to their employment, but money cannot be used to manage services such as day and/or vocational services, rehabilitation services, supported living or respite services (Ministry of Health 2012).

As Purcal et al. (2014) illustrate, the demand-side of the equation (i.e. who controls the budget) is not the only important consideration and we need to pay equal attention to supply-side issues (i.e. the providers of services). Even if people with disability have control of their funding, if they lack ability to direct the kinds of services they want or need, this can limit choice. In their study of Australian individual funding systems pre-NDIS, Purcal et al. (2014) note that Western Australia has operated individual funding systems since the 1980s, but block-funding is still the dominant way of funding disability providers. Limitations on availability of providers can limit choice about sources of support for individuals. This further demonstrates an important point about the degree to which market forces sit at the heart of these schemes. Norway has operated individual funding since 2000 and has moved to offer more control, but without creating a significant market for disability services. Rather than individuals having direct control over funds, they choose a provider to work with and through this play a greater role in managing their care. A study by Christensen and Pilling (2014) found more than half of individuals chose to work with their municipality, with just over a third opting for a user-led cooperative and the remainder receiving funds personally (11 percent) or through a private organization (two percent). Rather than focusing on enhancing consumer rights through a market, Norway has focused on offering individual choice and control in everyday life through public and user-led support stressing a role in management.

As this section has sought to illustrate, although there is an international trend towards individual funding systems, there are some important differences in how these systems have developed and operate. What this means is we need to be careful when

Table 1 International examples of individual funding programs and their key features

Program	Country	Services	Funds paid directly to indiv. (or family member)	Funds paid dir. to indiv. or managed via host/3rd party	Host provider required to manage funds	Vouchers given to individual
Direct payments	UK, US, Australia	Personal care, social care, health	✓	✓		
Individual budget	England	Social care		✓		
Personal budget, personal health budget	UK	Health		✓		
Housebound Aid and Attendance Allowance	US	Health, personal care, social care	✓			
Cash for Counselling and Self-directed care	US	Health and social care		✓		
Consumer-directed Family Support	US	Respite care, personal care and social care			✓	
Special services at home	Canada	Personal care and social care	✓			
Individualized funding	New Zealand	Personal care and social care			✓	
Local area co-ordination	Australia	Respite care, personal care and social care	✓			
Personal assistance budget	Belgium	Personal care and social care		✓		
Cash for care	France	Personal care and social care		✓		
Cash payments for care	Germany	Personal care, social care, transport, nursing, workplace assistance		✓		
Personal budgets	Nether-lands	Personal care, nursing care, support services and respite care		✓		
Cash payments	Austria	Personal care and social care	✓			
Home care service vouchers	Finland	Personal care, social care and health				✓
Assistance allowance	Sweden	Personal care and social care	✓			
User-controlled personal assistance	Norway	Personal care, social care		✓		

thinking about what lessons we draw. When we add this observation to concerns about the quality of the evidence base, this suggests we should take care in extrapolating findings.

Impact of individual funding systems

In assessing the efficacy of a policy initiative, any handbooks on evaluation stress the need to go back to the aims and objectives of a program in order to check the degree to which it had the intended impact (Dickinson and O'Flynn 2016). This proves to be a challenge in relation to individual funding initiatives, where there are multiple conflicting philosophies concerning what this agenda should deliver. Indeed, it is a well-rehearsed argument that the popularity of individualized funding is a result of it knitting together two dominant policy trends in advanced democracies: neoliberal public sector reform, which seeks to strip power away from large government bureaucracies, and human rights discourses, which aim to maximize the scope for self-actualization amongst people who have been denied full citizenship in the past (Needham 2011). Although on the surface the philosophies of these two positions may seem similar to the extent that they afford people with disability more choice, Roulstone and Morgan (2009) have argued they are growing increasingly apart.

Tensions between these two strands have surfaced in the UK in debates over the degree to which person-centeredness and individualized funding aim to develop citizen-rights or consumer-rights (Ferguson 2007). Consumer-rights are typically conceived as being concerned with affording people with disability the right to make individual choices within a free market. This is arguably a version of 'shallow' personalization as defined by Leadbeater (2004). People with disability are able to purchase services, which allows for modest customization and adaptation to their needs, but without transformation of the power balance between individuals with disability, communities, and the state. Citizen-rights – associated with 'deep' personalization (Leadbeater 2004) – are also concerned with individual freedom, but in this case in relation to democratic values and inclusion in society. They go beyond customizing services to giving people with disability a greater role and greater responsibilities in designing solutions. Leadbeater (2004) has argued that most public service systems are able to accommodate greater consumer-rights through some minor adjustments to existing systems, but to achieve citizen-rights involves more than just a change to practices of service delivery – it requires a

shift in power, so that design and control of services becomes bottom-up rather than top-down.

It is important to recognize the multiple and potentially conflicting driving forces behind this international policy trend; if there are differing perspectives on what success looks like, this has implications for drawing lessons from the evidence base. In the remainder of this section themes from the evidence base are explored concerning claims that have most frequently been made for individual funding systems, namely whether individual funding mechanisms save money and/or improve consumer satisfaction and outcomes. But it is important to remember that assessments as to relative success of initiatives should relate to their particular aims.

Do individual budgets save money?

