

Forgotten Families

Raising children with disabilities in Tasmania

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Social Action and Research Centre Anglicare Tasmania

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Abbreviations

ABA	Applied Behavioural Analysis
ABS	Australian Bureau of Statistics
ACD	Association for Children with Disabilities
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
AIHW	Australian Institute of Health and Welfare
ASD	Autism Spectrum Disorder
CAAS	Continence Aids Assistance Scheme
CES	Community Equipment Scheme
CSE	Child Social Exclusion Index
CSTDA	Commonwealth State/Territory Disability Agreement
DDA	Disability Discrimination Act
DEST	Commonwealth Department of Education, Science and Training
DHHS	Department of Health and Human Services, Tasmania
DoE	Department of Education, Tasmania
DoHA	Commonwealth Department of Health and Ageing
DPAC	Department of Premier and Cabinet, Tasmania
DSP	Disability Support Pension
ECIS	Early Childhood Intervention Service
FTE	Full Time Equivalent
HACC	Home and Community Care Program
HREOC	Human Rights and Equal Opportunity Commission
IEP	Individual Education Plan
ISP	Individual Support Package
ISS	Inclusion Support Subsidy
NGO	Non-Government Organisation
NWRH	North West Regional Hospital
PTAS	Patient Travel Assistance Scheme
SARC	Social Action and Research Centre, Anglicare Tasmania
SWPBS	School Wide Positive Behaviour Support
WAT	Wheelchair Accessible Taxi

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Executive Summary and Recommendations

There are over 8,000 children with disabilities in Tasmania who are being cared for by their families yet their experiences are rarely heard. This report documents the daily lives of families with disabled children from across the state who are living on low incomes. It explores the additional disability-related costs they face, their experiences of accessing and using support services and what could be done to improve their situation.

Caring for a child with a disability is not easy and when the child has a severe or profound disability caring responsibilities are well beyond those normally carried by parents, are long term and do not necessarily diminish as the child gets older. They can be so high that they impact negatively on all family members and severely test the family's ability to sustain a caring role. In addition there is a strong association between childhood disability and low family income so that families with a disabled child have a high risk of poverty due to additional disability related expenses, low incomes, sustained periods on government benefits and barriers to entering or retaining employment. It has been estimated that children with disabilities on average cost three times as much as non-disabled children. There are currently approximately 5,000 low income families caring for children with disabilities in Tasmania who can have difficulties in managing day-to-day, in paying the bills on time and in affording the essentials of life like appropriate housing, transport, food and social participation.

Despite a range of policies, initiatives and services spread across different sectors the research found that the support system for families with disabled children is characterised by fragmentation, under-resourcing and a lack of any overarching comprehensive framework within which to address the issues they face. It means that they have to fight for information about what assistance is available and then fight again to access adequate levels of assistance to help them meet their day-to-day care responsibilities. This in turn means that many families access very little or no support at all from formal services and are struggling to cope. This battle is repeated across the service sectors and includes access to Centrelink benefits, to support in the community like personal care, to respite, to childcare and to aids and equipment.

Many services for children with disabilities are delivered through the education system. Tasmania has adopted the principle of inclusion and has achieved the highest rates of inclusion of children with disabilities in mainstream schooling in Australia. Most people, including parents, were supportive of the idea of inclusion but the research demonstrated that its implementation has been inconsistent so that some families have very good experiences and others negative experiences. The same is true in the health sector and although families were complementary about their experiences of accessing specialist health services they also pointed to gaps. These included shortfalls in what primary health care services can offer, in getting a diagnosis and the way in which diagnoses and medical reports were delivered, in subsidies available to meet some of the financial costs and in the links between acute health and community services. A particular gap was in getting access to adequate levels of therapy particularly for school aged children and to assistance in dealing with difficult behaviours. These pressures can be particularly acute for families dealing with autism.

Nevertheless many families involved in the research had good things to say about aspects of the services they had accessed and the skills of professionals they had encountered along the way. What they particularly valued and which had had a positive impact on their situation was flexibility to meet individual needs, a recognition of the impact of disability on the whole family, financial subsidies to meet additional costs, readily accessible information and one point of contact with services. They voiced an overwhelming need for a pathway through services which could provide support from the point of identification of a disability or developmental delay through to their child's transition into adulthood and beyond.

This report recommends a number of changes which would greatly improve the situation of families caring for children with disabilities and the quality of their lives.

Recommendations

Policy Framework

- **Recommendation 1:** That the Department of Premier and Cabinet develop a Tasmanian framework for specialist support to children with disabilities and developmental delays and their families from birth through to adulthood. This should:
 - acknowledge that supporting families improves a child's wellbeing;
 - be developed and integrated into the Disability Framework for Action during the review process in 2008;
 - provide a vision of what supports families should expect and be entitled to;
 - be linked to a comprehensive early intervention strategy which can promote the early identification of problems and the timely provision of appropriate support; and
 - be linked to universal childhood services available to all children and families and inclusive of the needs of families with disabled children.

- **Recommendation 2:** That the Department of Premier and Cabinet require government agencies to prioritise the needs of disabled children and their families in Disability Action Plans and any related targets and benchmarks.

Dealing with Unmet Need

- **Recommendation 3:** That the Tasmanian Minister for Health and Human Services include in the Review of Disability Services the urgent need to upgrade the support offered to families caring for children with disabilities including:
 - ensuring that routine data is collected about unsuccessful requests and under-met demand for respite and holiday care, personal care and support and other disability services in order to monitor levels of unmet need;
 - ensuring that budget provision is made to meet levels of unmet need; and
 - committing to funding increases to Disability Services of 8% per annum from 2009 to improve the quality and quantity of services and meet the projected growth in demand. Within this funding increase the following should be prioritised:
 - development of a range of accessible and appropriate respite options for children with the goal of achieving a legal minimum entitlement to respite with a benchmark of four weeks' annual leave and ten days' sick leave for primary carers by 2020;
 - increased access to domestic assistance and to personal support; and
 - increased funding to the Community Equipment Scheme to meet current demand and allow for an increased limit on expenditure for individual items.

Income Support

- **Recommendation 4:** That the Commonwealth Government through the Minister for Families, Community Services and Indigenous Affairs establish a universal disability allowance to meet the additional costs associated with disability.

- **Recommendation 5:** That the Minister for Families, Community Services and Indigenous Affairs direct Centrelink to conduct comprehensive disability awareness training with all Centrelink staff annually.

- **Recommendation 6:** That the Minister for Families, Community Services and Indigenous Affairs commit to a review of the way in which Centrelink benefits are provided to people with life-long disabilities and their families in order to provide a consistent approach which recognises support needs and which eradicates unnecessary demands for information.

- **Recommendation 7:** That the Minister for Families, Community Services and Indigenous Affairs direct Centrelink to publicise more widely the benefits available to carers and how to claim them and operate as a signpost or gateway to other services for families caring for children with disabilities.
- **Recommendation 8:** That the Minister for Families, Community Services and Indigenous Affairs direct Centrelink to routinely provide information to doctors required to complete 'treating doctor's reports' about the application process and what is required in terms of recording the impact of any disability or condition on carers.
- **Recommendation 9:** That the State Government review the concessions system to ensure that it offers an effective mechanism for providing low income Tasmanians with a reasonable standard of living. This involves equalising eligibility for concessions between Pension Concession and Health Care Card holders, especially for the heating allowance, vehicle registration concessions, the licence discount and private bus concessions.

Support in the Community

- **Recommendation 10:** That the Minister for Health and Human Services commit \$500,000 to pilot local area coordination in three different locations in Tasmania with a commitment to ongoing recurrent annual funding and expansion state wide if outcomes are satisfactory.
- **Recommendation 11:** That the Minister for Health and Human Services establish a broad communications strategy for families with disabled children which includes:
 - short directories of local services and support networks which are regularly updated;
 - more in-depth and informative booklets covering local and national services; and
 - a resource centre with information on disabilities and conditions which can also subsidise the cost of bringing 'experts' into the state.
- **Recommendation 12:** That the Minister for Health and Human Services increase the availability of hosted respite by funding the further promotion of the scheme and the realities of hosting to potential host families.
- **Recommendation 13:** That the Minister for Health and Human Services develop strategies to professionalise the disability workforce to ensure they have good interpersonal and communication skills, are reliable and consistent, have access to good quality training about disability awareness and family-sensitive practice and have clarity around their duties including flexible work practices.

Social Participation and Support Networks

- **Recommendation 14:** That the Australian Government through the Minister for Families, Communities and Indigenous Affairs commit to an expansion of the MyTime support group program to all families caring for children with disabilities up to 16 years.
- **Recommendation 15:** That the Tasmanian Minister for Health and Human Services ensure full participation of Tasmania in the Siblings Australia National Reference Group to promote a network of sibling support groups across the state.

Aids and Equipment

- **Recommendation 16:** That the Australian Government extend the Medicare Scheme to ensure that people with disabilities can claim the cost of essential equipment less other funding sources like community equipment schemes.
- **Recommendation 17:** That the Australian and State Governments commit to fully funding the cost of disposable nappies and associated continence aids for Pension Concession Card and Health Care Card holders for individuals with disabilities over the age of four years.

Health Services

- **Recommendation 18:** That the Minister for Health and Human Services establish procedures to ensure a planned hospital discharge for children with disabilities. This should include:
 - assessing the parent's capacity to care;
 - ensuring community support arrangements are in place;
 - informing relevant service providers in the community; and
 - distributing information to parents outlining the disability service system and all appropriate support agencies.
- **Recommendation 19:** That the Minister for Health and Human Services restore the later developmental check undertaken by Family, Child and Youth Health nurses and ensure that it is available to all children when they reach three years of age.
- **Recommendation 20:** That the Minister for Health and Human Services establish a comprehensive state wide therapy service linked to the proposed Tasmanian framework for specialist supports to children with disabilities and developmental delays and their families from birth through to adulthood.
- **Recommendation 21:** That the Minister for Health and Human Services ensure that behaviour management and sleep programs are available to families caring for children with disabilities and/or developmental delays.

Mainstream services

Transport

- **Recommendation 22:** That the Minister for Health and Human Services increase funding to the Patient Transport Access Scheme so it meets the actual costs of transport, accommodation and living expenses while away from home and ensures that concessionary rates and subsidies are based on real economic modelling relative to the incomes of concession-eligible people accessing specialist health services.
- **Recommendation 23:** That the Minister for Health and Human Services commit to an extension of the current Patient Transport Access Scheme so that concession card holders can access transport and accommodation subsidies to specialist medical services within the 75 kilometre boundary and that the scheme covers both access to specialist medical services and allied health practitioners when referred by medical specialist.
- **Recommendation 24:** That the Minister for Health and Human Services increase funding to the Community Equipment Scheme to provide assistance to people with disabilities to modify vehicles.

Housing

- **Recommendation 25:** That the Minister for Health and Human Services develop a model to improve access to home modifications for those buying their home which incorporates waiving of state government duties on loans, provision of low interest loans to contribute towards the costs of modifications and free advice on and/or brokerage of the design and management of proposed modifications.
- **Recommendation 26:** That the State Government direct funding to Housing Tasmania to increase the supply of affordable housing stock which is constructed according to universal design principles and located close to services.

Employment

- **Recommendation 27:** That the Minister for Health and Human Services commit to ensuring the expansion of high quality affordable child care services for children with disabilities which also give priority access to the siblings of disabled children.
- **Recommendation 28:** That the Commonwealth Minister for Employment and Workplace Relations commit to programs to increase awareness among employers about the need for flexible workplace environments and family workplace policies to increase attachment to the labour market.

Education

- **Recommendation 29:** That the Minister for Education reiterates a clear commitment to inclusion values in Tasmanian schools so that all children with disabilities have an unequivocal right to be enrolled in mainstream schools.
- **Recommendation 30:** That the Minister for Education ensure the establishment of a clear accountability framework for schools in implementing inclusion values and educational outcomes. This should include accountability for ensuring individual education plans and transition planning are in place.
- **Recommendation 31:** That the Minister for Education commit to adequate resourcing for professional learning, training and support for inclusion including awareness raising among all school staff and for inclusion support for extra curricular activities.
- **Recommendation 32:** That the Minister for Education promote a wider range of educational options for children with disabilities including additional needs units in high schools.
- **Recommendation 33:** That the Minister for Education increase the Transport Assistance Program budget to ensure that families using weekday centre-based respite options are able to access assistance with transporting their children between school and respite.

Consultation and Representation

- **Recommendation 34:** That the Department of Premier and Cabinet establish a Family Advisory Committee as part of the Premier's Disability Advisory Council to ensure ongoing consultation with families.

1. Introduction

It is now generally accepted that the best model of care for children with disabilities, including those who are profoundly disabled, is family-based rather than institutional. This means that the majority of children with disabilities live with their families and are dependent on their parents to meet basic care and treatment needs. In theory they have the same access to mainstream services as other families and where this does not meet their needs, to specialist disability services. There is however a strong association between childhood disability and low family income and anecdotal evidence from both families and service providers suggests that there are considerable difficulties in managing and meeting needs across a range of programs and organisations. These difficulties are often not recognised or understood by either services or the general community.

This research set out to explore how well the family-based model of care is working for Tasmanian children with disabilities whose families are living on low incomes. Based on twenty-four in-depth interviews with parents and the experiences of a range of service providers, it paints a picture of the experiences of families in caring for a child with a disability and in accessing the services they need in order to do this effectively.

The study has been conducted against the backdrop of the Disability Framework for Action 2005-2008 (DPAC, 2005). This Framework outlines what the Government intends to do to promote the full participation of people with disabilities across state government agencies. This study highlights major gaps between the ideals of the Framework and what happens in practice for disabled children and their families.

1.1 Aims of the Research

The research aimed to identify the principal issues involved for low income families in caring for a child with a disability in order to contribute to improving the quality of policy and service delivery for disadvantaged families. In particular the research:

- explored the relationship between caring for a child with a disability, additional costs, low income and poverty in Tasmania;
- assessed the adequacy of current subsidies and services in meeting the needs of families with children with disabilities; and
- produced recommendations about how to improve the quality of life for low income Tasmanian families caring for disabled children.

The study was carried out by the Social Action and Research Centre (SARC) at Anglicare Tasmania over a nine month period from October 2006 to June 2007. It follows a previous piece of research conducted by SARC in 2006 which explored the experiences of the working age population of low income Tasmanians living with disabilities (Hinton, 2006).

1.2 Defining Disability

Children with disabilities exist on a continuum from profound to mild impairment and are not a homogeneous group. They may have a physical, sensory, mental, emotional, learning or

cognitive impairment or a complex mix of any of these and there is great variation in childhood experiences. There are those whose disability is easily identifiable at birth and life long and others who acquire a disability or developmental delay later on in childhood like a brain injury or autism.

Disability is also a multi-dimensional concept involving interaction between the condition, personal factors and the environment which determines the ability to function and participate in society (AIHW, 2004). Some children at the lower end of the spectrum may encounter small barriers which they can overcome, for instance those living with asthma or mild behavioural disorders. Others with a profound impairment face a much higher risk of social exclusion. Yet how far a disability leads to significant impairment is partly defined by the environment; for example a child who is wheelchair dependent may not be disabled in the school environment if it is fully accessible. This also means that how disability in a child is defined can vary between organisations and contexts and be a matter of debate and interpretation.

For the Australian Bureau of Statistics (ABS, 2004) disability is defined as the presence of one of seventeen restrictions, limitations or impairments that has lasted or is likely to last for a period of six months and which restricts everyday activities. A person with a disability may also have a core activity restriction if the disability limits their capacity in the areas of self care, communication or mobility. This means they are likely to have special needs at school or may be unable to attend an ordinary school. The ABS defines levels of core activity restriction as:

- mild where there is no difficulty with self care, mobility or communication but where the person uses aids and equipment;
- moderate when the person does not need assistance but has difficulty with these activities;
- severe when the person sometimes needs assistance; and
- profound when the person is unable to perform these activities or always needs assistance.

The ability to perform many core activities comes after reaching certain developmental stages so the focus is on the difficulties a child experiences due to their condition rather than the difficulties all young children experience.

The children with disabilities described in this report range from those with mild to moderate impairment to those with a severe or profound core activity limitation.

1.3 Research Methods

The study used a qualitative approach which entailed:

- **in-depth interviews with 24 families** caring for children with disabilities. Potential interviewees were contacted through service providers, advocacy groups and peak organisations for particular kinds of disability. This means that all the families in the sample were in touch with one more specialist disability services. The criteria for involvement was:
 - being the primary carer of a child or children with a disability aged 0-16 years; and
 - being in receipt of a Health Care Card or Pension Concession Card.

The sample was constructed as far as possible to represent a range of circumstances including different household structures and levels of workforce participation, type of

disability, level of impairment, age and sex of the child, use of services and geographical location. Sixteen interviews were conducted with the mother and a further eight with both parents using a piloted semi-structured questionnaire.

- **interviews with service providers** to map the service network and document their perspectives about providing services to families caring for children with disabilities. Altogether over 30 service providers and other stakeholders were interviewed using a semi structured questionnaire. These included representatives from both government services, like the Education Department and Disability Services, and community based organisations.
- **collation of policy documents and statistical and research material** to review the research literature and provide a policy and statistical framework for the research. This included collating any information on service usage and unmet need among families with disabled children in Tasmania.

Families were asked to complete adapted versions of the Australian Unity Wellbeing Index¹ (Cummins, 2005) and hardship indicators from the Household Expenditure Survey. These were administered to respondents at the end of the interview and used to indicate levels of general wellbeing and financial hardship.

Interviews lasted from one to two hours and were taped and transcribed. All interviewees signed a consent form for the release of the information and were also remunerated for their participation. As far as possible verbatim notes were taken during interviews with service providers.

Quotes from interviews have been used throughout the report to illuminate experiences and perspectives. However all names and identifying details have been changed to protect people's privacy.

1.4 Profile of the Research Participants

The research explored the experiences of 24 families. This included six households where more than one child had a disability and meant that the research was able to investigate the circumstances of 33 children with disabilities. National data also shows that most children with disabilities have more than one condition or impairment with the severely disabled commonly having physical, sensory and learning difficulties. This was reflected in our research sample with many of the children having multiple disabilities making it difficult to categorise them. The sample included:

- 9 children with an autism spectrum disorder including three with Asberger's syndrome
- 6 with an intellectual disability including one with Down syndrome
- 6 with epilepsy
- 4 with cerebral palsy
- 3 children with a hearing impairment
- 3 children with a vision impairment
- 2 with an acquired brain injury
- 2 with spina bifida
- 2 with muscular dystrophy
- 1 with obsessive compulsive disorder
- 1 with a chromosomal disorder

¹ The Australian Unity Wellbeing Index monitors the subjective wellbeing of the Australian population through a telephone interview with 2,000 Australians representing the national population geographic distribution.