One of the arguments made for pursuing an individual funding approach is that these mechanisms have the potential to save money for the public purse. It is recognized that funds for disability services have not always been spent in the most effective or appropriate ways. There is also a particular feature of the Australasian policy context that is distinct from those found in the remainder of the world. Australia and New Zealand have in recent years expressed a keen interest in 'social investment' approaches to welfare (New Zealand Productivity Commission 2015), where interventions are adopted explicitly on the basis that they will reduce future welfare liability. Within this context, social insurance schemes such as the NDIS are seen as a helpful way to ensure long-term wellbeing and reduce expenditure. Such approaches also aim to have net positive benefits on the economy, for example by engaging individuals in the workforce, reducing welfare payments, and generating tax revenue. These initiatives build, in part, on examples such as WorkCover and the Transport Accident Commission in Australia, and the Accident Compensation Corporation in New Zealand (a no-fault personal injury cover for all residents and visitors). In recent years these schemes have moved on from simply funding services to investing in preventative approaches as a way of reducing claims. The language of investment features heavily in the Productivity Commission's report on the NDIS (2011), and the design of the system encompasses the features that Lister (2003) identified as core to a social investment approach. These include investment in human and social capital; a focus on the future; an attempt to adapt individuals to the knowledge economy in order

to enhance global competitiveness; and an integration of economic and social policy.

Locating the NDIS within a social investment approach places it in a different standing vis-à-vis the individual than we find in other welfare systems (e.g. England). Although other systems have focused on upstream interventions to prevent the use of more acute services, this has a different focus within the actuarial approach of the NDIS and New Zealand social service reforms. Demonstrating the value of preventative services is notoriously difficult (Dickinson and O'Flynn 2016). From the existing evidence base it is not easy to tell whether the NDIS will be successful in its investment approach, particularly given it is underpinned by an ethos different from many of the extant individualized systems of funding.

In relation to whether individualized funding saves money, it is also often argued that it is difficult to evaluate cost given that there is not sufficiently detailed data available, or accurately-costed comparison groups (Gadsby 2013). Capturing the full implementation costs of an initiative is also a challenge, particularly in relation to labour and human capital costs. For example, English studies found that while care packages were not more expensive for those with personal budgets, their care management costs were higher (Glendinning et al. 2008; Jones et al. 2012). Counter-intuitively, care managers spent longer on assessments of people with individual budgets (Jones et al. 2012). Costs for individual funding systems are often underestimated and host agencies are required to work unrealistic schedules (Fisher et al. 2010; Laragy and Ottman 2011).

In New Zealand, research into individual funding shows spending in this area has grown from \$10 million in 2009–10 to \$39 million in 2013–14. But over this period the cost per user declined from \$28,035 per annum to \$20,212, representing a 28 percent decrease (Field et al. 2015, 13). These changes could be an indication of cost control, but there is the possibility that the mix of people using individual funding is changing so that those with lower allocations are now being included. However, analysis of those with complex needs shows that individual funding users do better at cost containment than comparative groups of non-individual fund users. Further, there seem to be substantially lower residential care costs in the individual fund group than the non-users, suggesting that these mechanisms allow people to avoid transitioning to residential care. However, the evaluation notes that they could not say with certainty that individual fund users and comparison groups share similar features, due to difficulties with the data they drew on.

In its recent review of personalized commissioning in English adult social care, the National Audit Office (2016, 8) was clear that it did not expect individual funding systems to make savings for the public purse: 'The Department expects the value-for-money of personalized commissioning to come from improved outcomes for users, not necessarily from savings'. However, there has been a seven percent reduction in spending on adult social care between 2010 and 2015, and in some places this has meant local governments have adopted payment rates at their own level, rather than that of the market. The implication of this is that some individuals will struggle to afford services should these trends continue.

Do individual budgets improve consumer satisfaction and outcomes?

Individualized funding systems, we are frequently told, are better for people with disabilities. Yet the evidence base presents something of a mixed picture about satisfaction and outcomes. Again, there is the inevitable health warning about the degree to which evaluating individual funding systems and making statements about satisfaction and outcomes is possible. There are not vast numbers of studies that have been able to investigate outcomes using validated tools and control groups.

The National Audit Office (2016, 12) found 'no link between the proportion of users with personal budgets and overall levels of user satisfaction'. However, other studies have demonstrated a clear link between satisfaction and the use of individual budgets within the same country (Gadsby 2013; Waters and Hatton 2014). It is possible that the National Audit Office's observations relate to patterns in aggregated data across entire populations, as opposed to individuals. The third national survey of personal budget holders in England (Waters and Hatton 2014) examined data at the level of the individual and found that more than three quarters of personal budget holders reported their budget having a positive impact on five of the 15 areas they asked about, including dignity, independence, arranging support, paid relationships and quality of life. Two thirds also cited positive impacts in a further six areas relating to mental health, control over life, feeling safe, family relationships, paid relationships, and self-esteem. Slasberg et al. (2015) took issue with the national survey of personal budget holders, arguing that it simply measures the experience of having an individual budget in comparison with no service at all, and therefore is likely to make the findings look more positive than they in fact are.

Improved choice is often argued to be an important result of individualized funding systems, and the evidence suggests that this is likely to be particularly challenging for those in rural and remote areas, where availability of services is restricted (Dew et al. 2013). In their study of individual budget pilots in England, Netten et al. (2012, 1568) found that those in receipt of these mechanisms reported a 'greater sense of control', and this was not dependent on the plan being in place or the level of resources allocated to the individual. Ipsos MORI (2011), by contrast, found that the payment mechanism was important in the degree to which individuals had choice over services. They found that managed budget holders were generally unaware that they could choose providers and were often not offered choice of providers. 'On balance, it appeared that only direct payments offered a genuine choice to budget holders' (2). Similar observations have been made by Slasberg and Beresford (2015, 479), who argue that direct payments are the only mechanism that have significant impacts on outcomes for consumers: 'Whilst policy-makers saw it as a triumph for consumerist notions of choice, it is better understood as a triumph for needs-based planning, but carried out in a person-centered way'. This observation again reiterates the idea that it may not be the funding that has the impact, but the care planning process, as we saw in the Norwegian experience.

Laragy and Ottman (2011) remind us that although increased choice might be highly valued by some, not everyone wants to self-manage. In their study they found that self-management might have the capacity to increase isolation over time. Regardless of the ability of individuals to navigate systems, the literature demonstrates that implementing individual funding systems without attending to broader systems of brokerage and support planning is problematic.

Arksey and Baxter (2012) found individualized funding had led to better relationships with service providers, and Graham (2015) noted that relationships with personal assistants (purchased through individual budgets) were valued for their social links as much as the provision of services. Similarly, carers are an important resource in care relationships for many individuals with disabilities. Larkin (2015) found that more than half of those they interviewed believed that having a personal budget had improved the relationship between carers and consumers.

Gadsby et al. (2013) concluded the evidence demonstrating the impact of individual budgets on health and wellbeing is 'weak'. Other studies have found 'modest improvements in levels of psychopathology' (Spaulding-Givens and Lacasse 2015,

78), slightly higher quality of life indicators (although not statistically significant) (Netten et al. 2012), and some improvement in quality of life and satisfaction (Barczyk and Lincove 2010). Waters and Hatton (2014, 6) also found that individuals were more likely to report better outcomes where local government made 'the process easy, and they feel fully included in budget setting and support planning'. Further, better outcomes were reported where individuals had spent budgets on community or leisure activities and personal assistants, rather than 'traditional services'. What this evidence suggests is there are links to improved satisfaction but only where there are appropriate management systems in place: improvements are not simply guaranteed according to the use of these mechanisms. Added to this, there are debates concerning the ability of some individuals to benefit from these systems. It has been argued that some individuals may have cognitive limitations that impede their capacity to control individual funding processes (Dowse 2009; Lymbery 2012).

What needs to be in place to make individual funding systems effective?

As the description of the efficacy of individualized funding systems demonstrates, there is not an inherent intrinsic value to these mechanisms, and their effect is in part a result of the way they are implemented. If there is one message in this literature it is that how you implement is as important as what you implement. Careful thought needs to be given to both supply (i.e. who controls budget and how and how budgets are allocated) and demand-side factors (i.e. contracting mechanisms, market stewardship). Further, different groups may require different things: some groups may wish to control their own care and others may not. More time is needed to support care planning for individual budgets than traditional services (Jacobs et al. 2011).

Laragy and Ottman (2011) argue that implementation is often a challenge with individual funding systems, and implementation strategies are often not well developed. They outline a series of factors that need to be in place to support individual funding schemes:

- Choice over whether to receive traditional services or self-manage;
- Support appropriate to cognitive, physical and cultural needs to be an active participant in planning;
- Mechanisms to review appropriate to capacity and individual needs;

- Culturally appropriate information and support services;
- Provision of adequate resources to meet needs and ability to quickly reassess when needed;
- Support services to manage administrative responsibilities;
- Clear guidelines about what is allowed and what not, allowing for maximum flexibility and creativity;
- Support from peers (i.e. other consumers or families);
- Support for support workers and to protect working conditions.

In their study of barriers to the use of individual budgets in rural and remote areas, Dew et al. (2013) note similar challenges, including: a lack of information and advice; limited local service options and capacity; higher costs and fewer services; and the complexity of self-managing individual funding packages.

A key message in the implementation of individual funding systems relates to ensuring there is appropriate advocacy and support in place (Jepson et al. 2015). Without this, there is a danger that individual funding is seen as an exercise in cutting costs, with individuals or families performing functions of government. There needs to be clear and ongoing assistance over the life course to support individuals

in an ongoing way, as and when issues arise and circumstances change (Arksey and Baxter 2012). **Table 2** summarizes the main findings of the review regarding cost savings, impact on outcomes, and implementation factors.

Discussion

This section considers the implications of this evidence base for the NDIS and Australian disability services. As noted in the methodology, papers relating to aged care were excluded from the review as the NDIS is not available for entry to those aged over 65. However, it is worth noting that the lessons from this literature are quite similar, with the exception that older people are even less favourable of these approaches than younger people with disabilities (Dickinson and Malbon, forthcoming). What this literature does demonstrate is that effective care coordination is crucial and that this is more, rather than less, time-consuming in individualized systems of care.

Despite early enthusiasm for the concept of individual funding systems, there are growing criticisms and uncertainties as to their efficacy. Some criticism may be driven by the public service context in some countries, rather than due to individual budg-

Table 2 Summary of review findings

Does individual funding save money?	Does individual funding improve consumer outcomes?	What needs to be in place to make individual funding systems effective?
Possibly, most likely for those who receive greatest \$ value care packages. But some costs may be passed on to providers or consumers. Note the difficulties in evaluating this with certainty.	Little evidence of improved outcomes, but better satisfaction for some groups. Enhanced choice dependent on effective market stewardship and also ability to use budgets in different ways. Again, noting difficulties in evaluating outcomes effectively.	<ul style="list-style-type: none"> • Choice over whether to receive traditional services or self-manage; • Support appropriate to cognitive, physical and cultural needs to be an active participant in planning; • Mechanisms to review appropriate to capacity and individual needs; • Culturally appropriate information and support services; • Provision of adequate resources to meet needs and ability to quickly reassess when needed; • Support services to manage administrative responsibilities; • Clear guidelines about what is allowed and what not, allowing for maximum flexibility and creativity; • Support from peers (i.e. other consumers or families); • Support for support workers and to protect working conditions

ets specifically. UK public services have in recent years witnessed an austerity agenda, ushering in significant cuts to benefits and eligibility for services, and increased emphasis on individual responsibility and voluntarism for the provision of welfare (Featherstone et al. 2012). Beresford (2012), amongst others, has argued that far from protecting the most vulnerable people in British society, cuts have actually targeted people with disability. Studies from the US and other jurisdictions confirm that many individuals with disability live in poverty, dependent on limited welfare funding and family members (Inoue et al. 2014). Against this background, some waning enthusiasm for individual funding mechanisms could be due to their use in helping to cut overall spending through tightening care funding.