A number of children were also described as having behavioural issues including Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) and/or challenging behaviour. About one third had impairments which affected their mobility and 11 used a wheelchair. Nineteen families were caring for children with severe or profound disabilities and five families for children at the mild to moderate end of the spectrum. The sample included both boys and girls spread across the age range but with larger numbers in the primary school age groups. It also included families from across the state living in both urban and rural environments.

Table 1: Age and Sex of Children

Sex	0-5 years	6-12 years	13-16 years	Total
Male	3	10	5	18
Female	4	6	5	15
Total	7	16	10	33

Table 2: Location of Research Participants

Location	Urban	Rural	Total
South	9	2	11
North	6	4	10
North West	0	3	3
Total	15	9	24

The majority of interviews were with two-parent families (16). However the research also included seven single parent households and two children being cared for by grandparents. Although six households were only caring for the disabled child most also had other non-disabled children in their care. This meant that the research was able to explore the impact of disability on a total of 32 siblings living with a disabled brother or sister.

The economic circumstances of families varied. Ten families were buying their own home, nine were living in public housing, four were renting in the private rental sector and one family, who were currently homeless, were staying with relatives. Just over half (14) of the families interviewed were entirely dependent on Centrelink benefits for their income. Indeed a number of these families considered the care needs of their child(ren) were so high that it was a two-person job to respond to them. A further five families had some income from part-time employment and five from full time employment. However as the criteria for participation in the research was having access to a Health Care Card or Pension Concession Card this places them at the bottom of the income spectrum for the population as a whole.

The high rate of sickness and disability among parents was striking. There were five households where one of the parents was also disabled and in receipt of the Disability Support Pension. In a further four households a parent was on long term sick leave, on compensation payments or in two cases sick but getting no additional benefits. This included a grandmother caring for her disabled grandson and also for her husband who had dementia.

1.5 Limitations of the Research

This was a qualitative piece of research based on interviews with a small number of families. This has imposed some limitations on the research and its findings. They are:

- **the sample.** Rather than being described as representative the sample aimed to encompass a broad range of circumstances in order to tease out the variety of experiences people had in managing on a low income and in accessing support services. This means it has not been possible to undertake quantitative analysis or to draw firm conclusions about the overall population of children with disabilities in Tasmania. However it is possible to gain a better understanding of the difficulties facing families and the commonalities and diversity of these difficulties.
- **identifying research participants.** The concern of the research was to describe the 'ordinary' experience of looking after a child with a disability. The majority of participants were contacted through services who were asked to identify and approach those who they would see as 'typical' service users. This means that exceptional cases of hardship and difficulty – those which sporadically hit the front pages of the newspaper – have not been documented and that most participants are the population who are in touch with services. It is anticipated that there are numbers of families in Tasmania who do not access services that they might be entitled to and are living with very little or no support. This means that the findings of this study are only the tip of the iceberg in terms of the difficulties families may be facing.
- **talking to children.** The aim of the research was to find out about how families, as a unit, were coping with the care and other needs imposed by a child's disability. This meant that interviews were held exclusively with parents rather than children with disabilities. It is vital that disabled children are consulted about their needs and the services they receive directly rather than through family advocacy. However it was considered that this would be a different piece of research and was not included in the research methods.
- **Aboriginal and Torres Strait Islanders.** Little is known about the level of disability among Indigenous children in Tasmanian but it has often been suggested that rates among Indigenous people are high (AIHW, 2005). The sample did not include any families who identified as being Indigenous. This means that the research has not been able to address the particular issues that these families might face in coping with childhood disability.
- **children with mental illness.** About 7% of Australian children have long term mental or behavioural problems (AIHW, 2005) and those living in low income or one parent families and those in step or blended families are more likely than others to have mental health problems. These might include depressive disorders, conduct disorders and attention deficit disorder (ADD or ADHD). Unless a child with these conditions also has a disability or long term impairment as defined by the Disability Services Act, they are not categorised as being disabled for the purposes of access to services. This means that families coping solely with mental health issues have not been targeted in the research sample. However the sample does include families where these issues were part of a complex picture of multiple disabilities and many were coping with ADD or ADHD and challenging behaviour².

² Challenging behaviour is behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or the behaviour is likely to seriously limit or deny access to the use of ordinary community facilities (Centre for Developmental Disability Health Victoria).

- **parents with intellectual disabilities.** An issue raised by a number of service providers but which was not reflected in the research were the difficulties inherent in providing services to parents with disabilities, particularly intellectual disabilities, who are also caring for disabled children. They commented on the additional support such families required and the number who escaped identification until the family was unable to cope and reached a crisis point. This is an area worthy of a separate piece of research in its own right.



2. Background

This section provides a backdrop to the qualitative research findings by collating what information is available about children with disabilities in Tasmania, examining the links between childhood disability and poverty and providing an overview of the policy and service framework within which families caring for children with disabilities operate.

2.1 Children with Disabilities in Tasmania

There is no fully comprehensive information about how many families are caring for disabled children either in Tasmania or at a national level. Information about them is often collected in departmental silos and based on service usage data which excludes those who are not in touch with services. This makes it difficult to synthesise what information there is into a meaningful picture (AIHW, 2004) and to plan appropriate budgets and services.

The main national population data source on disability is the 2003 ABS Survey of Disability, Ageing and Carers (ABS, 2004). Using this and a variety of other data sources the Australian Institute of Health and Welfare (AIHW, 2006) collated what is known about children with disabilities in Australia and the experiences of their families. This shows that:

- about 1 in 12 children aged up to 14 years (or 8.3% of all children) have a disability and about half of these have a severe or profound core activity limitation. This equates to approximately 4% of the total Australian child population who have significant care needs well in excess of non-disabled children.
- the most prevalent disabilities among children aged 0-14 years are intellectual disability (4.3%) and physical/diverse disability (4.2%). Three percent (3.4%) have a sensory disability and 2.1% a psychiatric disability. There are also an estimated 0.6% with an acquired brain injury aged under 15 years. Autism and intellectual disability are associated with a high proportion of severe/profound core activity limitation.
- boys are more likely than girls to have a disability – 10% compared with 6.5% among girls – and to have a severe/profound core activity limitation.
- the proportion of children with profound or severe core activity limitation is highest among those from low income households with those in the lowest income quintile over four times more likely to have a profound disability than those in the highest quintile (AIHW, 2005).
- ninety nine percent of children with disabilities live with their family and 91% of primary carers of those with severe/profound disabilities are mothers. Well over half of these primary carers (59%) provide forty or more hours per week of direct care to the child.

These figures are only reliable at a broad national level and cannot be reliably and directly extrapolated to produce estimates for Tasmania. However the ABS has also undertaken work on the small area estimation of disability in Australia (Elazar & Conn, 2004) based on numerous data sources. Table 3 shows the estimated distribution and severity of disability across regions among Tasmanian children.³

³ From Small Area Estimates of Disability Release 1A and Release 3 completed by the ABS for National Disability Administrators. It should be emphasised that these estimates are a tool and that some regions will differ from predictions because of local effects that are not captured by the calculations. This means that they should be used in conjunction with an understanding of local area characteristics and their quality limitations.

Table 3: Tasmanian Children with Disabilities by Age and Level of Impairment

Region	Age			Level of Impairment 0-14s	
	0-4	5-9	10-14	0-14	Severe/Profound
South	717	1470	1838	4025	2327
North	409	900	1046	2355	1369
North West	327	728	879	1934	1115
Totals	1453	3098	3763	8314	4811

Notes: These figures are based on estimated private dwelling populations for each LGA for 2003. This means that they exclude those living in institutions or residing in hospitals. They also exclude Flinders Island and King Island.

According to the ABS data there are over 8,300 children aged 0-14 years in Tasmania (or 8.6% of the state's 0-14 population) with a disability of some kind with an estimated 4,800 falling into the severe and profound category. It is this group who will have the biggest need for services. In addition there are a further 3,220 in the 15-19 age group. These figures match those for the Australia population as a whole (AIHW, 2006) where 8.3% of the child population⁴ are living with a disability. Extrapolating from AIHW figures there would be an estimated 4,150 children with an intellectual disability and 4,050 with a physical/diverse disability in Tasmania. There would be about 3,280 children with a sensory disability and at least 580 with an acquired brain injury.

How many of these children live in low income households? Nationally 62% of primary carers of co-resident children aged 0-14 years with a disability are reliant on a Government pension or benefit as their principal source of income (AIHW, 2004). These figures are comparable to research elsewhere. Work done in the UK (Sharma, 2002) indicates that up to 55% of families with disabled children live in poverty or on its margins. Extrapolating these figures to Tasmania means that approaching three fifths of families with disabled children (or approximately 5,000 families) would be living on incomes low enough to class them as poor.

The numbers of children living with disabilities has been growing and many more are identified with a disability than thirty years ago. Although methodological problems mean that it is difficult to assess the prevalence of disability among children over time more now survive with complex multiple disabilities and rare conditions due to advances in medical technology.

In particular there has been a rapid increase in the numbers diagnosed with autism spectrum disorders (ASDs) but it is unclear whether this increase is real and caused by environmental factors or whether it is due to increased awareness and diagnosis. ASDs are life-long developmental disabilities which affect the way in which a person communicates and relates to others and which usually appear during the first three years of life. A report exploring the prevalence of autism in Australia (Macdermott et al, 2007) found that one child in every 160 in the 6-12 year age range was autistic. This means that approximately 224 primary school-aged children in Tasmania have autism⁵. About 25% of this population are high functioning and may be of average or above average intelligence and classified as having Asperger's Syndrome.

⁴ As at June 2005 there were 96,500 children aged 0-14 in Tasmania. Based on ABS Population Data by Age and Sex Tasmania.

⁵ Based on the primary school aged population of 35,812 as in the Department of Education's Annual Report 2005-2006.

Others may have severely compromised functional abilities and require constant supervision. Because the disability is often invisible and not well understood parents can experience higher levels of stress and isolation while at the same time be offered less support. The increase in numbers opens up a new area in terms of services required to support families coping with ASD.

Although overall the number of people with severe or profound core activity limitations is projected to increase by 4.8% between 2006 and 2010, the number of children aged 0-14 with this level of impairment is expected to decrease by 1.7% nationally and by 6.3% in Tasmania (AIHW, 2007).

2.2 Childhood Disability and Poverty

The association between disability and poverty is well known and poverty has been shown to be associated with many of the variables that can increase the risk of disability (US Department of Education, 2002) including poorer health, low birth weight, lower IQ scores and low educational attainment. Among children the available national and international research data shows:

- **a strong association between childhood disability and low family income.** Families caring for children with disabilities have a high risk of poverty because of the additional disability related expenses, low incomes, sustained periods on government benefits and barriers to entering or retaining employment. Parents are less likely to be in full time work and more likely to feel they don't have enough money to meet the child's basic needs and to go into debt (Sharma, 2002). In the UK it has been estimated that at least 55% of families with children with disabilities live in poverty or on its margins and that three quarters of these families are located in the bottom half of the income distribution. The birth or diagnosis of a disabled child is a trigger event for family poverty (AIHW, 2004).
- families incur **a range of additional on-going costs** like heating, housing, clothing and equipment. On average children with disabilities cost three times as much as non-disabled children (Dobson and Middleton, 1998). The costs are more significant for those on low incomes, if the disability is severe or profound or if there is more than one child with a disability in the household.
- **high rates of single parenthood** among families with disabled children exacerbate poverty issues. The child disability rate in single parent households is estimated to be twice that of two parent households (AIHW, 2004). One study found that 30% of single parents with disabled children were in significant financial difficulty compared to 17% of couples (Gordon et al, 2000).
- **significant barriers to entering paid employment** particularly for mothers. Parents of disabled children are much less likely to be in full time work and if they do work it is often in low quality employment supplemented by state benefits. Sixty two percent of mothers who are primary carers of children with disabilities are not in the labour force compared with 36% of other mothers with children of the same age (AIHW, 2006). A major barrier to work is the lack of affordable and appropriate childcare and holiday care.

- a high risk of entering a **life cycle of poverty** for both families and the disabled children they care for. Families are likely to continue to care for their disabled children into adult life (Gordon et al, 2000). This means they retain their low economic status and there is a second trigger event for poverty when the child with a disability leaves school with no suitable regular day occupation. Children with disabilities are more likely than non-disabled children to leave school without qualifications and 70% of disabled adults rely on government benefits.
- well documented **difficulties for families in accessing the services they need** for information, respite, domiciliary support, childcare, financial support, housing, aids and equipment, appropriate education and transport. Waiting for treatment, services or equipment is a universal experience but particularly acute for lower income households because they are unable to pay to access other options. Parents report a constant battle to find out about what services are available to them and then in accessing them successfully.

The links between poverty, disadvantage and childhood disability are significant in a state which has a relatively high rate of social exclusion for children generally when compared to national averages. Thirty six percent of all Tasmanian children (or over one third) aged 0-15 years fall into the lowest national Child Social Exclusion (CSE)⁶ decile compared to the next highest state which is Queensland at 25% (Harding et al, 2006). Tasmanian children account for a larger share of the population in the bottom decile than they do in the population of Australian children as a whole. This means that they are more likely to be living in a single parent family, with no one in employment and with parents who have low levels of education.

Strategies to tackle child poverty have focussed on improving pathways for parents to enter the workforce as a route to inclusion. However for families with disabled children this route is impaired. There is little access to appropriate childcare, there are difficulties in employers recognising additional parental responsibilities and there are few subsidies to meet the extra costs involved for parents with disabled children to participate in the workforce.

2.3 The Policy Context

There have been a number of research studies conducted in Australia about the issues facing families with children with disabilities, the resilience factors which allow them to sustain the care required and how best to support them to reduce the risk of family breakdown (SPRC, 2003, Owen et al 2002, NSW, 2005). They show that disabled children who have two parents, higher incomes and are fully integrated into mainstream schools cope better and have better outcomes. They also identify the key supports which families need. They are:

- a wide range of flexible support, both formal and informal, throughout the family's life which places the family, rather than the child, at the centre;
- a recognition that needs differ over time; and
- early intervention.

Evidence that early intervention can counteract biological and environmental disadvantage and set children on more positive trajectories continues to build and shows that it is both possible and cost effective to intervene early in the life cycle to prevent later problems (Flood,

⁶ The CSE has been developed by the National Centre for Social and Economic Modelling (NATSEM) as a tool for the calculation of indices of risk of social exclusion for children on a geographical basis.

2004). The greatest benefits can be achieved during the first two to three years of life. For children with disabilities this is particularly crucial and the earlier a child is identified as having a developmental delay or disability the greater the likelihood that the child will benefit from intervention strategies designed to compensate for needs. Families also benefit from support given to them. This means that investment in comprehensive and coordinated early intervention services will generate long term benefits for children and families, give disabled children prompt access to appropriate services to ensure their inclusion, promote normal development and break the cycle of poverty and deprivation. How far has Tasmania been able to provide the policy framework required to meet these support needs?

The Tasmanian Government aims to provide integrated and coordinated services that build on the strength of families and communities and support them to care for and protect their children. The Children, Young Persons and Their Families Act 1997 sets out to maximise children's opportunities to grow up in a safe and stable environment and reach their full potential. It also makes provision for the appointment of a Commissioner for Children which is an independent office responsible to Parliament. Functions include promoting the rights and well being of children and examining policies, practices and services provided to them and any laws affecting their health, welfare, care, protection and development. Children with disabilities present a complex picture as they require services across a range of disciplines and government departments. This means that any examination of relevant policy initiatives must range across the Department of Education (DoE) and the Department of Health and Human Services (DHHS) and encompass disability specific services as well as childhood and family support services.

The recent key legislative and policy initiatives which govern the current provision of services to families caring for children with disabilities in Tasmania are:

- **Disability Discrimination Act (DDA) 1992** is the main Commonwealth legislation governing the rights of people with a disability. It makes discrimination on the grounds of disability unlawful and provides a framework for the setting of disability standards including standards for access to premises and education. The Human Rights and Equal Opportunity Commission (HREOC) is the body charged with protecting these rights and advocating on behalf of disabled people.
- **Disability Services Act Tasmania 1992** which outlines the standards to be complied with in the provision of services and the basic principles and objectives in respect of persons with disabilities including what kind of disability is governed by the Act.
- **Anti-Discrimination Act 1998** which prohibits discrimination and provides for the investigation and conciliation of, and inquiry into, complaints of discrimination and other forms of prohibited conduct. It promotes acceptance of the fundamental principle that all persons regardless of specified attributes including disability have a basic right to participate in public and social life without unfair discrimination, victimisation or harassment.
- **Commonwealth State/Territory Disability Agreement (CSTDA)** which provides the national framework for the funding and provision of disability support services for those requiring on-going and long term support. It clarifies Federal and State/Territory responsibilities with the main CSTDA services being accommodation and community support, community access and respite and employment services. The CSTDA has been criticised for entrenching the fragmentation of service provision and constraining resources available to meet the needs. Recent debates have explored redrawing the demarcation line between Commonwealth and State responsibilities.

- **Disability Framework for Action 2005-2010** which lays out a 'whole of government framework' for Tasmanians with disabilities and is based on the seven guiding principles as specified in the Disability Services Act 1992 – equity, access, inclusiveness, autonomy, recognising and supporting diversity, non-discrimination and prioritising resources. With reference to children the Framework identifies a rise in the numbers with disabilities and aims to expand support options and networks for families, reduce the incidence of out-of-home care and assist young people to make sustainable transitions into independent living. It does not however provide a basis for developing a comprehensive support system for families.

The Premier is responsible for overseeing the implementation of the Framework with assistance from a **Disability Advisory Council** reporting annually to the Cabinet Policy Committee. This process is assisted by the establishment of a **Disability Bureau** within the Department of Premier and Cabinet (DPAC) to promote the Framework and all government agencies are now required to prepare a Disability Action Plan documenting how commitments in the Framework will be met and listing priorities, targets, benchmarks and action taken to promote disability awareness. A **Ministers Disability Advisory Committee** consisting of 12 community members has also been appointed to advise on the provision of specialist disability services. Implementation of the Framework will be reviewed in 2008.

Education-based provision is central to services for children with disabilities and there have been a number of initiatives in the education sector to improve provision for them and reinforce a commitment to inclusive schooling. These are:

- **Inclusion of Students with Disabilities in Regular Schools Policy 1995.** This is based on the underlying principle that placement in regular schools is the preferred educational option for students with disabilities in Tasmania. It seeks to ensure that they gain access to education in the same learning environment as their peers and refers to the **1995 Equity in Schooling Policy** whereby all students in government schools should have equitable access to the benefits of education regardless of disability.
- **Atelier Report 2004** commissioned in response to concerns that inclusion practice was not consistent across the state. It reviewed all services for students with special and/or additional educational needs and resourcing and staffing models. It resulted in a number of initiatives including the establishment of an Institute for Inclusive Learning Communities to support and enhance professional learning opportunities, and the development of an Inclusive Education for All resource to support schools in implementing inclusive learning.