Debates also exist about what the 'active ingredient' is within individual funding. This has been a particular feature in UK debates, where there are multiple variants of funding forms. Here discussions center around whether improvements relate to the availability of individual funding, or simply better case management (e.g. Ipsos MORI 2011; Slasberg et al. 2012). Other contributions suggest implementation of the personalization agenda is falling short. Spicker (2013, 1259) observes that

personalization sometimes falls short of the claims made for it. It is not always effective, because matching people to resources is time-consuming, difficult and dependent on so many conditions that mismatches are inevitable. It may be inefficient, because it is difficult to deliver selective services without either misplaced provision or inappropriate denial of services. There is only limited support to be found for the belief that services have become more responsible to individual circumstances, as a consequence of personalization, or that they are better matched to need. The case for personalization has to be argued and proved in the context in which it is applied.

What these lessons suggest for the Australian context is that paying attention to implementation is an absolutely critical factor in making successful change. This fact has been acknowledged in recent months by the Productivity Commission (2017) in a review of the scheme's costs and other recent evaluations of the NDIS (e.g. Warr et al. 2017), where it has been noted that the speed at which the scheme is being implemented is posing some potential challenges to its success. What is clear from the literature is that appropriate care planning, advocacy and brokerage functions and ongoing support will be needed if those who access individual funding are to achieve their desired outcomes. There are limitations to these functions at present (Warr et al. 2017). Market stewardship is also a critical activity – particularly, but not

exclusively, in rural and remote areas. As yet, there is limited evidence in the literature about how this might be achieved. In more recent years, a growing body of contributions has emerged that outlines the potential implications of changes to the supply-side as a result of individual funding systems. For example, Roulstone and Kwang Hwang (2015, 849) examine developments in Sweden, England and Wales and found that their impact has been a loss of collective services and impulses, 'ideas that were central to the development of the independent living movement and its founding principles.' If the NDIS is concerned with achieving better integration of those with disabilities into broader society, care must be taken not to erode existing collective drivers and further individualize services. Moreover, the integration agenda also raises important questions about what can be achieved through individualizing care funding, but not other sources of funding. If integration is to be achieved, the NDIS will need to work closely with a range of mainstream services (e.g. health, employment, human services). The past 30 years of collaboration literature suggests this is not an easy task (Dickinson 2014), and in some cases individual funding schemes have reignited age-old boundary debates (Glendinning et al. 2011; Dickinson and Carey 2017).

Finally, it is worth remembering that while international evidence about implementation is important, the NDIS approach is distinct in its approach to welfare (Needham and Dickinson 2017). This approach is based on a principle of social investment with a focus on early intervention as a way of reducing future state liabilities. This kind of scheme has been successful in Australia in relation to road traffic accidents and work-related accidents and a similar ethos can be found in New Zealand's recent social service reforms (New Zealand Productivity Commission 2015). The distinctive aspects of these reform processes mean that we cannot easily draw on evidence from other countries, and further research will be needed in order to examine the degree to which these schemes meet their aims, and the degree of success in improving disability services in comparison with other systems.

Conclusions

This review has explored the growing evidence base on the topic of individual funding. There is at present somewhat of an international trend for individual funding schemes, and Australia has joined this through the development of the NDIS. Despite a burgeoning literature about individual funding, the quality of the evidence is limited. There are a num-

ber of different kinds of schemes that fit in this category, with distinct ways of operating factors such as who holds budgets, what they can be spent on, and provider contracting mechanisms. Added to this we find that some of the approaches taken to evaluating these schemes lack rigor, making it difficult to be certain about their efficacy. In addition to issues over the quality of evidence, we find a more philosophical challenge in the sense that these schemes weave together multiple different competing drivers about whether individual funding is intended to uphold consumer or citizen-rights. The Australasian approach to disability services has developed a rather distinct approach, based on particular notions of social investment. This means that we must be even more careful in drawing on the existing evidence.

What the evidence suggests is that despite initial enthusiasm for these schemes, there is growing skepticism as to their efficacy. Concerns have been expressed about the ability of these schemes to achieve their aims of being more cost effective, improving choice and control for consumers, and improving outcomes for individuals with disability. What is not clear from the literature is whether these are inevitable features of these schemes, or whether these factors relate to the ways in which they have been implemented and the degree to which they have been appropriately supported. The review outlines a number of factors that require particular attention during the implementation process in order to ensure that all parties are appropriately supported. Finally, the review notes the distinctive flavour of social service reforms in Australia and New Zealand, arguing that we will need longitudinal research to examine the degree to which such an approach is effective.

ACKNOWLEDGMENTS

The author would like to acknowledge Laura Thomas for her support in searching the literature and seeking out sources of literature and George Cox for his editing support.

References

- Alakeson, V 2010. International development in self-directed care, *Issue Brief (Commonwealth Fund)*, 78, 1-11.
- Arksey, H & Baxter, K 2012. Exploring the temporal aspects of direct payments, *British Journal of Social Work*, 42, 147-64.
- Australian Government Productivity Commission 2011. *Disability Care and Support: Productivity Commission Inquiry Report*, Productivity Commission, Melbourne.
- Australian Government Productivity Commission 2017. *National Disability Insurance Scheme (NDIS) Costs, Productivity Commission position paper overview and recommendations*, Productivity Commission, Canberra.
- Barczyk, AN & Lincove, JA 2010. Cash and counseling: a model for self-directed care programs to empower individuals with serious mental illnesses, *Social Work in mental Health*, 8, 209-24.
- Beresford, P 2012. From 'vulnerable' to vanguard: challenging the Coalition, *Soundings*, 50, 46-57.
- Christensen, K & Pilling, D 2014. Policies of personalisation in Norway and England: On the impact of political context, *Journal of Social Policy*, 43, 479-96.
- Dew, A, Bulkeley, K, Veitch, C, Bundy, A, Lincoln, M, Brentall, J, Gallego, G & Griffiths, S 2013. Carer and service providers' experiences of individual funding models for children with a disability in rural and remote areas, *Health and Social Care in the Community*, 21, 432-41.
- Dickinson, H 2014. *Performing governance: Partnerships, culture and New Labour*, Palgrave MacMillan, Basingstoke.
- Dickinson, H & Carey, G 2017. Managing care integration during the implementation of large-scale reforms: The case of the Australian National Disability Insurance Scheme, *Journal of Integrated Care*, 25(1), 6-16.
- Dickinson, H & Glasby, J 2010. *The personalisation agenda: Implications for the Third Sector*, Third Sector Research Centre, Birmingham.
- Dickinson, H & Malbon, E forthcoming 2017. *Aged care reform: stewardship roles and aged care*, Municipal Association of Victoria, Melbourne.
- Dickinson, H & O'Flynn, J 2016. *Evaluating outcomes in health and social care*, Policy Press, Bristol.
- Dowse, L 2009. 'Some people are never going to be able to do that': challenges for people with intellectual disability in the 21st century, *Disability and Society*, 24, 571-84.
- Featherstone, B, Ince, A, Mackinnon, D, Strauss, K & Cumbers, A 2012. Progressive localism and the construction of political alternatives, *Transactions of the Institute of British Geographers*, 37, 177-82.
- Ferguson, I 2007. Increasing user choice or privatizing risk?, *British Journal of Social Work*, 37, 387-403.

Field, A, Mcgechie, M & King, J 2015. Individualised funding analysis: report for Manawanui InCharge. Manawanui InCharge, Auckland.

Fisher, KR, Gleeson, R, Edwards, R, Purcal, C, Sitek, T, Dinning, B, Laragy, C, D'aegher, L & Thompson, D 2010. Effectiveness of individual funding approaches for disability support, Occasional Paper 29, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Canberra.

Forder, J, Jones, K, Glendinning, C, Caiels, J, Welch, E, Baxter, K, Davidson, J, Windle, K, Irvine, A, King, D & Dolan, P 2012. *Evaluation of the personal health budget pilot programme*, PSSRU, Kent.

Gadsby, EW 2013. *Personal budgets and health: a review of the evidence*, Policy Research Unit in Commissioning and the Healthcare System, Kent.

Gibson, MJ & Redfoot, DL 2007. Comparing long-term care in Germany and the United States, *AARP, Washington DC*.

Glendinning, C, Challis, D, Fernandez, JL, Jacobs, S, Jones, K, Knapp, M, Manthorpe, J, Moran, N, Netten, A, Stevens, M & Wilberforce, M 2008. IBSEN: Evaluation of the Individual Budgets Pilot Programme., Final Report. SPRU, University of York.

Glendinning, C, Moran, N, Challis, D, Fernandez, J, L, Jacobs, S, Jones, K, Knapp, M, Manthorpe, J, Netten, A, Stevens, M & Wilberforce, M 2011. Personalisation and partnership: Competing objectives in English Adult Social Care? The individual budget pilot projects and the NHS, *Social Policy & Society*, 10, 151-62.

Graham, K 2015. Cash payments in context: (self) regulation in the new social relations of assistance, *Disability and Society*, 30, 597-613.

Inoue, M, Lombe, M, Putnam, M & Mahoney, K 2014. Understanding saving and purchase patterns of consumers in a self-directed care program: The West Virginia Experience, *Journal of Policy Practice*, 13, 101-17.

Institute Of Medicine (Us) Committee On Disability In America 2007. *The future of disability in America*, National Academies Press (US), Washington (DC), Organization and Support of Disability Research. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK11436/>

Ipsos MORI 2011. *Users of social care personal budgets*, Ipsos MORI, London.

Jacobs, S, Abdell, J, Stevens, M, Wilberforce, M, Challis, D, Manthorpe, J, Fernandez, J.L, Glendinning, C, Jones, K, Knapp, M, Moran, N. & Netten, A 2011. The personalization of care services and the early impact on staff activity patterns, *Journal of Social Work*, 13, 141-63.

Jepson, M, Laybourne, A, Williams, V, Cyhlarova, E, Williamson, T & Robotham, D 2015. Indirect payments:

when the Mental Capacity Act interacts with the personalisation agenda, *Health and Social Care in the Community*.

Jones, K, Netten, A, Fernandez, JL, Knapp, M, Challis, D, Glendinning, C, Jacobs, S, Manthorpe, J, Moran, N, Stevens, M & Wilberforce, M 2012. The impact of individual budgets on the targeting of support: findings from a national evaluation of pilot projects in England, *Public Money & Management*, 417-23.

Jones, K, Netten, A, Rabiee, P, Glendinning, C, Arksey, H & Moran, N 2014. Can individual budgets have an impact on carers and the caring role?, *Ageing & Society*, 34, 157-75.