The DoE also supports a **Parent Reference Group** made up of representatives of parent stakeholder groups and organisations. The group operates as a formal consultative mechanism with parents and aims to promote increased parent participation in issues relevant to educational provision for children with disabilities. Most recently a **reference group of school principals** has been established to examine the enrolment options for children with disabilities, including combining mainstream and special schooling, professional learning for staff and consultation processes with parents. The reference group had not reported at the time of publication.

There have been a number of initiatives to improve support available to families and to children across the board. These include:

- **Stronger Families and Communities Strategy.** This is a Commonwealth initiative announced in 2000 to provide families, children and communities with the opportunity to build a better future. It targets children with the aim of giving them the best start possible and emphasises the importance of prevention, early intervention and capacity building. It has funded a number of projects in Tasmania.
- **Our Kids Bureau.** This was set up in 2002 in response to persistent evidence that the wellbeing of Tasmanian children was lower than it could be, that there was a poor fit between needs and services and that early intervention can result in long term gains. It aimed to take a strategic leadership role in developing and managing policy and programs for children under 12 years. It developed the **Our Kids Action Plan 2004-2007** with a number of initiatives to improve the health and wellbeing of children in Tasmania through a range of service reforms, partnerships and service improvement activities. These included reviews of:
 - **the Tasmanian Family Support System** (DHHS, 2005). The review aimed to identify and evaluate support currently available to families and ways of improving it. It found that services had developed in an ad hoc manner resulting in poor coordination, difficulties in access and severe limitations to the support available.
 - **Children's Therapy Services** (Evolving Ways, 2006). This identified a lack of a policy framework which has fostered inequities in access to therapy services across the state and an inability to focus on early intervention.
- **Whole of Government Policy Framework for the Early Years 2005.** This is based on the principle that maximum gains will result from intervention during the early years of childhood in order to prevent problems in later life. It aims to develop a strategic framework for the early years which will bring players together to counter the diversity and fragmentation of the current service network. It was endorsed by Cabinet in September 2005 and is being developed and implemented by DPAC.
- **Tasmanian Early Years Foundation Act 2005.** This created a non profit foundation to promote and support the well being, development and learning of Tasmanian children aged 0-6 years through grants for evidence based early childhood programs and promoting research and public awareness about the importance of the early years. In order to maximise resources for early childhood initiatives the foundation will build on core government recurrent funding by seeking public donations and forming sponsorship partnerships with corporations.
- **Report on Child Protection Services in Tasmania 2006.** This examined the current service system and made recommendations about how to improve it. It included implementing protocols with Disability Services to ensure that children with disabilities have access to services to prevent them becoming involved in the child protection system. A position has been established to develop a strategic framework to provide services to children with disabilities who are subject to care and protection orders or at risk of abuse or neglect and to strengthen collaboration between key service providers.

Although there are many policies and initiatives across different sectors which impact on children with disabilities and the families who support them there is no comprehensive overarching framework within which to address the issues they face. Neither is there currently a comprehensive early intervention strategy to support the early identification of problems and

provide the resources to prevent them from escalating. Although other jurisdictions have put significant amounts of funding into early parenting and family support programs these services remain limited and uncoordinated in Tasmania.

2.4 Overview of the Service System

The government – both at a state and a federal level – provides a range of services to support families who are caring for children with disabilities. The basis for the provision and funding of specialist disability services for those who require ongoing or long term support is the CSTDA which determines how much money is received by jurisdictions from the Commonwealth.

The Commonwealth provides:

- income support including the Carer Allowance (child) and Carer Payment (child)
- some accommodation, respite and recreation services
- joint funding with states and territories for the Home and Community Care Program (HACC), aids and appliances, advocacy and information and print disability services;
- Continence Aids Assistance Scheme (CAAS)
- provision of pharmaceutical and other medical benefits

The State Government has day-to-day responsibility for most support programs for children with disabilities and their families. These include health, therapy and respite services, information and family support, concessions and subsidies, aids and equipment, housing and education services. In Tasmania the lead agency for disability specific services is Disability Services – a program located in the Department of Health and Human Services. Disability Services aim to provide a range of specialist services, are mandated to assist access to generic services and have a regulatory role in policy, planning, monitoring and purchasing of services.

Although services are funded by state and federal money under the CSTDA many are delivered under government contract by the **non-government sector**. They include respite and support with personal care in the home, family support services, information, advocacy and referral, holiday, childcare and recreational opportunities.

In addition there are a range of consumer organisations promoting the interests of children with particular kinds of disabilities, their families and carers. They receive little government funding, may or may not have paid workers or office premises and often rely on fund-raising to support their activities. They can offer parent support groups and camps, information and advocacy, seminars and conferences. They may also provide training and awareness-raising to health and community care practitioners about particular kinds of disabilities. Some are able to offer limited financial assistance to help fund the purchase of specialist equipment or to meet other disability related expenses. Others engage in lobbying and campaigning work to promote change.

Because of the lack of an overarching framework to guide provision for families services have grown up in an ad hoc way across the state and the service network varies from region to region. This can be very confusing for families who are new to the state or who move from one part of the state to another.

Overall the diversity created by the division of responsibilities between federal, state and non-government organisations as well as regional differences has fostered a fragmented service

system and a divided disability sector. There are many competing perspectives and priorities where families and carers may be in conflict with service providers, children's needs are pitted against adults', advocacy groups for different conditions compete with each other for priority and attention and there is a continual battle between state and federal government about responsibilities. Competition for funding between groups has worsened the situation and meant that the disability sector is unable to take a united stance in advocating for resources and implementing policy changes.

2.5 Service Usage and Unmet Need

The primary source of data about the services accessed by children with disabilities in Australia is the ABS Survey of Disability, Ageing and Carers (ABS, 2004) and the CSTDA national minimum data set (CSTDA NMDS) providing annual data on disability services. The figures show that the bulk of care activity for children with severe/profound disability falls on families with some assistance from formal services. Ninety four percent of these children receive informal assistance with core activities, 69% have a combination of formal and informal help and 26% have informal support only.⁷ The national figures also show considerable unmet need for services with 48% of primary carers reporting needing more support, especially for respite (48%) and for financial assistance (34%).

A recent report by the Standing Committee on Community Affairs (The Senate, 2007) into disability services funding and the CSTDA criticises both Federal and State/Territory Governments for the poor condition of disability services across Australia. The report identifies a crisis in disability services and finds that 'physical or intellectual disability today equates almost ineluctably with lesser opportunities, services, social inclusion and quality of life than the rest of the community takes for granted'. It makes 29 recommendations with the primary one being a joint commitment from all governments to provide additional funding for specialist services and support to meet unmet need. The Federal Government's response to date has been an offer of zero growth funding with no additional resources for the next CSTDA agreement and a push to abandon the collective CSTDA process in order to deal with jurisdictions individually. The States/Territories however are demanding that the Commonwealth commit to a multilateral agreement which should at least match the funds individual jurisdictions put into the disability sector.

This national picture is reflected in Tasmania where despite the fact that under the current five year CSTDA agreement Tasmania has increased its funding for disability services by more than 74% the Commonwealth contribution has risen by only 15%. This has resulted in continual reports in the media of difficulties in accessing essential services and families reaching crisis situations when their support needs are not met.

In the education system there have been public concerns about cuts in funding to support inclusion and the lack of a career structure for teacher aides, stress for teachers and a shortage of speech pathologists and guidance officers. In response the State Government has rejected calls for a review of inclusion policy and behaviour management in schools but promised more support for teachers dealing with disruptive pupils and working closely with parents of children with disabilities to improve behaviour.

Many of these issues are now entering the consciousness of the general public in Tasmania and the new Tasmania *Together* plan (Tasmania *Together* Progress Board, 2006) identifies a growing community concern about disability services in the state.

⁷ These figures have been rounded.

3. Caring for Children with Disabilities

The birth or diagnosis of a child with a disability is a major event for families and as well as the impact on household finances parents find themselves meeting a range of additional care needs. Those children with severe and profound disabilities may require long term, continual care and be highly dependent upon their family to meet their basic needs. Unlike non-disabled children these care needs do not necessarily diminish as the child gets older and may indeed increase. In previous decades many of these children would have been raised in institutionalised settings but now most of this care is provided by parents and when the disability is severe they become 'career carers' and the family home becomes a residential placement (Eyler, 2005).

This section describes what it means to care for a child with a disability and how families find out about and get access to the support that might be available to them.

3.1 Diagnosis

Interviewees were asked to describe how they found out about their child's disability. Some had received a diagnosis shortly after the birth, others had children who had developed conditions later on in childhood or who had not identified any problems until their child failed to reach developmental milestones. For some families it had been a slow process of knowing something was wrong but having to wait months or years to get a diagnosis. And a number were living without any diagnosis at all.

The moment of diagnosis has been described as a point of crisis and trauma (SPRC, 2003) and this was certainly true for many of the interviewees. They described difficult situations where they had been given the diagnosis with little support and expected to digest an overwhelming amount of information at a time when they were in shock, grieving or in denial. A number of families expressed dissatisfaction with the way in which the news had been broken to them and the amount of information available to them at that time. This can have a longer term impact on their ability to cope with and adjust to the situation and a lengthy period may be required to both accept the disability and then to accept that they need help and support.

Declan is Down syndrome. I came out of theatre and as soon as I woke up and went back to my room the doctor came and told me. I had no family or anyone with me when they told me. How do you tell someone your child's got Down syndrome? I could have had family with me or a nurse with me or somebody. But she just come in and told me and left the room again and I was just left there. Once they found out he was Down then, even though they knew he had it, it was waiting and hoping they had made a mistake. (Dot caring for Declan aged 8 months with Down syndrome)

She was born full term and nothing was identified before I was pregnant. It was a traumatic birth and they rushed her straight off. On the second day when they brought her in she wouldn't feed so the nurse found she had a cleft palate. Things just went downhill progressively from there. She was in intensive care for a couple of days and then she was in the special care nursery for two months which was extremely stressful. They did a number of tests and it all came back okay so we were positive, I guess we were a bit in denial I suppose. Then we got the test results back and she has a very rare chromosomal condition. No one could tell us what the future held. When we went in to see our paediatrician he was in total shock so he just blurted it out and he hadn't prepared so he had nothing to tell me about it. So that was very difficult and I'm sure

it was for him as well. You are in a big cloud and all your expectations have been blown away and people don't have any answers and it's very tough. (Kate caring for Daisy aged 2 with cerebral palsy)

You have your four month check up and he wasn't like other babies, he wasn't rolling and he never cried. I used to have to wake him up to feed him. The nurse said he is blind, retarded, deaf, take him home and I'll call a paediatrician when I can. I thought this is terrible, you don't talk to parents like this. Maybe we knew but we didn't want to know. He had the tests and they said he had a form of muscular dystrophy. When I was told I had no one sitting with me. I was crying my eyes out. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

Getting a diagnosis can be a critical starting point for access to intervention and services and means that those with a visible disability like Down syndrome, spina bifida or cerebral palsy may have an easier pathway into services and support. However significant numbers of children are diagnosed in the pre-school years when families may just know something is wrong but are unable to label it. This is particularly true for children with conditions like autism where one of the main symptoms is about delays in communication so a diagnosis has to wait until a 'normal' child would be talking or until it becomes obvious in social environments like school. The same delays in diagnosis can be true for children with epilepsy where less severe forms can manifest as periods of absence which generate learning or behaviour issues over a period of months before any diagnosis is made. It can take up to a year to get a diagnosis for epilepsy as the tests do not necessarily identify abnormal brain activity.

As a parent I knew there was something drastically wrong. He was okay until 18 months and then it just seemed to all fall down. Whether it's then you start noticing the developmental side and gauge them against other children. It took 18 months to try and get someone to take it seriously. You go to your doctor and they say he's fine, stop panicking. You do and then a few months go by and you start worrying again when they don't reach the milestones. There was no speech, very bad gross motor skills, he didn't walk till very late, very bad fine motor control. When someone said autism I didn't know anything about it so I went home and searched the internet and had a big cry when they said it's lifelong. He was diagnosed officially. They just gave me three pamphlets and said your child's got autism. (Angela caring for Dean aged 7 with autism)

We found out he had epilepsy when he was in Prep. He kept asking the teacher to repeat herself and she got a bit shirty about it. The doctor told us he had epilepsy. He was a premie baby with meningitis, so we always expected something to come around and bite us on the backside. There were vacancies and he was losing quite a bit of information. (Kerry caring for Laurie aged 13 with epilepsy and Tim aged 12 with autism)

I demanded an MRI when he was 18 months old and said there's something wrong with this child. The paediatrician I went to said no, no he's fine, he's smiling. I said no there's something wrong, I've raised five kids, I know there's something wrong. The MRI came back and he said well it's worse than what we thought. All you can do is love what you've got. He's cerebral palsy, epilepsy and acquired brain damage. He lost a lot of white matter plus he's got frontal lobe damage. People think oh there's nothing wrong with him. Have him for six months they'd soon see. There's a lot wrong with him. (Jackie caring for grandson Jake aged 6 with multiple disabilities)

Others were still waiting for a diagnosis and had become involved in a round of appointments with different health practitioners to try and get one, often at their own expense. It was clear

from parents talking about their experiences that getting a diagnosis was very important to them and they were prepared to push for one. Professionals on the other hand can be reluctant to diagnose or to say that there is a developmental delay for fear of labelling the child. Most families did not find this approach helpful and the lack of a diagnosis could mean compromising the child's eligibility for vital services.

The psychiatrist said she didn't believe in labelling. I said to her in total frustration as far as I was concerned she's already been labelled. She gets labelled by the kids at school and the teachers at school. She gets labelled everywhere she goes because she's different. So I would rather have a label that explains why she's different than just not be able to say anything. She said we can't categorically say she's got Asperger's, it's extremely likely. I've heard so many parents who've been in that situation. So basically I just tell people she's got Asperger's. You need it for funding primarily but you also need to give it to the child and to yourself so you have a reason why she or he behaves in the way they do no matter what things you put into place that would work with other children. For your own sanity you need a label and most definitely for funding. The biggest problem is getting a firm diagnosis in writing. Who do you go to and if you do find someone it costs \$700 so where do you find \$700 to pay for the diagnosis in the first place? (Gerry caring for three children with autism aged 8, 7 and 6 years)

He has to have a diagnosis by the end of the year otherwise we forfeit him getting an aide next year and he wouldn't survive without an aide so it's not really an option. But my husband doesn't want him diagnosed. We also need it for the Carers Allowance. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

There were families who, despite years of trying, were unable to get a firm diagnosis.

He was sick with eye problems, skin disorders, stomach problems right from the beginning and he's spent most of his life in and out of hospital. I took him to paediatricians, private psychiatrists and psychologists which cost us a fortune and they just could not pinpoint it. They said Sean's got multiple disorders. When he was born he cried continually and in the hospital they just couldn't stop him. The paediatricians said if I had been a younger mother when I had had him I probably would have killed him if I hadn't had that experience behind me of already raising five children. Experts over the years have said they have never come across a child like him. (Liz caring for Sean aged 12 with multiple disabilities)

3.2 Care Needs

Children with severe and profound disabilities can be highly dependent on their family for meeting their basic care needs like eating and drinking, toileting and bathing, communication and mobility and the majority of parents provide care well in excess of other parents. Although some children in the research sample were able to meet most of their daily care needs themselves, others were totally reliant on their parents. Interviewees described the care regimes they were responsible for and what a typical day looked like.

It's 24/7. We have to do everything from dressing to feeding. He can't talk, but we know what he wants. With feeding we both do it different. Des has him in the wheelchair and feed him from front on so you have to watch both his hands because he

will just grab things. He will sometimes have six weetabix and cornflakes in a big bowl for breakfast and he might take five minutes to eat it or he might take half an hour. He has to have massive spoonfuls because if there isn't a big heap in his mouth he won't eat it because he thinks there's nothing on the spoon. I sit on the floor behind him so I have more control. Just even with drinking some days he'll have three, four, five bottles but other days you might be there all day just trying to get two drinks into him. Sometimes he won't drink during the day. Sometimes when I feed him I have to get the girls to sit on his legs and once he starts rocking there's no way you can control him. Even in the wheelchair I bring it right up to stop him kicking his legs and try and keep him still long enough for him to have something to eat and drink. I have times where he's in a terrible mood and he just gets into a fetal position and it takes all our time to pull an arm down to put a jumper on, he won't let you do nothing. He's quite strong. I got a smack on the mouth this morning. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

The spina bifida affects his walking, his bladder and bowel control. He has a shunt which drains the fluid from the brain. So it affects him mentally, physically and sometimes emotionally. It's the whole thing. He will have a good day and then three bad days and then another good day. He has splints to strengthen his ankles. He has no control over bladder and bowels so we can be catheterising every four hours. We do a bowel wash out every second day. So he's full on and it's all go. There's never a dull moment and if mum don't do it, dad does it. It's bathing and showering. He doesn't like anyone else doing it. It's time consuming and every day is a learning process, it's something different everyday. The toileting is worse because we are having trouble with his bladder. At the moment as soon as he stands he just leaks. He takes it all in his stride and it doesn't get him down and like the doctors said to us if he's not worried about it you shouldn't be worried about it. (Kath and Jack caring for Nick aged 14 with spina bifida)

A number of children on top of their physical disability also have challenging behaviours which can be violent and aggressive and which can make it nearly impossible to take them out of the house or put them in social situations. It can mean a need for constant supervision, night time disturbances and physical damage to the home, to themselves and to others in the family. The behaviours associated with autism can be particularly difficult to deal with.

You're in the thick of it dealing with a child who can't toilet themselves and is very violent. He would mess his pants and you would go and put him on the toilet and be trying to help him and he would go bang as hard as he could right into your head. I was scared I was going to get hurt. He would kick you and pinch and bite. He wasn't able to control the anger. He's getting better. At one stage if we left him for five minutes he'd be up on the roof. At times in the past we've had to watch him constantly because he will hurt Finn and he does still hurt him. Now we're starting to worry because he's picked up knives a couple of times and threatened that he's going to cut himself. (Di and Tony caring for Rowan aged 10 with Asperger's)

She requires constant care. She's obsessive about food and extremely active and physical and very tiring. If you don't watch she tries to get into the food cupboard and because she's obsessive about food she would eat everything and make herself sick. So we have to lock everything away from her. You have to watch her with the water because she turns all the taps on and then she'll drink all the water. You can't let her outside because she'd run on the road because she has no fear of cars or of anything. You have to know where Chloe is, you have to know what she's doing, you have to watch her all the time. Her bedroom has a lock on the door and if I have to do something and I can't watch her

for 10 minutes I put her in there with her toys and lock the door and do whatever I have to do. That's my sanity. She won't let me drink a cup of coffee. If I have a cup of coffee she will be on me the whole time trying to get the coffee. You have to watch her in the garden because she eats the plants. Some nights she will sleep really well, others I have to get up two or three times a night to put her back to bed or to change her because she soils during the night. If she soils and you don't go in and change her she takes it off and you don't really want to know about it so you have to go in and change her otherwise it's just too difficult to clean it up in the morning. She has medication to sleep because otherwise she wouldn't go to sleep at all. She has a wicked sense of humour but intellectually you can't see any progress in her ability to do things. She can help dress herself and undress quite well and she will do that often. She can sort of feed herself but you have to supervise it very strictly. (Doreen caring for Chloe aged 16 with severe autism)

The same family commented on the difficulties of dealing with continence and these were common to many families who participated in the research.

Continence is such a big issue with us. I often wish it wasn't an issue, that she didn't have it because she would be so much easier to handle without it but she does and she's 16 years old and it's not going to get any easier and it's never going to go away. It's so frustrating. Some days I will get her up, shower her and dress her and within 10 or 15 minutes of having breakfast she's soiled and I have to start again. Do you know how frustrating that can be at times? That in itself is enough to send you to La La Land along with everything else you have to deal with. (Doreen caring for Chloe aged 16 with severe autism)

Parents can find themselves responsible for tasks which require the combined professional skills of nurses, teachers and therapists. They monitor the child's condition, perform medical tasks and stick to medical regimes, schedule appointments and act as advocates. Although a child with a disability may be generally in good health there are multiple demands placed on families by the round of tests, assessments and treatments, meetings with doctors, therapists and a range of other professional workers. As one mother said, 'I am juggling, I have two diaries, his and mine, trying to manage the day to day life around the appointments.' As the child gets larger and heavier meeting these needs can become more challenging. Parents may have to learn nursing skills and how to perform complex procedures. A number were waiting for operations and parents were gearing up for the additional care needs that any surgery might generate. Again these medical procedures were very emotionally taxing for carers and a drain on their time and energy.

When I got home from the hospital with Rosie we were still feeding intravenously – through her nose. I had to do that and I'm not a nurse. It was twenty four hours round the clock, nine different medicines. Here I am exhausted getting two or three hours sleep a night and had to come home and play nurse. I had all these medicines and thought I am so tired I am going to muck up on the medicines. Some were due at 2 in the morning, some at 4 and she only had to find the chord and rip it out and I couldn't put it back in so we had to go in to the hospital. One trip was five o' clock in the morning to get it replaced so she could have a feed. That happened a couple of times. They wanted me to learn but I said no. I was already out of my comfort zone with all the medicines, suppositories. I didn't feel comfortable at all. So the first 17 months were absolutely awful, that's no exaggeration. Everyone in the house just had to take a huge back seat, they were lucky to get food when we were in hospital for three weeks. But things have settled down. Now and again she will sit on the couch by herself for a

while so I can do something with the other kids. But she's very full time. (Jill and David caring for Emma aged 7 with autism and Rosie aged 2 with cerebral palsy and epilepsy)

She's been having surgery recently. She was going to have it in early January, then they decided they would put it back until February. It's to break her left hip and turn it around and put it into its proper place and reform another socket and put a plate over it. After surgery she got really scared and wouldn't sleep at night so it's all over the place at the moment. We get stressed out because when she first came out of hospital she wasn't sleeping all night. She's been just crying and crying. (Jane and Mike caring for Lisa aged 4 with cerebral palsy)

Some families lived with the fear of a sudden deterioration in their child's condition and finding themselves in a life or death situation.

He has terrible nights and we're up and down with the epilepsy because you never know when it's going to break out again. He's on medication but he had a grand mal at half past four in the morning. I wasn't prepared. They say one per cent do die but usually it's an older person. But you think every breath is going to be his last, it's awful. You are always watching him. I listen all the time. (Jackie caring for grandson Jake aged 6 with multiple disabilities)

What was particularly difficult for families to deal with and which extracted a heavy emotional strain was when the child's condition was continually changing, altering their behaviour and skills.

All her symptoms seem to vary every two weeks, monthly, so something always changes, it's never the same. When I say she can't get dressed, she knows the trousers go on her legs and the shirt goes on top, but instead of taking a t-shirt off and putting a new one on, she will put the new one over the old one or a pair of trousers over a pair of trousers, or the jumper on upside down with the head through the waistline. Shoes are always going on the wrong feet. I'm not entirely sure whether it's a regression in the brain, in the skill or whether because of the brain activity she seems to lose concentration on a task. What I've noticed in the past few weeks as I've been getting more and more exhausted and frustrated is just the emotional impact. The other night she was just picking her nose and by the time I got to her she had blood all down her. She hadn't thought to stop and just kept going. She had it all over the bed, all over her clothes and she had no comprehension of the state she was in. I sorted her out, came out and bawled my eyes out. I've got to the point where I don't feel I know her because I don't feel I can communicate with her. (Sally caring for Claire aged 6 with epilepsy)

At the moment we have a little boy who is totally different to the little boy we had at Christmas. So his personality and everything changed. He's back in nappies and there's no toilet training anymore. Sometimes he can't walk because he doesn't know where his legs are, so you have to lift him. He's eight so he's getting to be a big boy and he's heavy. So every day it's different. We now have to relearn what he likes to eat. He was eating everything, now he only eats certain foods. Because he doesn't speak very well and his speech is very delayed and he lost a lot of sign language he gets very frustrated trying to tell you what he wants. It's a lot of guess work. You have to bath him and shower him, have to dress him because he can't dress himself anymore or undress himself. It's a hassle getting clothes on and off him. He doesn't sleep well at night. He's gone back to a sedative but that only really gets him to sleep but doesn't keep him asleep all night. He usually ends up in our bed kicking and pulling hair. It's a two person job. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

3.3 The Impact on Families

The multiple demands placed on parents by the care needs of their children can mean the whole family is under a great deal of unrelenting stress. Although most families do cope and very few resort to out-of-home placements there is a heavy cost in terms of the quality of family life. The added strain of caring, as well as financial disadvantage, can lead to strains on relationships, deterioration in the health of the primary carers and a negative impact on other children in the family. For some people caring for their disabled child had become such an integral part of their lives that they found it difficult to describe what impact it had had on the family as a whole.

We've grown with Ellie's disability, it hasn't suddenly been forced on us like a car accident. We don't know any different. For me I just go along with each day as it comes. (Sandy caring for Ellie aged 16 with cerebral palsy and vision impairment)

Others were able to describe in detail how it had changed their lives. In particular many were very sleep deprived. This is not the sleep deprivation common to most families who have young children because it can continue for years and years. It means that practical things like doing the housework or just managing day-to-day become impossible.

He's had a huge impact on us, he probably runs our lives, our family life because if he doesn't it doesn't function well and we have to consider him in everything that we do. (Di and Tony caring for Rowan aged 10 with Asberger's)

We live with it because we can't do anything else. We can't go anywhere. We have to be on call twenty four hours, or I do, and the school are always asking me for information, how do I deal with him, what do I do? I don't specialise in anything, all I specialise in is dealing with him. (Liz caring for Sean aged 12 with multiple disabilities)

Research participants were asked to rate their level of satisfaction with various aspects of their lives on a scale of one to ten with ten being completely satisfied and one being not satisfied at all. Table 4 shows that families caring for children with disabilities had lower levels of satisfaction with most aspects of their life compared to the general population in Tasmania. They had particularly high levels of dissatisfaction with their future security but were also not happy with their health, standard of living or their ability to participate socially.

Table 4: Life Satisfaction Mean Scores

Satisfaction Indicator	Families	Tasmanian Population*
Your life as a whole	5.0	7.3
Your standard of living	4.8	7.7
Your health	4.5	7.0
Feeling part of your community	4.8	7.0
Your future security	4.0	6.7

* Figures taken from the Tasmanian Community Survey. See Madden and Law, 2005.
Note: Questions replicated from the Australian Unity Wellbeing Index.

3.3.1 Strains on relationships

Two thirds of primary carers of children with a severe/profound disability consider that it has impacted negatively on their relationship with their spouse (AIHW, 2006). This was certainly reflected in this research where six couples described in some detail how the lack of time or energy they had to put into their relationship had caused a lot of problems.

It's hard for me and Scott (Marge's partner) because we don't get any time together because I'm always busy so that puts a strain on us. I haven't got time to sit down and play a game on the computer with him. By the time she goes to bed I'm so tired. (Marge caring for Rachel aged 5 with autism)

We do go through bad patches between us because there is so much stress and there's not enough help. It's just put so much stress on our marriage. We manage to cope and take it in turns looking after her through the night time. Day time we take it in turns feeding her and doing the daily chores. (Jane and Mike caring for Lisa aged 4 with cerebral palsy)

Mark and I it was either going to break us or bring us closer together. I am with Tina all the time so Tamieka and her father have spent a lot of time together without me being here. There have been a lot of fights and not having our own time. Apart from that we've coped, we've had to cope. I go and see a doctor and talk about things. It's a psychiatrist. I used to go weekly and now I just go monthly and we've covered a lot of ground. Mark, he doesn't like talking about it and he doesn't like people coming into our place not knowing that Tina is here. She can scare a few people off. (Viv caring for Tina aged 16 with a chromosomal disorder)

In one case it meant that the relationship had broken down altogether.

Her Dad didn't cope and he left. When I had her he was great for the first two months and then it went downhill. He couldn't cope that she was unwell and he wasn't getting anything he needed. I didn't even have time for myself. (Kate caring for Daisy aged 2 with cerebral palsy)

3.3.2 Health and wellbeing

Primary carers, usually mothers, can experience high levels of stress and a negative impact on their general wellbeing. Coping day-to-day and particularly coping with uncertainty can mean poor physical health and high levels of anxiety and depression. A number of mothers described ignoring their own health problems.

We are very tired all the time and I have a lot of problems now with arthritis, my shoulders and hands from lifting. You are not having proper meals. It's okay when he's at school, you can have lunch and try to have breakfast when he leaves for school but school holidays and weekends most times you don't eat until night when he's gone to bed. So you don't have anything because you don't have time to eat. So you have a poor diet. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

It builds up and you get tired. The disability alone is tiring because it's ongoing, it's not curable and it's not going to go away. It's very unknown and it's wearing and stressful and you don't get any respite. So physically I get migraines and I've had them everyday for the last week. I know it's because I'm under stress at the moment because I haven't

had enough sleep. My body gets worn down so then you get sore throats and colds. You can't afford to take yourself off to the doctor because what will the doctor say, rest, how can you rest? A weekend is just an extension of the week, it's not a weekend. (Gerry caring for three children with autism aged 8, 7 and 6 years)

It's been up and down, it's been a real roller coaster especially when she first had surgery. It was horrible. You just don't know where it's heading. I was on anti-depressants for two years to deal with it and I've been off them for 18 months or so. It did get to me to see her going through these surgeries and not being able to do anything to help but you deal with it. (Winnie caring for Tess aged 8 with vision impairment)

3.3.3 Siblings

Parents were especially concerned about the impact of meeting the disabled child's needs on their brothers and sisters. They were aware that siblings were inevitably losing much of their attention and that their needs fell by the wayside in their efforts to cope with strict care routines or unusual behaviours. They did not always see it in a negative light and as one mother said, 'He has been forced to grow up sooner than I would like but he's got a whole lot more experience and depth of character because of it'. But most parents were concerned about the negative impact on other children in the family and although they did their best to compensate by arranging outings or treats when they could they were very conscious of what the other children were missing out on.

Basically it took a lot of time away from Jim which is very unfair. They are very close but now he's independent I realise how much he misses out on. Jim never had the benefit of going on holiday like other kids because I could only afford to take a fortnight. So he missed out on a lot which you can't really compensate for. (Tracey caring for Zoe aged 14 with a hearing impairment)

Attention seeking behaviour among siblings was also causing difficulties and in two families siblings had experiencing bullying at school because of the disability of their brother or sister. It had also had a big impact on their own social life.

Laura is having counselling and she has an eating disorder and it's all for attention. She is very, very overweight at the moment. This one, Sonia, we have behaviour problems from her because of her need for attention and a lot of copy cat behaviour like kicking walls and windows. She has copied a lot of the behaviours. This, 'they're special', that's probably the worst thing you could call a disabled child, special, because Laura says why aren't I special? A siblings' group down here would be really, really good. They need a lot more than what they get so they are not feeling like second rate people and trying to get the attention. They don't get anything at all and it really does affect them. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

I find other people make it the hardest. Last year they had been playing with this friend for a couple of weeks. The mother came here, saw Simon, and that was it. You can't catch it, but that was that friendship gone. They also get bullied at school and a few kids know about Simon and they keep saying I ran him over in the van a couple of times to get him like that. It plays on their minds. Our oldest stands up for him. She says no one is talking about my brother no more. But the school can only see the faults in her for standing up for herself. She is very defensive about her brother. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

With his brother, he has times where he has trouble bringing friends home and things because he never knows what sort of mood Tom is going to be in or what he's going to do. He misses out on such a lot of things. He needs to be able to do things with other brothers and sisters so he knows he's not the only one who's got a brother who is different. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

Two families had experience of sibling groups which their children had attended and which gave them the opportunity to meet other children who were coping with similar problems. They had found them very valuable. Unfortunately there are few groups for siblings in Tasmania.

3.3.4 Social participation

Families coping with disability can find themselves excluded from social activities outside the home. This may be to do with general fatigue and not having the time or energy to socialise. There may be financial barriers imposed by having to meet the additional disability-related costs. They may be fearful of leaving their child or find dealing with difficult behaviours in social situations too distressing. Families in the sample described all these situations. Some felt caring demands meant it was impossible to make and to keep friends. Others described family and friends as no longer wishing to visit because they found the disability too distressing or disconcerting or the behaviours too difficult to deal with.

I feel reluctant to go out when she's at school and could have a seizure. I have got to stop that a little bit, and start trying to do things when she's at school. But just to know I am just two minutes away has always been a big relief. I just get a bit panicked when I think it will take me two hours to bus into the hospital and the carer will be waiting there forever before I get in there. It does make it hard just to get out. Luckily there are a few parents that live around the place that I catch up with but a lot of them have started going back to work. It does make it tricky to go out for a cuppa. (Sally caring for Claire aged 6 with epilepsy)

It's a very lonely life. You don't tend to make many friends. If you do have friends that come round they spend their time looking at him. So you tend to become very isolated and I'm sure a lot of people with disabled children will tell you the same thing. It's very isolating, lonely. The only people you have anything really to do with are people associated with his care, medical professionals or other parents with disabled children. That's about it and most of those parents you don't do a lot of socialising because they are all very busy and no one has energy. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

With the autism my social circle has diminished quite a lot. I don't have a lot of friends because they say how is it going and you launch into it and they don't know what to say and they don't feel very comfortable with it. It consumes your life that much that having outside people around you doesn't happen that often, you don't have a lot of social contacts. I have a couple of friends who are great but they won't take him. They say I'd love to but I don't know what to do. Not having any money going out to dinner, \$60 or \$70 is something to justify even once a month. It's very hard if you've already planned out six weeks of your money on your bills. I've become extremely house bound. I don't know whether it's a form of depression. I've got to a point where I don't leave here that often. It would be nice every now and again to go to the beach with an adult friend to talk to but people are busy. You can't get together where your kids socialise with other kids because they just don't. So it's very isolated. (Angela caring for Dean aged 7 with autism)

Many families spoke of the loneliness they experienced. One grandmother found it particularly isolating.

You feel isolated, because you're not with the young mums. They walk away, you have nothing in common. I have a network of friends out here but they don't have children, so it's different. He will muck up in front of them because he needs the attention. (Jackie caring for grandson Jake aged 6 with multiple disabilities)

What was particularly hard was dealing with the perceptions of others about their child's behaviour and the criticism and judgements this could engender. This meant that some interviewees felt that it was easier to cope and they got more sympathy and help if their child had a more visible disability.

When he misbehaves when we're out and we go through our calming routine people don't understand what we're trying to do. If we disciplined him it would only inflame the situation. They think we're being too lenient, but you can't shout at him or smack him or whatever people expect of you. We do that sometimes because we're normal parents and we lose our temper with all these things stacked on top of each other and we get to the point where we're tired, run down and we don't have any more energy. We yell at him and it makes it worse. (Di and Tony caring for Rowan aged 10 with Asberger's)

If you have a child with a severe physical disability and they are confined to a wheelchair in some ways the demands of dealing with that child are very great but the emotional demands are not as great. Children on the spectrum or with ADHD are emotionally constantly making demands on you. People see my children and you wouldn't think they had a disability. That is hard because when they behave badly people assume it's bad discipline and they can be quite judgemental. The hidden disabilities are far more difficult for people to cope with than the obvious ones like cerebral palsy or being blind or deaf. People make more allowances because they can see there's a problem and their expectations aren't as high. (Gerry caring for three children with autism aged 8, 7 and 6 years)

The child with a disability also has to cope with restricted social opportunities.

I would love her to be able to get out and do things, extra curricular things, but they are all dependent on her condition at the time. We enrolled her in Guides last year but the hours it's at in the evenings I don't think it will work. I would love to get her into music or dance but there's nothing really, really local. It's simple things like popping round to a friend's place after school, she can't do that without me because a lot of the parents are not educated about her epilepsy. There are one or two who are comfortable with it but I don't know how you would go about educating every parent. (Sally caring for Claire aged 6 with epilepsy)

It's him having someone to do things with him, somewhere for him to go. He doesn't have anything to do and he needs more to do. Being not able to walk is his problem. There is nowhere around here for him to go. (Janine caring for Andy aged 16 with cerebral palsy)

One mother had participated extensively as a volunteer to 'repay' the attention given to her autistic son.

If you have a kid with high needs I feel you have to help out as much as you can, help them feel like the amount of work they're putting into your child at school, that you

somehow are balancing that by what you do. So I was doing the book club for them, I was the treasurer of their parent's association which involved doing the uniforms because nobody would do it. I was supporting the person who did that. I did the cattle sales in the summer, countless other things, car parking for the fair when they have it here. (Di and Tony caring for Rowan aged 10 with Asberger's)

What a number of families wanted to see were more opportunities for the whole family to meet other families coping with similar situations.

They could provide camps several times a year at minimal cost to families with children with disabilities and where the siblings could come too. At the camp they could have support people so that parents have some respite from their kids, meetings with support people maybe about unusual discipline techniques or taking the mums out for lunch somewhere. Something where mothers and fathers can go out and meet with other parents who have children with various disabilities and also normal children. So there's activities for children, support for the parents, time out and it doesn't cost you anything. There are camps around like that but if you have to pay \$300 for a family. On a low income where am I going to save \$300? (Gerry caring for three children with autism aged 8, 7 and 6 years)

The introduction of the Companion Card in February 2007 provides an opportunity to expand social opportunities for people with disabilities including adolescents. Those unable to attend community venues or activities without support and who have a lifelong disability which will not improve can use the Companion Card to get free admission for a companion. This substantially reduces the costs associated with participation. Few families in the research however had heard about the initiative and if they had they did not necessarily consider that it applied to their own child.