Kavanagh, AM, Kmjacki, L, Beer, A, Lamontagne, AD & Bentley, R 2013. Time trends in socio-economic inequalities for women and men with disabilities in Australia: evidence of persisting inequalities, *International Journal of Equity in Health*, 12, 73.

Kmjacki, L, Emerson, E, Llewellyn, G & Kavanagh, AM 2016. Prevalence and risk of violence against people with and without disabilities: findings from an Australian population-based study, *Australian and New Zealand Journal of Public Health*, 40, 16-21.

Laragy, C & Ottman, G 2011. Towards a framework for implementing individual funding based on an Australian case study, *Journal of Policy and Practice in Intellectual Disabilities*, 8, 18-27.

Larkin, M 2015. Developing the knowledge base about carers and personalisation: contributions made by an exploration of carers' perspectives on personal budgets and the carer-service user relationship, *Health and Social Care in the Community*, 23, 33-41.

Leadbeater, C 2004. *Personalisation through participation: A new script for public services*, Demos, London.

Lister, R 2003. Investing in the citizen-worker of the future: Transformations in citizenship and the state under New Labour, *Social Policy and Administration*, 37, 427-43.

Llewellyn, G 2014. *Report of audit of disability research in australia. supplement*, The University of Sydney, Sydney.

Lymbery, M 2012. Social work and personalisation, *British Journal of Social Work*, 42, 783-92.

Manthorpe, J, Martineau, S, Ridley, J, Cornes, M, Rosenguard, A & Hunter, S 2015. Embarking on self-directed support in Scotland: a focused scoping review of the literature, *European Journal of Social Work*, 18, 36-50.

Milner, A, Lamontagne, AD, Aitken, Z, Bentley, R & Kavanagh, AM 2014. Employment status and mental health among persons with and without a disability: evidence from an Australian cohort study, *Journal of Epidemiological Community Health*, 68, 1064-71.

Ministry of Health 2012. *Your guide to individualised funding*, Ministry of Health, Wellington.

Mitchell, W, Brooks, J & Glendinning, C 2015. Carer's roles in personal budgets: tensions and dilemmas in front line practice, *British Journal of Social Work*, 45, 1433-50.

Mithen, J, Aitken, Z, Ziersch, A & Kavanagh, AM 2015. Inequalities in social capital and health between people with and without disabilities, *Social Science & Medicine*, 126, 26-35.

Moran, N, Arksey, H, Glendinning, C, Jones, K, Netten, A. & Rabiee, P 2011a. Personalisation and carers: whose rights? Whose benefits?, *British Journal of Social Work*, doi: 10.1093/bjsw/bcr075.

Moran, N, Glendinning, C, Stevens, M, Manthorpe, J, Jacobs, S, Wilberforce, M, Knapp, M, Challis, D, Fernandez, JL, Jones, K & Netten, A 2011b. Joining up government by integrating funding streams? The experiences of the individual budget pilot projects for older and disabled people in England, *International Journal of Public Administration*, 34, 232-43.

National Audit Office 2016. *Personalised commissioning in adult social care*, National Audit Office, London.

National People With Disabilities And Carer Council 2009. *Shut out: The experience of people with disabilities and their families in Australia*, Commonwealth of Australia, Canberra.

Needham, C 2010. Debate: Personalized public services—a new state/citizen contract?, *Public Money & Management*, 30, 136-8.

Needham, C 2011. *Personalising public services: Understanding the personalisation narrative*, Policy Press, Bristol.

Needham, C & Dickinson, H 2017 forthcoming. 'Any one of us could be among that number': Comparing the policy narratives for individualized funding in Australia and England, *Social Policy & Administration*.

Netten, A, Jones, K, Knapp, M, Fernandez, JL, Challis, D, Glendinning, C, Jacobs, S, Manthorpe, J, Moran, N, Stevens, M & Wilberforce, M 2012. Personalisation through individual budgets: Does it work and for whom?, *British Journal of Social Work*, 42, 1556-73.

New Zealand Productivity Commission 2015. *More effective social services*, New Zealand Productivity Commission, Wellington.

OECD 2009. *Sickness, disability and work: Keeping on track in the economic downturn*, OECD, Paris.

Oliver, M & Sapey, B 2006. *Social work with disabled people*, Palgrave Macmillan, New York.

Probono 2017. NDIS achieves 'major milestone', *Probono*, 21 August, viewed 24 August 2017 <https://>

probonoaustralia.com.au/news/2017/08/ndis-achieves-major-milestone

Purcal, C, Fisher, KR & Laragy, C 2014. Analysing choice in Australian Individual funding disability policies, *Australian Journal of Public Administration*, 73, 88-102.

Roulstone, A & Kwang Hwang, S 2015. Disabled people, choices and collective organisations: examining the potential of cooperatives in future social support, *Disability and Society*, 30, 849.

Roulstone, A & Morgan, H 2009. Neo-liberal individualism or self-directed support: are we all speaking the same language on modernising adult social care?, *Social Policy and Society*, 8, 333-45.

Slasberg, C & Beresford, P 2015. Building on the original strengths of direct payments to create a better future for social care, *Disability and Society*, 30, 479-83.

Slasberg, C, Beresford, P & Schofield, P 2012. How self directed support is failing to deliver personal budgets and personalisation, *Research, Policy and Planning*, 29, 161-77.

Slasberg, C, Beresford, P & Schofield, P 2015. Further lessons from the continuing failure of the national strategy to deliver personal budgets and personalisation, *Research, Policy and Planning*, 31, 43-53.

Spaulding-Givens, JC & Lacasse, JR 2015. Self-directed care: Participants' service utilization and outcomes, *Psychiatric Rehabilitation Journal*, 38, 74-80.

Spicker, P 2013. Personalisation falls short, *British Journal of Social Work*, 43, 1259-75.

Warr, D, Dickinson, H, Olney, S, Hargrave, J, Karanikolas, A, Kasidis, V, Katsikis, G, Ozge, J, Peters, D, Wheeler, J & Wilcox, M 2017. *Choice, control and the NDIS*, University of Melbourne, Melbourne.

Waters, J & Hatton, C 2014. *Third national personal budget survey. think local act personal*, In Control Publications, London.

Webber, M, Treacy, S, Carr, S, Clark, M & Parker, G 2014. The effectiveness of personal budgets for people with mental health problems: a systematic review, *Journal of Mental Health*, 23, 146-55.

Whalan, J, Acton, P & Harmer, J 2014. *A review of the capabilities of the National Disability Insurance Agency*, Australian Department of Human Services, Canberra.

Williams, F 2009. *Claiming and framing in the making of care policies: The recognition and redistribution of care*, The United Nations Research Institute for Social Development (UNRISD), Geneva.

Appendix 1: Items included in review

Study	Country	Focus of paper	Methods used	Findings	Lessons and implications
Purcal et al. (2014)	Australia	Comparison of individual funding policies across Australian states and territories in terms of ability of ability to support consumer choice.	Literature review, secondary analysis of data and 23 interviews with government administrators.	Significant variation across jurisdictions, particularly in rural areas.	NDIS will need to focus on market management if it is to enable personal choice and safeguard rights of individuals.
Laragy and Ottman (2011)	Australia	Case study of individual funding program in not for profit disability agency.	Observation and semi-structured interviews over 2 phases (11 families phase one, 7 families phase two)	Individual funding improved outcomes for those who want to take control and exercise flexibility.	Self-direction not suitable or desirable for all, services need to be culturally appropriate and important to protect working conditions of support workers.
Dew et al. (2013)	Australia	The benefits and barriers of using individual funding to access therapy in rural and remote areas.	8 focus groups with 60 government and non-government providers, interviews with 10 carers.	Greater access to and choice of therapy with individual funding.	Barriers in terms of information and advice, limited service options and high process and complexity of self-managing packages.
Jepson et al. (2015)	England	Investigation of practices around 'indirect payments' for individuals who lack capacity to consent.	67 interviews with social work practitioners and 18 recipients of indirect payments.	Care must be taken to ensure extension of direct payments to those who lack capacity is in their best interests and not simply a cost-cutting exercise.	Care must be taken to ensure that the benefits of direct payments do not just accrue to those with the capacity and or support to manage a budget.
Moran et al. (2011)	England	Exploration for reasons in failing to integrate multiple funding streams in Individual Budget pilots.	Semi-structured interviews in 13 pilot sites with lead officers at multiple time points.	Failure to integrate broader funding streams with exception of Supporting People funding.	Multiple different barriers to integration including concerns over legislation, accountability, market management and potential demand increase.
Larkin (2015)	England	Study of impact of personal budgets on service-user-carer relationship	23 semi-structured interviews with carers.	Many reported enhanced relationship between carer and service user as a result of personal budget.	Can have positive implications for carers but also bring stresses in managing personal budgets.

Arksey and Baxter (2012)	England	Longitudinal study of direct payments from the perspectives of disabled people.	30 participants interviews three times across 3 years.	Many reported reduced pressure on families although employing family or friends are personal assistant can raise challenges.	Need for more continuing input from direct payment advisers for disabled people.
Hatton (2014)	England	Study of trends and variations in adults with learning disabilities using self-directed support and direct payments	Analysis of local authority returns to Health and Social Care Information Centre.	Rapid increase in self-directed support but direct payment levels static. Wide geographical variation in uptake.	Universal provision of self-directed support not been achieved and likely that some areas need additional support.
Graham (2015)	England	Study of people with learning disabilities who use direct payments to employ personal assistants and their relationships.	Unstructured interviews with eight people with learning difficulties (employers), their 'supporters' and personal assistants.	The relationship between people with disabilities and personal assistants is a complex one and is not sufficiently accommodated within the policy framework.	Need to ensure that appropriate regulatory processes are in place to protect both personal assistants and people with disabilities.
Mitchell et al. (2015)	England	Study of the ways in which practitioners balance the needs and interests of service users and carers.	Nine focus groups (47 participants) with practitioners.	Inconsistencies in practice between areas and team members. Some parts of personalisation process appeared ad hoc.	It is a challenge for practitioners to balance competing demands and also ensure equitable but sensitive carer inclusion. Needs careful thought as to how to balance this.
Glendinning et al. (2015)	England	Study of practice relating to carers' roles in assessment, support planning and management of personal budgets.	Interviews with 14 pairs of consumers and carers.	Although personalisation may enhance choice and control for consumers, this does not extend to family members. Carers seen as resource or co-worker, rather than co-client.	Need more systematic and consistent approaches to the conduct of carers' assessments.
Jones and Netten (2010)	England	Evaluation of the cost implications of implementing individual budgets.	Interviews with individual budgets lead in 12 local governments.	Average cost of introducing individual budgets was £290,000 for year 1 and £140,000 - £170,000 year 2.	It is important not to underestimate the costs involved with introducing new systems. Authorities with most experience in this area tended to identify highest costs.