3.3.5 Coping

Most families demonstrate enormous resilience in caring for children with disabilities and there are useful questions which can be asked about what coping mechanisms allow them to keep going. There are the range of both informal and formal support services which can bolster the capacity of families to care, but how do they perceive their situation? Interviewees spoke about not only the difficult things but also about the small successes or joys and of course about their attachment to their children. As one mother said:

These children open your life up to a lot of lovely things and opportunities. (Angela caring for Dean aged 7 with autism)

People say how do you do it, well we just do it, how does any parent do it? The negative of that is because we do it and don't complain easily, people think it is easy and it's not. We don't make a big song and dance about it because to us they're just our kids. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

They also appreciated the people they had met who had provided them with some support and enriched their lives.

We have met some beautiful, wonderful people through this. There are so many great people out there doing a great job. So that's the plus side to it, if there is a plus side. Make a Wish turned up at Christmas one year with that much stuff it was unbelievable. There are so many volunteers who give up their time for nothing while the politicians bury their heads. (Jill and David caring for Emma aged 7 with autism and Rosie aged 2 with cerebral palsy and epilepsy)

Many gained strength from knowing there were always people in a worse situation so they were lucky to be able to count their blessings.

It sounds bleak, life has got nothing much. But that's not how it is at all. I am lucky to have the life I have. I have reasonably healthy children that I love to pieces, I live in a beautiful part of Australia where a lot of things are for nothing. I don't have to cope with poverty and droughts and floods that people overseas have to cope with. I don't worry that my children will be shot when they walk out of the door. So there are a whole lot of blessings I have. Each week I have food on the table and the kids have a roof over their heads. (Gerry caring for three children with autism aged 8, 7 and 6 years)

We used to be why has this happened and be down in the dumps all the time. But the doctor said if it's not worrying Nick, look at him and you be the same and take whatever troubles. Since he said that we have all our troubles, we are struggling with unemployment, making the dollar last, plus medical needs. We are not on rock bottom but we are nearly there. We have these troubles but just laugh it off and get through. People say all the problems you've got but you're so happy and there's no point bitching or grumbling about it. People are not going to feel sorry for you, you have to make your own way in life. So we've done that. (Kath and Jack caring for Nick aged 14 with spina bifida)

3.4 Finding Out About Help

Given the demands of caring many families will require support to be able to sustain that care as their child grows. On finding out about the disability they may have a need for information about the disability or condition and treatments, information on benefit entitlements, on support groups and on practical help with caring for the child. How do families find out about what support might be available to them?

Two key points for accessing information are on discharge from the hospital and through child and family health nurses who have some level of contact with most families. Nurses conduct regular developmental checks during a child's first 18 months and may be the first to pick up on developmental delays. However parents described very diverse experiences. One mother who had a baby with Down syndrome had found things had fallen into place. Although a diagnosis of Down is not necessarily an automatic passport to services and depends on functionality she had had a relatively easy introduction to services available to her.

The hospital put me in contact with a lot of people, pretty much everybody. They let everybody know that he was born, the health clinic sister was notified, my GP, just everybody, Early Learning, St Giles and the physio. The hospital were excellent but it was a lot of information to comprehend at the time as well. So that side of things is really good. (Dot caring for Declan aged 8 months with Down syndrome)

In contrast other families reported great difficulties in accessing information and services.

She was in hospital for a month. We did have a social worker but she didn't do much, she didn't find out much at all. It was hard. We didn't know what to do, no services, we didn't know where to start even to see what we were entitled to. It has been very difficult to get anywhere. I don't know what's out there, it's so hard. (Jane and Mike caring for Lisa aged 4 with cerebral palsy)

Of course families are often under a great deal of stress and although they may be presented with information are unable to absorb it or make use of it. As one mother said:

Initially life was so stressful and scary and emotional that we honestly did not have time. We were in hospital all the time and finding out one thing and then another thing about her. She was fed every two hours through a nasal gastric tube and she would vomit all day and everyday. I can't even remember. It is all blurred. (Kate caring for Daisy aged 2 with cerebral palsy)

However what is striking is the range of experiences about how parents with a disabled child are given information about support services suggesting a lack of protocols or guidance for staff. Indeed the common experience for the majority of families was about having to engage in a constant battle to find out what was available to them and to get agencies and professionals to understand their needs. Getting help can depend on asking the right questions and services tend to assume that someone else will have passed on necessary information – the nurses, the doctor or Disability Services.

Tina was four before I even knew that there was a kindergarten for special children. In that four years I didn't know of anything. I wasn't even getting the payment from Centrelink. (A service provider) just assumed that Centrelink had told me and it was seven years I went without any payment. I knew nothing. I knew nothing about respite, about carers that can come into your house, how Tina could have been on a pension so we could have got things cheaper because we paid top dollar for everything. In the last five years I have found out so much more than I have ever known. I was a lot weaker person then and I would sit back and not question things. I didn't even know about a scheme for the nappies where you can get a bit of a rebate. (Viv caring for Tina aged 16 with a chromosomal disorder)

Practically all the families in the research had experienced a lack of clarity about where to access support, about the responsibilities of different departments and the decision-making processes involved. This had left them confused and frustrated. It had left them making numerous phone calls which got them nowhere. This situation was true for parents who had previously held professional jobs and found themselves disempowered by not having used services before and by more disadvantaged families who had lower expectations and fewer resources to access information and their entitlements. One mother described how she had got to the point of collapse before the functions of various government departments and the assistance she could tap into was explained to her.

We had a really good talk about what is expected of him (service coordinator at Disability Services). I wasn't quite aware of his role and what he could help us with. It's very unclear and unless you ask how do you know? This was in front of the doctor and he asked the question can you show me around the maze of disability services? So we learnt a lot that day. But I certainly think it needs to be clearer so people can understand and know where to go. (Kate caring for Daisy aged 2 with cerebral palsy)

We have really worked hard to find people who could help us but there is very, very, very little to access. (A service provider) has given us a little bit although nobody ever explained to us what services they have that we can tap into. (Di and Tony caring for Rowan aged 10 with Asberger's)

The Association for Children with Disabilities does produce a guide (ACD, 2004) which aims to offer a one stop shop for both families and service providers with information about services.

However it has proved difficult to keep it up to date and services have been reluctant to notify ACD to provide changes. Some interviewees had been lucky and had quickly made contact with an organisation, or an individual who had gone out of their way to put them in touch with the services they needed. But for most families the most useful source of information, and the source which they trusted over and above professional advice, had been other parents.

It wasn't through Early Learning that we found out, it was the fact that we were talking to other parents. Everything I've found out is through conversations with other families. We just found out about a holiday program they have for children with disabilities. We never knew anything about that and apparently they can go as soon as one starts school and Meg has been at school for two years. We just don't get enough information on what we are entitled to and I find as the kids are getting older you don't have that group thing anymore, like at Early Learning, so you get less information about things. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

The links between agencies aren't there and you hear about it from other parents, other people. Every now and again you come across a good person and you think great you've been so helpful but generally you've no idea what's out there unless you go out and make 100 phone calls and try to find it out yourself. It's very difficult and there needs to be some sort of central coordination. (Angela caring for Dean aged 7 with autism)

One father considered that this lack of information was a deliberate policy to ration scarce resources:

It's probably deliberately done that way because if you think of resources available if everybody knew you wouldn't get much of anything. If only twenty people know about a holiday program twenty people can fully participate whereas if two hundred know people miss out. So rather than releasing a book about everything you're entitled to state wide they say if only a handful know we have the resources. I can only imagine the expenses involved. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

The need to be proactive about finding out what support was available was daunting to many families. They found it very difficult to ask for help, either because they did not want to be seen as not being able to cope or because they were depressed and found it very difficult to do anything, let alone seek out support.

People don't ask for help because they don't like to be turned down, or seen as not coping. They don't like to be judged. Because I don't ask for help no one offers it because they think I'm managing fine but it's not like someone waves a flag and says this is where you can come for help. (Gerry caring for three children with autism aged 8, 7 and 6 years)

If I don't know the answer to something I will go and find it but there are probably a lot of people out there who wouldn't. If I was in one of my depression states I wouldn't. I know that for a fact. (Dot caring for Declan aged 8 months with Down syndrome)

3.5 Summary

Given the pressures of meeting a range of additional care needs and the strain this places on all family members what families wanted to see was easily available information about the full range of services, supports and entitlements available to them so that they could then take their own decisions about whether to use them or not.

As soon as someone finds out their child is disabled there should be a pamphlet, take it in your own time and read it, but this is all the things you're entitled to. (Viv caring for Tina aged 16 with a chromosomal disorder)

For us it's about knowing what services are available. That's the part that frustrates me. If there is something there for these children then we should know about it. The things that are available they don't tell you about. I heard the other day that you can get a house cleaner for an hour and a half a week and that's the first I've ever heard about it. I've been in many different environments for children with disabilities and I've never, ever heard of that before. We just need to know, whether we access them or not is our choice but we need to know they are there. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

What families found however was a dearth of information which left many struggling to cope with very little assistance.



4. Sources of Income

The research targeted low income families defined as households in receipt of a Health Care Card or Pension Concession Card. A person qualifies for a card if they receive Centrelink benefits and/or are in low paid employment. In our sample just over half the families were entirely reliant on Centrelink benefits and the rest received some income from employment. This section describes their experiences of accessing Centrelink benefits and of participating in employment.

4.1 Centrelink Services

There are two payments for parents or carers caring for children aged 0-16 years with disabilities. These are:

- **Carer Payment (child)** which is payable to those providing constant care to a 'profoundly disabled child'⁸ aged under 16 or caring for two or more children with disabilities. This is subject to an income and assets test and is currently \$525.10 per fortnight for a single person and \$438.50 each for a couple. It is possible to take breaks from caring for up to 63 days in any one year (for example when using respite services) and to do voluntary or paid work or study for up to 25 hours per week and continue to receive Carer Payment. This is in addition to any time the child might spend in hospital.
- **Carer Allowance (child)** is a fortnightly payment of \$98.50 which is not means tested and is paid in addition to Carer Payment or on its own. The child must be under 16, dependent and living in the carer's household and with a disability which is permanent or for an extended period. In addition the child must either have been diagnosed by a treating health professional as having as 'recognised disability' (a limited number of disabilities listed on the Carer Allowance claim form) or have had their functional ability, emotional state, behaviour and special needs assessed under the Child Disability Assessment Tool and been given a score of +1. This score indicates that the child has a significant physical, intellectual or psychiatric disability. As with Carer Payment a total of 63 days per year respite may be taken in addition to time the child spends in hospital without jeopardising the allowance.

Families in receipt of Carer Payment (child) and/or living on a low income can access a **Pension Concession Card or Health Care Card**. A Health Care Card is also available to children whose carers are in receipt of the Carer Allowance whatever their income. This entitles them to a range of concessions on national, state and local government services as well as some private sector concessions. If a child is assessed as having little or no functional disability under the Child Disability Assessment Tool but still requires substantially more care than a child of the same age without a disability they may also be entitled to a Health Care Card without their carer being in receipt of Carer Allowance. To qualify they must require at least 14 hours' care per week of additional attention.

⁸ 'Profound disability' as defined by Centrelink means:

- a severe multiple disability or medical condition requiring continuous personal care for six months or more where the child has at least three of the following: all food by tube, a tracheostomy, on a ventilator for 8 or more hours a day, faecal incontinence, unable to stand without support, requiring personal care at least twice between 10pm and 6am.
- a terminal illness
- a severe disability where a child aged 6-16 requires continuous personal care for 6+ months, where the carer's capacity for work is severely restricted and where the child engages in one or more behaviours listed in the Social Security Act i.e. repeatedly engaging in behaviour which is dangerous, aggressive or violent, sexually explicit or inappropriate.
- where two or more children together require a level of care equivalent to the level required by a profoundly disabled child.

Adult Health Care Card holders are the most financially disadvantaged group in Tasmania and unlike Pension Concession Card holders are ineligible for rates remissions, motor vehicle registration concessions, driver's license fee concessions and heating allowance⁹. Families were critical of these inequities.

If they made a pension card available to us it may not save on fuel but it saves on registration. That makes a huge difference. It saves on rates and taxes which gives you the extra to put into the home for your children. Someone who is properly disabled and entitled to a pension card can get all these community services but there's no community help available for anyone like Zoe because they don't get a pension card. (Tracey caring for Zoe aged 14 with a hearing impairment)

Once a child turns 16 the Centrelink payment system changes. Instead of receiving Carer Allowance (Child) parents are invited to be assessed for Carer Allowance (Adult) which is similar but with different eligibility criteria. Children will also become eligible for the Disability Support Pension or, if they do not qualify, for Youth Allowance. They may also be able to access Mobility Allowance and Pensioner Education Supplement.

4.2 Welfare Reform

From July 2006 the Federal Government implemented changes to encourage more people off welfare and back into the workforce. The reforms targeted people with disabilities, single parents and the very long term unemployed. They meant that sole and partnered parents who applied for benefits from July 2006 moved from Parenting Payment onto the lower Newstart Allowance and were required to seek part-time work for a minimum of 15 hours per week when their youngest child turned six. In recognition of the difficulties faced by families caring for children and for adults with disabilities the reforms included a number of modifications:

- parents caring for a child with an illness or disability have an exemption from mutual work obligations which would require them to seek part-time employment and are able to remain on Parenting Payment.
- a broadening of the criteria for the Carer Payment resulting in a five-fold increase in the number of parents eligible. In 2005 two out of three claims for the Carer Payment were rejected because children were not considered disabled enough.
- announcement of a review of the assessment process for payments to carers of children with disabilities in recognition of the difficulties in arguing about degrees of disability and the overwhelming nature of giving up work to care for a disabled person.
- from October 2007 an annual payment of \$1,000 for each child under 16 who qualifies their parent or carer for Carer Payment (child) and \$600 for recipients of Carer Allowance (child). This is in recognition of the additional disability related costs they face.

On the negative side applicants for the Carer Allowance, who could previously backdate claims for up to twelve months, can now only backdate claims for up to 12 weeks before the claim was made. There are concerns that these changes will have a severe impact on carers. They often do not know the payment exists for some time after the start of their caring responsibilities especially if they do not receive a Centrelink benefit already. It can also take a considerable time

⁹ A payment of \$56 per year to assist eligible pensioners with heating costs.

to obtain a diagnosis or ascertain the nature of any condition. This means many do not claim or delay their claim which can have a significant impact on their income. This was certainly true for a number of families in the research.

4.3 Experiences of Centrelink

Among the research participants 14 families were entirely dependent on Centrelink benefits for their income, five had some income from part-time employment and five from full time employment. Families were claiming a range of benefits including Disability Support Pension, Family Tax Benefits, Parenting Payment Single and Partnered and Child Support. In families where the child had just turned 16 the child was now getting Disability Support Pension in their own right and in some cases the Mobility Allowance.

When asked about their sources of income a number of families were confused about the names of the payments and unsure about what they got. As one mother said, 'I don't know what I get. It's in the bank and then you pay your bills, that's it. How anyone is supposed to understand any of the Centrelink stuff?' Two families emphasised that they needed help in dealing with Centrelink but that when they did have dealings with them they found them helpful and efficient.

However there were other families who reported considerable difficulties in their dealings with Centrelink. They complained both about difficulties in finding out about benefits available to them and then difficulties in the process involved in claiming those benefits.

4.3.1 Finding out about benefits

It can be several years after the birth or diagnosis of a child with a disability before a family finds out they may be entitled to Carer Allowance or Carer Payment. The demands of caring and adjusting to a caring role mean that families are poorly placed to investigate what benefits they might be entitled to particularly if they do not already receive Centrelink support. This means that the recent changes to backdating of the Carer Allowance may have a harsh impact on family income.

I got back dating on the Allowance and the Payment. I knew nothing. It was one of Tina's drivers. He said did you get that bonus money when everyone caring got \$1,000 and I went no what are you talking about? I said I'm not a carer and he said yes you are. I came in and rang Centrelink up and they said yes you should be getting this and that. This was only two years ago that all this happened. I had actually applied for it back in 1994 when she was four and Centrelink said no, I can't get it because Tina is not disabled enough. They didn't write me a letter or nothing, I just thought these people know. I left it and two years ago I went back to them and they said she should have been on this, this and this. Back then I suffered really badly from depression and I wouldn't have pushed anything. I believed everything people told me, I relied on people to tell me things and of course they didn't. Wouldn't you have thought back then that you could see that this girl wasn't coping, that she needed help? (Viv caring for Tina aged 16 with a chromosomal disorder)

I get Carer's Allowance for two children. The criteria for it is really hard to meet. No one told me about it initially. I didn't realise that for three years I could have got it. It was just one day by chance I was talking to a friend who has a child with a disability. Her child has cerebral palsy so of course they can get it. She said with autism and with

epilepsy that's not controlled easily you should be able to get it. I went and spoke to the paediatrician. She didn't have a clue, but said if I got her the forms she would fill them out for me. She did, sent them off and we got it 12 months ago. We wouldn't be able to survive without it. (Gerry caring for three children with autism aged 8, 7 and 6 years)

There were four families in the sample where both parents were involved more or less full time in the care of either one or two profoundly disabled children. They were very critical of the fact that they could only get one Carer Allowance.

4.3.2 Claiming benefits

Claiming carer benefits involves completing a claim form and getting a 'Treating Doctor's Report' for the Carer Allowance or a 'Doctor's Medical Report' for the Carer Payment. Any costs associated with medical examinations are covered by Medicare. Some families had doctors or paediatricians who understood the process and were good at doing the paperwork. Others were reliant on doctors who did not understand how to complete the doctor's report and who failed to detail the extent of care required by the child or the impact of the disability on the carer. These issues can be particularly prevalent when the child does not have a 'recognised disability' or a diagnosis or when the doctor is not well known to the family due to a recent move or change of surgery. This could adversely affect their application for assistance.

I am actually trying to get on the Carer's Payment. The doctor said I should be getting it because she needs full time care. They rejected it because the doctor wrote autistic and not severe autistic and autistic can just mean a little bit. So they said to go back to the doctor. But it's proof that she needs full time care because she's got two aides full time at school, so that's proof that she can't be left alone and I can't do certain things. It's supposed to be a hard payment to get. (Marge caring for Rachel aged 5 with autism)

We get the Carer's Allowance and I get the Carer's Payment. Because they are undiagnosed they probably wanted to know a little bit more information but the doctor said to us you will get it. It's probably hard when they are babies to prove but in her doctor's words she let them know that things weren't going to change and it was ongoing and in her medical experience she knew how to word it even though they were undiagnosed. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

I'm on Parenting Payment and Kath is on DSP and the Carer's Allowance for Nick. It wasn't difficult to get because he was born with spina bifida so we were lucky there. We don't get Carer's Payment. We queried that and they reckon he's not entitled to it, but I reckon he should be entitled to it because I'm looking after Kath and Nick as well, it's a full time job. When Kath went to the doctor's because she couldn't do much and I was doing half the stuff for her the doctor suggested I go off the Newstart Allowance which I was on and get the carer's pension so I'm caring for both of them. But when I tried to get it they reckoned I wasn't entitled to it so we've just battled on. So I was on Newstart and now I'm on the Parenting Payment. (Kath and Jack caring for Nick aged 14 with spina bifida)

Having a child with a 'recognised' disability listed on the claim form can simplify and speed up the application process.

I get the Carer's Allowance and I had to fight like blue murder to get it. If you fill out the Carer's Allowance form there is a lot of places they don't fit in. For instance they ask questions like can she do her own hair, or feed herself and there's only one section

in there that covers hearing so it's not an easy thing to get if your child's deaf. (Tracey caring for Zoe aged 14 with a hearing impairment)

It was just a form with the Down syndrome box to tick and that was it. Caden, my younger brother, was born without half of his jaw and his ear. But because it didn't have a classification on the Centrelink form mum couldn't get anything for him. He had his mouth wired up and only a small hole to put his feed in. Jason has got ADHD and all his mother has to do is hand over a tablet to him everyday and she got the Carer's Allowance. (Dot caring for Declan aged 8 months with Down syndrome)

Centrelink do not do any home assessments and some parents had been asked to bring their child into the office as part of the assessment process. This could be very problematic when the disability was severe.

To get them to believe you you have to take him in and say look bang what do you reckon. It's so much of a hassle to take him in. You have to get a wheelchair cab to take him down and take him back. We get a discount on it but it's still a killer. We've got a doctor coming here on Wednesday to assess Simon to fill out these forms. Then apparently once that's done and these forms are filled out by a doctor then we are going to have to see the social security doctor. But we are going to demand they come here because we can't go down there. They just expect you to grab him and do things like a normal child but you can't. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

What families found particularly frustrating was the fact that they were continually dealing with demands for information from Centrelink staff who, although they might have been benefit recipients for years, were unfamiliar with their case. This meant having to constantly repeat the same information about their child's disability which was frustrating and upsetting. They did not understand why they should have to repeat everything when it was already on Centrelink records.

I rang the other day to get someone to come out to help but she said I will help you go through the paper but we can't come out. We got to the end of the form and she said you can't sign in your name, Simon has to sign it. You have these doctor's reports saying Simon is not going to be able to do anything for himself and then you get things asking will he be better in six months, will he be able to work for 20 hours a week. One question was how many times has he run away from home? How many times has he fallen out of his wheelchair? (Sheila and Des caring for Simon aged 15 with multiple disabilities)

They will send me out a form for Tina to fill in. Can Tina fill out this and this? I've just been in there, said I'm her legal guardian and I will sort out all her payments. They say we will stop her payments. They don't think to look back at the history and see that this is what's happening with Tina. I didn't even know there was a social worker in there. If you're not happy with the decisions go and see a social worker. I said oh I didn't know you had one. Why can't we have the same person who knows about us rather than you're given a number and you have to go all over it again and sometimes I just can't be bothered. I have done it for 16 years and it sounds like a record. (Viv caring for Tina aged 16 with a chromosomal disorder)

This was particularly frustrating when their child moved onto the Disability Support Pension when they reached 16.

It took so long to get. I thought I'd give myself two weeks prior to her sixteenth to start the ball rolling. I knew she had to see doctors and this and that. I think it was nearly two months later she got it. She had to see the eye specialists and the doctors, get all those reports and I'm not sure whether she had one or two interviews with them and eventually they approved it. I thought already being a child with a disability I thought she'd go smoothly into being an adult one but it didn't. We just had to throw all the information that Centrelink had away and start again basically. (Sandy caring for Ellie aged 16 with cerebral palsy and vision impairment)

And there were families who were anticipating a battle at 16 to get onto the DSP rather than Newstart Allowance (if their child was not in education) even though they would continue to receive Carer Allowance. This transition to adult payments also throws up issues for families about how to manage their child's DSP particularly when they are unable to manage it for themselves. Parents can be nominated for permission to enquire about and to receive DSP payments on behalf of their child.

In July he turns 16 and that's when I will have to go and see Centrelink to see whether they can still pay his money into my money. His mind is like a three year old and if he had money he wouldn't know how. If he gets all his money people will just take advantage of him. He will buy a bottle of coke, pass a tenner over and not wait for any change. That will be a huge problem when he turns 16. Hopefully Centrelink can pay it into my bank and I can just give him \$5 or \$10 a day or whatever he needs. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

Centrelink do not monitor these sorts of arrangements and there is currently no requirement to keep the monies in a separate account or to retain receipts for any expenditure. Concerns have been raised about opportunities for abuse in the current system and Centrelink is currently reviewing the situation.

Families had also been given conflicting advice by Centrelink staff which further confused them.

Just the other day we talked to three different people and were given three different forms and I thought the lady I went to see knew everything about the disability thing. She told me I had to get a lawyer and become a power of attorney. I saw another bloke and he said no you don't need that form, you need this form. And then we saw someone else and they told me something different again. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

Some of the letters from them can be quite confusing and then you ring them up and they tell you one thing so you do it and then it's wrong. You ring the number again and you get someone else and they tell you to do something else. It's very confusing. (Kerry caring for Laurie aged 13 with epilepsy and Tim aged 12 with autism)

Lastly there were those families with some earnings from employment whose income fluctuated from week to week. This meant they had to constantly inform Centrelink about their weekly earnings. It could also mean that they lost access to the Health Care Card which had a big impact on their household budget.

You have to ring up all the time and say how much you've earned. They probably owe me money, I don't know. For three weeks my husband earned too much and they just cut me off. One week he earned nothing because he had to have time off for Dan and we had nothing. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

We did have a Health Care Card until very recently. We only miss out by \$80 a month in qualifying for it because of my part time work. It's made a huge difference because I lose more than that in benefits each month by not having it. But I had to be honest and if I was in a job where I could cut back those hours in a week so I could be just within the limit I would have done so but I have set hours. But I was eligible for it five years and never knew I was. So for five years I could have had help with my prescriptions, help with my doctors and I never realised. (Gerry caring for three children with autism aged 8, 7 and 6 years)

4.4 Experiences of Employment

It can be difficult to access and maintain employment while caring for a disabled child and this was reflected in the research. Research participants included five families where the father was in full time work with the mother at home as primary carer. However maintaining employment could be very dependant on having understanding employers and parents described the difficulties in dealing with encroachments on their working life from the demands of caring.

I have very, very good employers with regards to flexibility but as flexible as they are they roll their eyes occasionally and I end up working overnight shifts and things like that to make up the time. I was a store manager and they were totally inflexible. From day one I said to them I've got a disabled child, he's my priority. If anything goes wrong I'm away. That was the understanding right from the beginning. However putting that into practice, it just didn't happen. They would ring up in the middle of doctor's appointments and threaten me with the sack if I wasn't back in five minutes. It was very stressful. That's when we decided we were going to run our own business from home and be wonderful parents and look after our child. That was a good fairy tale and we went totally broke doing it. It was dropping off catalogues in letter boxes and we ran teams of people. Unfortunately the type of people you employ in that business, we didn't know there were so many dishonest people in the world. It left us totally flat broke, everything is gone. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

Some participants had had to give up their full time jobs to be able to cope with the demands of caring.

I was on paid full time work for a while. I was a departmental manager but issues regarding Dean's appointments for individual education plans, speech pathology and OTs, the staff around me and my manager basically got really agitated with the whole thing. So I cut back to part time work. I am currently on sick leave, unpaid sick leave, but which will soon turn into leave without pay. (Angela caring for Dean aged 7 with autism)

Doug had a full time job but he gave his work up three years ago to look after Tom because it was too much for me. He got suspended from school for ten weeks. I nearly had a nervous breakdown. Doug's boss wasn't happy and he had to give his job up that week. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

Parents barred from full time work because of caring responsibilities described the difficulties of maintaining part time work and the limited range of options open to them. Whatever work they took had to fit around the demands of caring. It often meant doing casual work or being self employed which gave them the flexibility to meet the needs of their child.

Basically I can only work school hours. I can't work the holidays, the kids are home so who's going to look after them. I have trained to be a teacher's aide because I know it's the only job really I can do where I'm at work when she's at school and I can have the time when I need to. I don't know of very many jobs where you can have those hours. I can work and earn up to \$200 before it affects my pension and I'll be getting just over \$200 with the work I'm doing. It's enough to give me a little bit extra to pay the bills but not too much extra that they take the pension away. If I lose the pension I have to make enough to survive on my own and that means I would probably have to work two jobs. I wouldn't get enough to make it easier to work full time and look after the children and have enough money to do everything with. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

I can't do paid work. You are expected to be there for certain hours, I can't do that with her. I was on maternity leave when she got sick and I went back to work for six months but it just wasn't a viable proposition. She has ear infections and has time off so I have to be self employed. I work on a contract basis and only get paid for the time I'm there, no sick leave, holiday leave or superannuation. If I want to take holiday I have to work heaps in advance to take two weeks off. So I've had two weeks holiday a year for the past nine years. It's all I get. Every contract is on the understanding that if I have to go in two minutes' notice I go in two minutes' notice. (Tracey caring for Zoe aged 14 with a hearing impairment)

Although wanting to work many primary carers were effectively prevented from gaining employment by the lack of flexible employment options and the demands of caring. This was compounded by their inability to use normal sources of childcare, like after school or holiday care, because of the severity of their child's disability and the costs involved.

I have no hope in hell of getting a job. I want to and I said to Mat what job can I get where I can have flexible days off? I have to be home here by 3.30 for Dan. The others are okay because they can go to after school care. But Dan just can't. There's just no job out there. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

Several families had been contacted by Centrelink about returning to work under the Welfare-to-Work reforms. This had caused some anxiety and even those who had not been contacted expressed concerns about the reforms and what the implications were for them.

When your child turns seven you have to work fifteen hours a week. So I was trying to see where we stood with that. She said as long as I can get a letter from the doctor stating Tess's condition and what not that I am exempt for 12 months and then they review it and you go and do it every 12 months. Because it would be impossible for me to work the way she is. So we are in the process of doing that at the moment, getting all the letters from the doctors just to prove that what I'm saying is true. They said if Tess wasn't classed as legally blind then I would have to go to work. I thought that would be a bit crazy especially as we go to Sydney every three months and if she gets an eyelash in her eye the school ring up and I have to go down and get that out. So it's 24 hours a day, not just school hours, it's all the time. She is legally blind but I have a file that thick of all Tess's notes and there was nothing in there that said legally blind. So she said you will have to get a letter from your doctor to verify that. (Winnie caring for Tess aged 8 with visual impairment)

I have had phone calls from Centrelink asking me if I would like training. I am already working two days and they say would you like to do more work and I say no, I've got a disabled child that I have to be home for at three o'clock. I have a boss who is really great and we have it all worked out so I'm home when Tim comes home from school and I don't have to start work until 9 o'clock or if I'm a bit late he's not worried. To put my boss on the spot to say I need more hours. My friend says Centrelink shouldn't be ringing me anyway because I've got a disabled child. I was just frightened because I've said no to them twice, they may do something to me. She says no, it's probably the computer rather than them. They must realise it needs to be very flexible if you have a child with a disability (Kerry caring for Tim aged 12 with autism and Laurie aged 13 with epilepsy)

If they ever tried to get David back into work I think I would die because having two disabled children the only reason I'm coping is because I've got David even though he isn't well. It's a two person job. (Jill and David caring for Rosie aged 2 with cerebral palsy and epilepsy and Emma aged 7 with autism)

Barriers to employment meant that most of those in the research sample lacked both savings and superannuation. They described how their savings had diminished since the birth or diagnosis of their disabled child and given the limitations on their ability to work how their superannuation was inadequate. This further disadvantages them into the future and promotes a life time of poverty.

4.5 Summary

Problems in gaining benefit entitlements or in participating in the workforce meant that many families in the sample had difficulties in maintaining a reasonable level of income. There were difficulties in finding out about what benefits they might be entitled to, in understanding the assessment process to determine eligibility and in providing the appropriate information. They wanted to see some consistency in the way their case was dealt with by Centrelink staff, a better understanding of the impact of their child's disability and the caring demands it placed on them and the option to have a home assessment. They also wanted to see Centrelink having a broader role in pointing people in the right direction to ensure they were accessing other services they might be entitled to.

They should make that carer's pension easier so you can just ring up and say you already have my details, you know what my child has. You shouldn't have to go through it all because it hurts and it's upsetting. It's finding the time to go and get the doctor and do the paperwork. You have to take the person with you and Centrelink don't understand that. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

My mother-in-law kept going back into Centrelink time after time after time when Tina was about two. Is there anything my daughter in law can get to help her with her daughter? No. They did not give out any information and one bloke at the counter even said to us don't waste our time and your money when I said are there other things we can get? Every time you go in there they only tell you about the thing you went in to talk about they don't say oh have you heard about the latest thing out, no. And then I'll hear about it down the track or through one of the other mothers at school. (Viv caring for Tina aged 16 with a chromosomal disorder)

Although there are some supports available to people with disabilities to enter the workforce there is nothing specific to assist primary carers to access or maintain employment. They wanted to see options available to them to combine their caring role with participation in employment, study and volunteer work rather than being condemned to a full time caring role and living on benefits for years to come.

I guess I wouldn't change her for the world, she's beautiful. But I'm a thirty year old woman and I'd like the opportunity to go out into the community and help part-time or at least have the chance to do some voluntary work, something. When its 24/7 you go mad, you really do, no matter how much you love that person. It is total selflessness and it's not acknowledged. (Kate caring for Daisy aged 2 with cerebral palsy)



5. Support with Day-to-Day Care

Given the care needs of many children with disabilities what help is available to families to assist them in meeting the day-to-day demands of caring and running a household? Services like childcare, respite, holiday programs and recreational facilities can play a vital part in ensuring families can continue to care and are not excluded from opportunities that other people take for granted. Carers require a flexible mix of services to provide ongoing support throughout the year which can change as the needs of the child and their family change. This section explores the range of support available and the experiences of families in accessing and using it.

5.1 Sources of Support and Help

There are six main sources of additional support with day-to-day care that families can draw on in Tasmania. These are:

- **informal support** provided by friends and family.
- **Disability Services** which aim to provide a gateway into both mainstream and specialist disability services for families. Although previously they were able to offer a case management service¹⁰ they now offer service coordination which ranges from one-off advice about where to go for assistance to intensive short-term case management for those with more complex needs. They have a resource team of allied health professionals providing specialist advice, assessment, interventions and education. They also offer centre based respite services, occasional holiday programs and assistance with meeting personal care and support needs above the levels which can be provided through HACC services. This is delivered through:
 - **short term support** to meet short term personal care needs with the expectation that any longer term or recurrent needs are met through HACC funding or by accessing an individual support package; and
 - **individual support packages (ISPs)** providing recurrent individualised packages of personal support and/or respite for periods of more than six months and for up to 34 hours of support per week. A major advantage of an ISP is that any unused hours can be carried over and used later or 'banked' up to a maximum of 50 hours. In some instances banked hours have been used to purchase essential aids and equipment which are unavailable from other funding sources. Funding shortages mean that this may not be available in future. Services can also be 'blended' so that a family caring for a child with a disability could have twenty five hours through an ISP, three hours of HACC funded domestic assistance and short term funding from the Carer Respite Program. Anyone can apply for an ISP but a shortage of funding means that in July 2007 there were more than 290 children and adults who had been assessed as requiring a package on the waiting list.
- the **Home and Community Care Program (HACC)**, a joint Commonwealth/State initiative which provides funding for personal care and support services to sustain people with disabilities and their carers in the community and to avoid premature admission into institutionalised care. The support offered includes personal care, home help, community nursing services and respite. It also includes minor home maintenance

¹⁰ Case management in the community care sector is a method of managing support provision to people with complex conditions or situations and includes assessment, case planning, implementation, monitoring and case closure. It is collaborative and client focussed.

and home modifications as well as some case management services and advocacy. It can cover transport for non medical needs and holiday programs for children with special needs. HACC services are delivered through a multitude of non-government organisations across the state. These organisations provide assistance with personal care such as showering, meal preparation, toileting, mobility and therapy as well as respite services.

The amount of personal care for any one individual is capped at 15 hours per week so it is difficult for the HACC program to meet the needs of families requiring more than two hours of care per day. A co-payment of \$5 is payable for one home visit capped at a maximum of \$10 per week regardless of the number of services or hours involved. Inability to pay cannot be used as a basis for refusing a service if clients have been assessed as requiring it. Non payment results in an exploration of the reasons and an offer to pay in instalments. Fee waivers are also considered and there is currently a lobby to remove fees altogether.

- **Commonwealth Carer Respite Centres** which are funded through the National Respite for Carers Program to assist primary carers to maintain their caring responsibilities. The support provided is flexible and can be tailored to individual needs. It can include respite, personal care and domestic assistance. There is a separate program for respite support for carers of young people with severe and profound disabilities. This has just received an additional \$6 million over the next four years to meet the needs of an estimated extra 1,000 carers.
- **Child care** available through family day care, centre-based care, playschools, after school and vacation programs which is, in theory, accessible to children with disabilities. In order to assist their inclusion support is available through the Commonwealth-funded **Inclusion Support Program**. This builds the capacity of eligible child care services (that is those which have childcare benefits) to include children who require additional support and employs facilitators to promote inclusive practice, provide information and organise inclusion training for childcare workers. The program is hosted and delivered in Tasmania through Lady Gowrie in the south, the Migrant Resource Centre in the north and Burnie City Council in the north west. The program has access to an 'inclusion support subsidy' (ISS) which enables the purchase of more support worker hours for individual children or of additional equipment for use in childcare centres. It also assists culturally and linguistically diverse and Indigenous children.
- **Other organisations** which represent the needs of people with particular kinds of disabilities or conditions. They may offer parent support groups and information sessions, limited financial support and case management services and assistance with fund raising for items of equipment. Disability Services also fund Advocacy Tasmania and the Association for Children with Disabilities to provide information and advocacy support to families. These organisations will support families by giving them information about their options, possibly accompanying them to appointments and/or writing letters and making phone calls.

5.2 Informal Support

Support from friends and family was obviously very important to a number of families in the research and a major factor in their ability to cope with the demands of caring. Mostly family members and particularly mothers but sometimes friends were involved in providing both emotional support and practical assistance like child minding, taking children to school, help around the house and generally being around to deal with whatever came up.