Jacobs et al. (2011)	England	Exploration of the impact of individual budget pilots on care coordinator work activity patterns.	Self-administered diary schedule in pilot and control sites and interviews with 48 care coordinators and 43 team managers.	Little difference in working patterns between individual budget pilots and controls, although more time was spent assessing needs and to conduct support planning activities with individual budgets.	Cannot assume that consumers controlling budgets will mean that this will take less time for care planners. Appropriate support mechanisms need to be in place.
Kendall and Cameron (2013)	England	Explores the impact that differing ideas about personalisation has on the way that self-directed support operates.	13 semi structured interviews with local government, user-led organisations and national experts.	Choice and control variously defined and self-directed support is not a guarantee of more empowerment. Budgetary cuts in some places had led to reduced support.	Need for clarity over what the vision for choice and control. These aspects are not consistent with aspirations of cost-cutting.
Jones et al. (2014)	England	Study of how individual budgets impact on carers and carer role.	Interviews with 129 carers across nine sites	Receipt of individual budget is significantly associated with positive impacts on carers' reported quality of life and social care outcomes – and at no additional public cost.	Individual budgets for people with disabilities can be cost-effective for carers.
Manthorpe et al. (2010)	England	Investigate the inter-relation of personal budgets with adult safeguarding.	Interviews with 14 safeguarding professionals	Concerns over safeguarding mostly related to greater use of direct payments and not broader issues of abuse.	Challenge to uphold principles of choice and control where individuals are being abused or neglected and at present practice not sufficiently sophisticated to deal with this.
Netten et al. (2012)	England	Reports on findings of individual budget pilots and their impact.	Randomised controlled trial including 959 individuals exploring experience through interviews and measurements of quality of life, health through validated instruments.	No impact on quality of life or in terms of other outcome indicators measures, but greater feeling of control, but this seems to apply to some user groups more than others.	Need to carefully consider different user groups and the suitability and process surrounding individual funding approaches. Also important to consider what timescale we will expect to see impacts take hold over and the amount of resource that needs to go into making individual budgets functional.

Jones et al. (2012)	England	Evaluation of individual budgets in terms of costs compared to conventional services across different user groups.	Randomised controlled trial including 959 individuals exploring experience through interviews and measurements of quality of life, health through validated instruments.	Care management costs higher for individual budgets but overall individual funding resource neutral.	Significantly different costs associated with different consumer groups. Care managers spent significantly longer with individual budget users than traditional services.
Glendinning et al. (2011)	England	Evaluation of individual budget pilots and the role that collaboration plays.	Semi-structured interviews with lead officers for individual budgets over two time periods.	Introduction of individual budgets in one area only had implications for other service areas.	Need to consider what the implications of individual budgets are for other mainstream services. Only funding a narrow range of care services may undermine an ethos of personalisation.
National Audit Office (2016)	England	Review of progress into personalised commissioning.	Evidence gathered from 9 local governments, 200 interviews with directors, managers, front-line staff, consumers and providers and national data.	Not all consumers benefit from personal budgets and how they are implemented is crucial. No evidence that personal budgets improve outcomes and no expectation that these save money.	Attention should be paid to how individual budgets are implemented as this is crucial to whether these mechanisms are able to have an impact in practice.
Waters and Hatton (2014)	England	Third national personal budget survey	2679 personal budget holders and 1328 carers of people in receipt of personal budget surveyed.	Large variations in delivery across place and groups of people. Not all local governments following best practice.	Important to focus on the process of personal budgets. Where these are not implemented well then personal budgets may not have the anticipated impact.
Ipsos MORI (2011)	England	Examine experiences of users of personal budgets in adult social care.	48 face-to-face interviews and 6 telephone interviews	Personalised support can produce positive outcomes, but differences in flexibility between direct payments and individual budgets.	Support is needed to switch providers where services not appropriate, not easy for individuals to do this without support.

Spaulding-Givens and Lacasse (2015)	USA	Examination of Florida Self-Directed Care program for individuals with severe and persistent mental illness.	Analysis of records of participants, 80 at stage 1 and 56 stage 2.	Nearly all participants remained living in community and functional assessment measure improved modestly.	Budgets were used to subsidise living expenses as many existing in poverty indicating need for additional support in enhancing employment readiness and supported employment opportunities.
Cook et al. (2010)	USA	Description of self-directed care program in Texas.	Early report of an RCT with records of 75 participants, their demographic, clinical and vocational characteristics and spending decisions	Participants largely happy to date and have purchased traditional and non-traditional services.	Individuals do not move entirely away from traditional services, but where supported to can benefit from spending money on different services.
Inoue et al. (2014)	US	Examination of budget/purchase experiences of participant in West Virginia's Medicaid Aged and Disabled Waiver program.	Analysis of administrative data including demographics, requests for goods/ services, personal options savings amount and personal options payments made.	Wide variety of goods saved for and purchased.	Many items purchased related to unmet need and poverty.
Barczyk and Lincove (2010)	US	Examine effectiveness of cash and counselling program and impact on individuals with serious mental illness.	Pre-survey focus groups, telephone surveys and post-survey focus groups.	Increased quality of life and satisfaction with services.	Change in role of social workers to focus on empowering individuals to control their own treatment.
Field et al. (2015)	New Zealand	Quantitative analysis of the cost patterns of Individualised Funding (IF) in New Zealand.	Analysis of Ministry of Health database and validated against client management system to examine who IF users are and how costs compare to non-IF.	Uptake of IF has grown and average cost of package of care decreased. IF looks more effective at containing costs in higher levels of complexity.	IF can be a useful lever for containing costs for disability services at a time of constrained budgets.
Power (2014)	Canada, England, US	Explores views of government officials and their views on personalisation and expectations for change.	Semi-structure interviews with 14 individuals.	Government officials cautious of the pitfalls and risk in self-led support.	More radical politics may be needed to allow self-led support to achieve desired outcomes on the ground.