We're a really big family. Everyone helps me. I could ring anybody up. I can ring anyone up about going to Centrelink and talk about things. My daughter is really good too. I don't know what I'd do without her. If (the support worker) couldn't shower Andy, well she'd shower him, get the tea. She will wash him of a morning. I get a lot of help. (Janine caring for Andy aged 16 with cerebral palsy)

My mum and dad are rocks I cling to. They take the boys individually or on Saturday mornings when they are not at their Dad's and I have to work. My sister also takes Laurie because she's less confident with Tim, he's too quick for her. My friends, if I need a shoulder to cry on or a coffee they are happy to come up. One day when I was sick they came up with tea for the kids and things like that. My next door neighbours, they are great. Tim escaped a couple of times and I get a message on my telephone, Tim's outside. (Kerry caring for Laurie aged 13 with epilepsy and Tim aged 12 with autism)

However other families described a number of limitations on the amount of informal support they were getting. Family are busy with their own lives and do not necessarily have the time to help. In some cases there had been a lengthy process of adjustment among the extended family to the child's disability, to understanding what it meant and to dealing confidently with the care demands generated by the condition. Parents are also ageing and where they might once have been able to provide substantial help this was no longer possible, particularly when the disabled child was now bigger and heavier and possibly more demanding.

We find now that we are getting a bit more help and support from the family. Before we didn't. They didn't know how to approach the situation, they didn't understand. They probably thought we didn't need any help. Also the grandparents work in full time jobs and they have other grandkids. Some days you can be at the point where you're going to have a nervous breakdown with appointments and the pressures of it all yet I don't think the family really understood and I don't think they do now. Initially both families weren't really sure about special needs children and quite standoffish for a while so we had to be really independent ourselves. Because of that we appeared like we were coping so they were not really sure how to approach it. But there is always help there if you want it. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

The peg feeding I said to mum the nurses are quite willing to show you and dad and she said that would be all right because you never know they may have to do it. My brother's wife wouldn't. Dad will baby sit as long as he doesn't have to change any nappies and he can't lift Dan. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

My sister lives here and she's been a big help, she's coped in her own way. I think it's been really hard for everyone as well. She hasn't been great with Daisy as in helping me with her but she was a great support for me. I think she was scared. Daisy's epilepsy is

life threatening and that's a big responsibility for a person without any kids. In the last few months she's had her a couple of times for a few hours which is really nice and she enjoyed it. (Kate caring for Daisy aged 2 with cerebral palsy)

I wouldn't leave her with my grandmother now, it would just be too much to ask. She is a few years older now and when Claire drops I struggle to get her up and onto her bed when she's dead weight so there's no way grandmother could move her. My grandmother to give her a cuddle has to sit down now. Mum does a lot of shift work so she helps where she can. She has always been great with the seizures. (Sally caring for Claire aged 6 with epilepsy)

A number of primary carers in the research sample were unable even to rely on their spouse to assist them. Fathers who were working did provide support in the evenings and at the weekends and in six families both parents were full time carers. However in a further five households the father had some kind of disability which made it difficult for him to be of much help.

My husband with his ABI he has a problem with memory. It's not very good but if I make lists for him he's fine. He's quite capable of doing domestic stuff around the house and of looking after himself. But he doesn't cope very well with the children. If I'm not there it's too much pressure on him to cope with them on his own. So if for any reason I'm not there a carer would be there instead. She is 16 now and I don't expect him to be changing her nappy, that's too much to ask of someone, to ask a guy. And to shower her that's too much to ask so I do all those things. He can feed her and watch her if I go up the shop for ten minutes. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

All of these factors meant that families who participated in the research were likely to get less informal help than a family with non-disabled children. Much of the help they did get was rare or on an occasional basis and decreased as the child got older. This reflects the findings of other research. A survey conducted in the UK (Beresford, 1995) found low levels of support from the extended family and almost half of the families interviewed said they had no help. Some interviewees in this research got no informal support at all.

I get no support whatsoever from family so it's just me and Mike. We do everything ourselves. I have all my family here but they don't bother with her because of her condition because she can't walk. They just push her to the side now. The other kids are up and running about and she's not. They are all close but there is only one sister who will come up and see her on the weekends. That's about it. But she doesn't look after her or anything she just comes to say hello to her. (Jane and Mike caring for Lisa aged 4 with cerebral palsy)

5.3 Disability Services

Eligibility for assistance from Disability Services is stipulated in the Tasmanian Disability Services Act 1992 and depends on having a level of impairment which imposes substantial limitations and/or a need for continuing support to access resources rather than the type of disability. The Act targets disabilities that:

- are attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of these impairments;

- are permanent or likely to be permanent;
- result in substantially reduced capacity for communication, learning or mobility and require continuing support services; and
- may or may not be of a chronic episodic nature.

Historically support provided by Disability Services was primarily targeted towards people with a developmental or intellectual disability. However the eligibility criteria and access to services was broadened in 2000 to fully comply with the provisions of the Disability Services Act and it now encompasses a broader range of physical and acquired disabilities. If a substantial limitation can be demonstrated a family can receive assistance from Disability Services yet most families with disabled children have little contact with them. In 2005-06 a total of 1093 children aged 0-14 were recorded as having received a service provided or funded by Disability Services.¹¹ A count of the number of children recorded as clients of Disability Services in January 2006 identified 317 cases (Jacob & Fanning, 2006). Although these figures are likely to vary from day to day, they do suggest that at any one time Disability Services are in active contact with only a small percentage (6%) of the total population of children with severe or profound disabilities in Tasmania.

Some of the families in the research had either never heard of Disability Services or had never been in contact with them. These were families whose children had substantial care needs. There were also two families who didn't know whether they had been in contact or not. As one family said, 'What do you mean by Disability Services?'

Someone said to me I should be in touch with Disability Services because there are probably services there I could access. I don't think I know enough about it, what they offer, how to access them. I potter along as I am. (Gerry caring for three children with autism aged 8, 7 and 6 years)

I didn't even know there was Disability Services. We've mainly done it ourselves since he was a baby, we have battled ourselves. When we tried to find some help, nobody would help us. I tried to find a nurse or someone to help Kath when she was crook. I couldn't get any help and we just battled ourselves. I don't know whether that was a good thing or a bad thing but we've coped. (Kath and Jack caring for Nick aged 14 with spina bifida)

For those that had been in contact it was usually either to access respite services or to get assistance with accessing essential equipment like wheelchairs or to assist with planning their child's future once they left school. The extent of this contact had been brief and meant that the majority of families had been registered and then put on the 'self-managed list'. This means that unless they make contact with Disability Services it is assumed they are managing.

I don't really talk to them much. I only go through the coordinator for the respite. I used to have a case manager there but I didn't see him much. They're alright but I don't really know, they seem alright when you talk to them. (Marge caring for Rachel aged 5 with autism)

As Disability Services themselves said they tend to get more involved with the 12 plus age group when there are fewer services available to disabled children.

I've only just started dealing with them. They told me that for Tina to be turning 18 I need to go through them to help me get a group home. She finishes respite when she's

¹¹ Commonwealth State Territory Disability Agreement National Minimum Data Set 2005-06 Tasmanian 12 Month Data (2007) Unpublished.

18 and I needed to know what my options were and they said you need to be registered with Disability Services. I said okay who are these, another mob? They came out and did the paperwork. They are all right, I can't actually pick a fault in them. (Viv caring for Tina aged 16 with a chromosomal disorder)

Those who had more extensive contact had found them helpful and said they had been given good advice and passed on to other services.

We've had contact with them throughout his whole life. They were really good at the beginning. As he got older he got his own support worker who now is getting a referral for a psychologist which the school can't do. (Liz caring for Sean aged 12 with multiple disabilities)

It's only if I'm having trouble with Andy or worries with him I can always ring his coordinator up and have a talk to her. They are very, very helpful especially when I wasn't well two years ago. I was put in hospital for six weeks and mum had to come and look after the children. They helped mum a lot. (Janine caring for Andy aged 16 with cerebral palsy)

However frustrations were expressed with the limitations of what Disability Services could offer. There are continual funding shortages and the move from case management to service coordination had impacted on families coping with complex needs. Case management is now only offered for short periods of time and when the disability is critical or particularly complex and/or the family is falling apart and unable to cope.

We did have a manager from Disability Services for a while and she said they would get another manager for us but now he hasn't got a case manager. He hasn't had a case manager for about four years. It is better with a case manager because you can go and talk to them and they can explain to you what things are out there and they help you. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

I find them very, very frustrating. I have a service coordinator and I've had a lot of dealings with them. Years ago, when Dean was first diagnosed, I contacted them and they said that they couldn't do anything for us. They can coordinate help but when it comes to actual therapy or support or maybe doing things which will enhance people's lives it isn't in their charter. If you push them hard enough, like we did, we got some funding through them. The only answer you get out of them is we don't provide that service, we'd like to but we don't have the funding. I asked them if they could clean the carpets once and didn't get an answer back. They say is there anything we could do to help? All I wanted was someone to come in once to maybe help clean up the garden, help with things that had got a bit out of control. As I have a child with continence and behavioural issues which include spilling things on the carpet I wanted the carpets cleaned. I just didn't get an answer back at all, not even a no despite constantly asking about it. (Angela caring for Dean aged 7 with autism)

Once every 12 months they might ring. You try and ring them and it's hopeless. Something happened and I was desperate for them to help me and they never returned my calls. We have a good guy now but I don't hear from them. When it used to be case managers it was good then, they would do everything. Then they changed to service coordinators because they wanted the parents to do everything. Well some of us can't do it. I sometimes don't have the balls to ring someone up and say I want this, this and this, help me. I don't do that I just get on with it. Someone said the more you jump up and down the more you get but I can't be bothered. I think they are useless. I don't

even know why they are there. They don't do anything for us. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

Parents were critical about the absence of case management. They were also critical about the lack of consistency in response where the service they received appeared to vary according to the skills and commitment of the individual service coordinator.

5.4 In-Home Care and Support

Personal care and support is provided by support workers coming into the home and meeting the basic care needs of the child like washing, dressing, feeding and toileting. It can also include helping the child to access health, social and leisure activities. It gives carers a break from routine care needs and allows them to participate in other activities. Support hours are available through the HACC Program and/or through an Individual Support Package (ISP) from Disability Services. A number of families in the research classified this kind of support as respite because it gave them a break from care responsibilities. This means that there is a lack of clarity in the minds of parents around what constitutes in home personal care and what constitutes respite for families with disabled children.

All interviewees were asked whether they got any help in meeting the care needs of their disabled child in their own home. Seven families had some help – and one was in receipt of a recurrent support package or ISP. Two of these families also had additional domestic assistance to help with household tasks like cleaning and washing. Several families were very happy with the help they got, felt it was adequate for their needs, appreciated the ability to bank hours with an ISP and had good relationships with the carers. Indeed carers had become very important figures in family life generally.

Thursday and Friday afternoons someone comes to help in the house, with housework and doing Chloe's shower in the evening and helps her to eat her dinner and supervises her. They come at half past four and leave at seven. It's pretty good. My carer is fantastic, I couldn't live without her and she's become part of the family, she really has. We are such good friends and I really look forward to the day she comes. It's because it gives me someone else to chat to outside the family. She sees how difficult life is for us and is very compassionate. It's so nice to have someone who really cares about us. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

They come each night from 5 to 6.30 except Saturdays. They've been coming for 11 years. They shower him, they get him under there and wash his hair and they cook the tea. They usually do the washing up and sometimes they sit with him and make sure he eats. If I need to go to a doctor or anything or to go shopping I can ring them up and they will come. I have to let them know the day before. They take me out shopping from 1 to 3.30 on a Friday. I can book them to go on a trip down to Devonport and then pay them through my hours. At Christmas I go to my parents place and stay and so my hours go into the bank. I get 15 free hours a week and if I don't use them up they go into the bank. (Janine caring for Andy aged 16 with cerebral palsy)

However other families had encountered difficulties. Although the exact role and duties of a

support worker should be negotiated with the service provider families reported a lack of clarity around duties, unreliability and inadequate skill levels, shortfalls in support hours and difficulties in using workers from more than one agency.

We get eight hours one week and 12 the next. Their primary responsibility is Daisy and I've never asked for anything else. I guess it just depends on the individuals and what they do. One carer she would do the washing and help and it meant that when I got home I didn't have to do all that. The other is fantastic with Daisy and she will wash up but she won't do anything else. That's hard as well. With her I go home and I have the whole house to clean. Daisy sleeps a lot so during her sleep she could be doing other things. I don't want to have to ask or to say this would make my life easier. You are so tired and you don't want to ask anymore. You don't want to explain and that's true with family as well. They say if you need us you must ask but I'm so sick of asking. If I have to ask someone something else I will just cry. That's where I'm at. (Kate caring for Daisy aged 2 with cerebral palsy)

They would come each day and get him out of bed, dress him for school, give him his breakfast. It used to be two and a half hours. And then it started that they could only find someone to come once every second day and then sometimes it was only once a week. At the time we were working with the Disability Services and there were three other services we were using and we were here, there and everywhere with them all. So we talked it all over between us and worked out we just worked with the one service. (Janine caring for Andy aged 16 with cerebral palsy)

Some had been allocated support hours through the HACC Program but the agency was then unable to find a support worker and as the program does not allow the banking of hours they were then lost.

They are very disorganised and the hours are not enough. The first carer we had was very unsatisfactory. She came late a few times. She didn't like changing his nappies. She wouldn't lift him if he fell onto the floor. She wouldn't go downstairs with him if he wanted to go downstairs. The next one was a guy called John and the word hopeless would come to mind. If he turned up on time it was a rarity if he turned up at all. He put Tony into a bath one day for an hour to go to sleep. Another time he had him in the bath and filled it up with hot water. Totally, totally inappropriate. I spoke to them for weeks and weeks before we could get him replaced. You can't plan, you can't organise anything around the care. It's not reliable, you don't know whether it's coming or not. We are probably owed at least 20 hours of care and we just lose it, it never gets made up. I'm supposed to have eight and a half hours on top of a regular five and a half hours, they have just topped it up by three hours in the last month. However we struggle to get the five and a half hours because they just don't turn up or they turn up half an hour late. Our care on the North West was extremely good. If something happened and somebody couldn't come we usually got a phone call in advance and they would give us the hours we had lost on another date. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

One family with a profoundly disabled son were not receiving any hands on help with his care because they said they were unaware that they could access it and unsure whether their son would find it acceptable. Despite difficulties in managing due to the mother's disability they met all his physical care needs themselves:

Kath got bad one year and couldn't do it and we got a registered nurse to come in. That was all right but he didn't like it much, a stranger in his house poking and prodding him

about. She was good but he just didn't like it and we felt there was no point upsetting him. She was through the hospital and she came through the doctor. She came a couple of hours every second day and she would supervise his wash out. But you could see that he wasn't very happy with it. He prefers Mum and Dad to do it. Apart from that we have done it ourselves. If one of us is sick we just manage to keep going to do his needs and worry about ourselves later on. (Kath and Jack caring for Nick aged 14 with spina bifida)

5.5 Respite Services

Respite supports families by providing carers with a break from the demands of caring and can be very important in allowing families to continue to care for a child at home. Having respite can mean both planned regular breaks or respite in an emergency situation. As well as the respite offered by play schemes, child care services, school holiday programs and accessing personal care and support services there are a number of dedicated respite services for children across the state. These are:

- **centre-based respite services:**
 - in the South six beds for children in Hobart run by Disability Services. St Giles run a four-bed unit in Kingston for a small number of families. They are also considering establishing an additional centre in the region for adolescents.
 - in the north a centre run by Disability Services and an all year round centre run by St Giles. St Giles have also developed an adolescent respite centre.
 - in the north west four beds in Latrobe only open at weekends and a year round facility for adults and children run by Devonfield Enterprises.

There is no charge to use centres run by Disability Services but a small fee of \$6-12 per night is payable for other respite. Centre-based respite services can also offer day respite, extended respite (for stays of 14 or more nights) and emergency respite.
- **in-home respite** where a carer comes into the home or takes the child out is provided by a number of agencies across the state through the HACC Program and through Carer Respite Centres. The number of hours provided per week is capped at 15 and fees payable depend on income and are means tested. Working parents may also have to contribute to the transport costs of support workers.
- **hosted respite** is provided in the home of a host family usually for up to two days a month and for children aged 5 to 18 years. There are approximately 55 host families across the State. Fees are set at HACC levels or \$5 per visit with hardship waivers available and the host family is reimbursed up to \$130 for a weekend. Strong relationships and friendships can develop between the two families.
- **other respite services** include:
 - a respite house in Risdon offering occasional respite to young people under 21 years so that parents can have an evening out. There is also the opportunity to leave children at the house overnight and it can occasionally be accessed during the week if urgent overnight respite is required.
 - the Adelphi Centre run by Langford Support Services. This is a three-bed house adapted for the needs of children. It costs up to \$450 a day and it depends on the mix of residents as to whether it is appropriate for any one family.
 - services providing day time activities for children with disabilities at weekends

- and during the school holidays.
- St Michaels in the North providing congregate care after school or at weekends.
- the Carer Respite Centre which can broker other options for families on an individual basis.

All respite services aim to provide for a range of disabilities including autism, epilepsy and challenging behaviour. However resident mix can be a big issue and if services are asked to cope with children who are aggressive or violent or have particularly complex health needs they may not be able to do so unless they can get the funding to provide one-to-one care. This means that some families are less likely than others to be able to access respite when they need it. Many requests for respite are also urgent in nature where the carer, for whatever reason, is unable to care and requires short term support. This means that respite services are often and inevitably used in emergency situations rather than in a planned way.

5.6 Experiences of Respite

As many interviewees demonstrated respite or short breaks from caring have very positive benefits for both children and their families. It gives parents and siblings time to themselves away from the constant demands of caring. Parents were also keen to point out what they saw as benefits for their children of using respite services. These included opportunities to experience another environment outside the home, different activities and meeting a wider range of people and, for older children, giving them a break from their family.

Yet there can also be a number of barriers which parents have to overcome in order to use respite and other studies have found that moving from a diagnosis to being ready to use respite can be a very complex emotional journey for many people. Of course some families may not want to be parted from their children and do not feel they need a break but asking for help can also be seen as a sign of inadequacy or not being able to cope. Parents may worry about the effects of separation on their child. They may feel the child is too young or they, as a parent, don't need it enough. One big factor is not being confident about the quality of the care their child will receive and these fears are regularly fuelled by media reports of abuses in respite services. This means that concerns about safety combined with feelings of guilt and loss in using respite services can increase rather than reduce the stress families experience and undermine any benefits gained from using services.

I would never put him into respite and Sean wouldn't accept that either. He has grown this attachment to me in a way that none of the other children did. He just cries and cries for you and wants you all the time. It wouldn't work because you would take him out of his safety zone. If you put him in a strange place he doesn't want to be there. I would never shift him off to respite. I couldn't. I would be pacing up and down all night worrying about him. They offer weekend respite but I wouldn't do that to him, he wouldn't adjust to it and he wouldn't like it and would be very angry with me so it's not an option. (Liz caring for Sean aged 12 with multiple disabilities)

The only respite they've ever offered is at the respite centre. There have been some very disturbing reports come out of there and I don't feel comfortable sending him up there. The support workers, they've all said don't send him up there, this has happened and this has happened. He will be left in the corner basically to sit and watch TV for eight hours a day. He would be kept safe but they are not trained up there to deal with children with autism, even though they might have experience. (Angela caring for Dean aged 7 with autism)

All these factors mean that it can take a build up of exhaustion and difficulties before the family

are willing to use services and school holidays can often be the breaking point.

I didn't until this holidays feel I needed that much respite. But this holidays yes, I'm really exhausted. It's so constant that by the end of the day I'm stuffed. You can get respite once a month but I might try and save it up for the holidays in case these holiday programs don't work out and just use it a little bit – an hour a week during the holidays. Even if it's just for me to go and sit in the backyard and not have to worry about her for an hour. (Sally caring for Claire aged 6 with epilepsy)

This last school holidays was very tough so I finally bit the bullet and rang respite. I just sat down and cried one day thinking there must be an easier way. I just suddenly thought I'm just so tired I just can't keep doing this. My cousin has been saying for the last six years we don't want you ending up in hospital and I'd seen it as a real weakness. It came to the point where I'm sitting on the couch crying and I thought this is ridiculous, it's just a phone call to people who are ready to step in when it gets too much. It is a huge decision handing your child over to people you don't know very well. I got a lovely lady who's volunteered to do three hours a fortnight with Tim. It will be after school so I can take Laurie to the movies or out for tea or just go shopping by myself. I only pay \$5 a visit which isn't a lot but it means a great deal to me. (Kerry caring for Tim aged 12 with autism and Laurie aged 13 with epilepsy)

5.6.1 Centre-based respite

Families can use centre-based respite in three different ways: on a regular basis, in an emergency situation or to cover a particular event like a wedding or holiday. Eight families in the research had made use of centre-based respite and six of these used centres on a regular basis. Families are required to provide clothing, toiletries, continence aids, dietary supplements and spending money and also complete a personal profile. They also have to give written permission for any prescribed medication to be administered. If children are sick they are sent home.

Although parents highly valued the break from care demands they also voiced a number of concerns about services. These concerns have been well documented in other studies (SCIE, 2004) and were reflected in this research. Firstly accessing services can be complicated and require time, resources like telephones, good organisational skills and forward planning. Accessing those centres provided by Disability Services means registering with them and then ringing monthly to book in. Bookings can also be made further in advance for a wedding or a holiday. However some families felt they had to paint a desperate picture to get any priority and were not necessarily able to be articulate about expressing the extent of their need.

You have to ring on the first day of the month to get any respite. I did and was told somebody would get back to me and nobody has so we have no respite for April at all. So the whole thing is a shambles. So the main problem is you can only ring on that particular day. That's the hardest part because we are at the hospital on that day so we've missed out because they didn't ring back so we can't book now until next month for the month after that and that's hard. We are going to have him at home for the whole school holidays. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

Secondly parents commented on the availability and quality of respite. They were concerned about not being able to get it when it was required, the limited choice in the kind of care provided and inadequate levels of communication with staff particularly around feedback about incidents. They were also concerned about high staff turnover in centres which meant a lack of continuity in who they dealt with.

We try to have it on a weekend so we can do something with our other children, normal things, like just go fishing. But sometimes you just can't get in because they have so

many permanent kids and people just give up. There is also no guarantee when he's at respite that he won't be sent home cos when they go if there's an emergency they ring you to see if you could bring your child home so this other child can go in. It's happened a lot and we bring him out because you don't know the circumstances. They are supposed to always have an emergency bed. The coordinators kept changing and changing. You would talk to a different person each time. There are some really good staff members there but every time you go up you see different ones all the time. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

We only want a break once a month but he's not getting that at the moment, he's not getting anything. There hasn't been any funding so we haven't been able to get respite. We haven't had any for nine months. When he plays up there they ring us and send him home because they can't handle him there. We were going to an engagement party and he played up and they said they would take him and then they changed their mind. They didn't have enough carers on to take him. Next month he was crook and they sent him home because they couldn't take him anywhere because he was pooing himself. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

Thirdly a big concern for families was the resident mix and the implications for their own child's safety and behaviour particularly when they were higher functioning children mixing with those with challenging or aggressive behaviours. Concerns can be particularly acute for non verbal children and those on the autistic spectrum particularly in an environment where there are regular reports of abuse.

Not very long ago he was up at respite and no one can explain what happened but he had a big mark up here and no explanation, just that it happened between a certain time. There were a couple of kids there who were pretty full on. I reckon one of the kids ran past him and clipped him and left a mark. We were supposed to get a report on that but we haven't heard anything yet. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

I was so unhappy with it. It was disgustingly filthy. Daisy is two but there was the whole spectrum from two to 18 and the whole spectrum of disability. So there's Daisy non verbal, not walking, tube fed to an 18 year old with a mild intellectual disability. It's not the right environment and anyone else would agree but it's the only option. It just wasn't right. There were boys who swore. The staff even said to me I wouldn't leave my two year old daughter here. It just wasn't right and for that to be our only option. You would never come across that in any childcare centre. Why should we have to accept that that is reasonable? It's not fair. (Kate caring for Daisy aged 2 with cerebral palsy)

She goes one night a week. She used to go two nights but we've had a lot of trouble at respite and I mean a lot of trouble. We've had Tina actually bashed up. He was a very boisterous boy and he pulled her around and scratched her under her eye, in her ear. That was this year. At the end of last year I don't think there's enough supervision and a boy came into her room and pulled her nappy down and her pyjamas down and interfered with her. So I kept her home for three months and then I realised I needed to send her back. I have nothing nice to say about that place even though I still send my daughter there. If there was another place to send her she would definitely be gone. (Viv caring for Tina aged 16 with a chromosomal disorder)

Fourthly once a child reaches 16 years and goes onto the Disability Support Pension the costs of centre-based respite can increase and this was of concern to a number of families.

She will soon be too old for one respite centre so she will have to go to the other. I've already started to organise visits there so she gets used to it. It used to be \$5 a night until you reach 16 and then it goes to \$25 a night. It's a lot and of course Tina was going in two nights after school and then one Sunday every fortnight and that was \$20. But now it will be \$75. (Viv caring for Tina aged 16 with a chromosomal disorder)

To help with the transition into independent supported accommodation for young adults one service provider considered that there should be transitional respite facilities available where young people could stay for a week or up to three months to adjust to independent living.

Lastly there can be difficulties using centre-based respite during school time. It is a parent's responsibility to get their child to and from school unless there are special circumstances. If they do get assistance through the education department either with access to a school bus or a conveyancing allowance (see page 120) then this is only from home to school and vice versa. School buses are provided on a contract basis so any variation in route is at the contractors' expense which makes it difficult to change routes to accommodate a child attending respite. This can be a big issue for those who live in more rural areas and at some distance from respite facilities. It means that low income families may be unable to access respite facilities during the week when it is quieter and more beds are available due to the difficulties and cost of providing alternative transport to school.

Now she's at school it's too difficult. They sent me a taxi which is really silly because I still have to go in there with her and then I have to wait until 9 until she starts school and the carer is there. The taxi comes at 8.30 so I'm there for about 20 minutes. They won't get her to school from respite so I'm going to have to try and get a weekend stay and I'll still have the same problem on Monday. (Marge caring for Rachel aged 5 with autism)

Bed availability can be further reduced when children are abandoned in respite and become long-term residents until a permanent solution can be found. At the time of writing there were two children residing long-term in respite.

5.6.2 In-home respite

Although studies show that families prefer home respite to breaks in respite centres there are also a number of difficulties with support workers coming into the home and/or taking the child on outings to give parents a break. Some families want to remain in the home while they had respite. Others want the child to be taken out and about into the community. But like personal care and support services the two big concerns were the lack of clarity about what sort of tasks support workers could be expected to perform at what cost and the unreliability of workers.

In-home respite is just a nightmare. I half expect them to ring up and say your carer for this afternoon is not coming. You can't plan and even when they do come you find you have to be there to help them. Apparently they are not supposed to lift. The male carers don't mind it but the female ones won't do it, they have a no-lifting policy. Why have a no-lifting policy when most people with a disability need to be lifted? What would happen if Tony had a seizure and he fell over? Would they just leave him there until I got home? So it's just the unreliability. And you don't want to ring up all the time and complain. The in-home respite we get is supposed to be time to rest and do what you want to do. But when you have someone come into your home for an hour or two, you're getting your cooking ready or catching up on your laundry or scrubbing the

bathroom. You're not having a rest, you're working. It's not respite. In the north west his permanent carer would take him home and go to the fair and he became part of the family. Here one of the carers took him to the zoo and spent the day with him there and we paid for them to get in. And then we got a call a week later to say we had to pay for the transport out and back. We had no idea, no one told us we would have to pay. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

When children were taken out into the community by their support workers families cited a lack of venues where the worker could take the child as an issue. This was particularly true if there was bad weather or the child had challenging behaviours.

5.6.3 Hosted respite

Families were asked for their views about respite with a host family. This was an option which had been accessed by two families in the research and they had been very happy with it. It allowed strong and trusting relationships to build up between the two families and gave the child with a disability access to another family environment. This was important given the unavailability or reluctance of the extended family to get involved in providing informal support.

He has a host family every month on Friday afternoon after school and they bring him home on Sunday so that's a bit of a relief. They are very good. (Jackie caring for grandson Jake aged 6 with multiple disabilities)

A number of families expressed interest in the idea of host families but were concerned that the service could be difficult to access.

There's a waiting list for that and we are on there waiting. Do they advertise for families? For Dean I would love it if he went to two parents and children as well to socialise with. Him being an only child he doesn't have children to play with and when children come around he doesn't have the skills to interact with them. (Angela caring for Dean aged 7 with autism)

Host family programs emphasised the difficulties of making appropriate matches particularly for those children with very high needs or behavioural issues who required a certain kind of environment. Interestingly, although there is currently an undersupply of host families in the north and north west with an estimated 16 children with disabilities on the waiting list, there is an oversupply of host families in the south who are waiting for a match with a family caring for a disabled child. The reasons for this are unclear given the large unmet demand for respite. The anxieties families have about accessing respite generally may well be significant. All programs however saw potential for expansion and were considering promotional opportunities and opportunities for providing flexible options, for example after-school care during the week and using a number of families to collaborate in offering respite to high needs children.

5.7 Child Care and Holiday Provision

In theory children with disabilities have access to the full range of children's services including family day care, centre-based long day care, occasional care, after school care and vacation care services and playgroups. There are also a varied array of services to support young families but they are fragmented and patchy (DHHS, 2005). They include a range of programs providing practical assistance to parents, community support networks, programs for young children,

home visiting services and so on.

Access to child care can be very important in sustaining the family and employment and in preventing relationship breakdown, burn out and entrenched social and economic disadvantage. It is particularly important when the normal channels of relief – like playing with other children or care within the extended family – are not available and when families become very isolated. During holidays when schools are closed many families caring for children with disabilities find there is no support for them at all and the situation can quickly deteriorate. Few employers will allow parents to take all the school holidays off which means they are forced to give up working or try to change their hours so that they get no break at all. Respite providers report a big demand for respite during school holidays which they are unable to meet.

It can also be difficult to access holiday and after school programs after a certain age. Many only provide for children up to 12 years, or for children with disabilities up to 18 years. But including teenagers with disabilities in programs which are mostly catering for the under-12s can be problematic. Staff may find it difficult to change a large 14 year old or to incorporate a wheelchair.

We haven't got the luxury of holiday programs for Sean because he needs to be monitored and supervised. People cringe at the thought of having him. They haven't got the skills or the people. To put him into the holiday program they said no because they would have to employ two people and it would cost a fortune. Unless you have plenty of money behind you to employ two people you can't do it. (Liz caring for Sean aged 12 with multiple disabilities)

There is now a push to get more children with disabilities into childcare particularly given the benefits in terms of life skills and role modelling. Funding and assistance are available through the Inclusion Support Program so that child care centres and other children's services should be able to accommodate most children, although aggression and violence can be difficult to deal with. Many children are referred to Inclusion Support by child care centres when they fail to meet developmental milestones. To be eligible for assistance they need to have a diagnosis, be undergoing assessment or have access to a Health Care Card.

He has always gone into holiday care programs and after school. They will give you funding through Lady Gowrie inclusion service for one carer to be with them all the time but they are not trained and have no idea what they're doing. But they are better than the aides because at least they have had childcare training. But it is really only babysitting. It could be done better. (Angela caring for Dean aged 7 with autism)

There are a number of barriers to accessing child care services. Firstly the cost can exclude many families. Child Care Benefit pays a percentage of a family's day care or after school fees in an 'approved childcare centre'. It is income tested and the number of hours of child care for which a person can receive Child Care Benefit in any week depends on the type and amount of care required and the reason for needing it. A person whose child attends an approved centre can get the Benefit for up to 20 hours of care a week. A family can claim up to 50 hours per week if they are working or looking for work, studying or training, doing voluntary work or caring for a child or adult with a disability. However, even with the Benefit, a number of families in the research were unable to afford this care.

They were charging us \$27 every time she went. She was getting a couple of hours, it's not long. She did that for a couple of months but the cost was too much. They weren't adding it all up properly and putting us out of pocket so we had to run short because of it and that's not what you need. The care was good. (Jane and Mike caring for Lisa aged

4 with cerebral palsy)

It's prohibitive. It's the first time I've had to use it and to have my children so many days in a holiday program. I got the bill the other day and I haven't paid it and it was nearly \$700 for the three children – even though I get a good percentage. So I lost money and worked for nothing and actually had to pay out extra money from somewhere to pay the childcare bills during the holidays. (Gerry caring for three children with autism aged 8, 7 and 6 years)

It's \$18 a day for me at childcare so I couldn't afford two days and it's really good for her because it's a positive environment. I then got some funding through Carer Respite to cover another day for six months, a temporary thing until we get a bit more permanent. So now I get from 10 to 5 Wednesday to Friday. Obviously we have appointments so sometimes she goes for half a day. (Kate caring for Daisy aged 2 with cerebral palsy)

Family Day Care is cheaper but as they are working from home few carers are willing to take children with disabilities as it can impact on their income. The additional needs of the child reduce the number of children they can care for. The Inclusion Support Program cannot cover the costs of an additional worker in a private home although it can provide excursion funding and training for carers.

It took ages to find family day care for her to look after her and then when they got one she would only look after her for two hours. By the time I got over there and back home I had to go straight back and get her again plus I was paying for it. So I thought what was the use of that? Centrelink was paying most of it and I was paying about \$40 a week. (Marge caring for Rachel aged 5 with autism)

However the main barrier for many families is not being aware of the Inclusion Support Program and assuming that their child will be too difficult or not welcome in services. It had involved some families in a long search to find a service where they were happy with the quality of the care and which was willing to take their child.

This year it just came to a head and I needed some time out so I went searching for a childcare centre that was happy to take her on board. That was a bit of a mission. A lot of people they weren't willing to treat her like a normal kid. She went to one centre and she didn't have her nappy changed and she was in the same seat all day. It was really disappointing. I found this childcare centre and they are gorgeous. They just love her and nothing is too big and it's given me faith again that there are nice people out there. I was up front and told them everything and they said let's do it, it sounds great. I rang lots and lots of centres. A lot are full. (Kate caring for Daisy aged 2 with cerebral palsy)

Holiday play schemes and camps which can incorporate children with disabilities are very welcome to parents and although provision is not consistent across the state there are a number of programs available. Some require a parent or carer to attend, others can provide a high enough level of care to give the parent a break. They include:

- **HACC funded school holiday programs** taking those with the highest needs and providing a program of activities where a family member also has to attend.
- **holiday programs run by Disability Services** providing outings and activities up to two days per week during the holidays.
- **respite centres and day services** offering additional day time activities and overnight stays during the holidays.
- **non-government organisations for particular conditions** or disabilities offering

holiday camps, for example, the Epilepsy Association.

Parents who had used holiday programs emphasised the benefits and how important they had been in helping them to cope. They provided a break, an opportunity to do something as a family, emotional support and generally refreshed them so that they could sustain the levels of care they were providing.

The holidays are a real hole for us so the program just provided a little bit of structure and got him out doing something and gave us that chance to have someone else organise something that we weren't totally responsible for. It gave us a little bit of respite. But now it's such a popular program that we don't get nearly as many activities as we used to. This holidays we got three activities a week. Because we don't have family down here or any other support if they've got spare places she slots us in. That is the only break that we've got down here. (Di and Tony caring for Rowan aged 10 with Asberger's)

Finding out about the holiday program was great. We only found that out from another parent, it's all word of mouth. For us with two in wheelchairs and Bradley it was hard to get out. But they had people there who met you at the car. For a family of five to go for a swimming lesson it wouldn't be cost effective but to have that offered, it was fantastic. We thoroughly enjoyed being able to get out. For us to pack up the car and drive to the beach, it's not worth it, but having people there to share the load. Whatever you do they actually have people there to take the kids for you and you can sit down and talk which is good. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

To me my respite is twice a year when I take him to Melbourne to muscular dystrophy camp. That is my break and I love it. Muscular Dystrophy Tasmania have sponsored Dan twice. They don't have to find a carer for him because I'm there. This time she did ask me did I want a carer and I said what about me and she said go and do something else but I won't because I like being with the guys. It's my counselling, I like being there and talking to them and having a good laugh. I enjoy it. I'm with people who understand and who know. I say I don't want to do this anymore and they say get over it and it's nice because they are very straight with me. I prefer for someone to say get over it, tomorrow is different, than someone go okay, do you need this, this and this. No I just want you to say shut up get on with it. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

5.8 Support Groups

Parents may be in touch with organisations representing the needs of people with particular kinds of disability or conditions. These organisations can provide information about the condition and the services available, workshops and forums on a range of topics and opportunities to make contact with other parents of children with similar disabilities. Some offer case management services, referrals, and limited financial assistance to purchase specialised equipment or to meet other needs. While there are those which focus on rare and unusual disabilities and rely on email networks others operate very proactively and as soon as they hear of a diagnosis will make contact with the family. However many rely on word of mouth or on health professionals to refer families to them. High rates of staff turnover particularly in hospitals mean that this often does not happen.

Research clearly shows that informal community support and the sharing of ideas and information with other parents can be critical for parents with children who have additional needs. However it also shows that only one in three families belong to a support group and that those in lower socio-economic groups are less likely to join them or to be in touch with organisations. This means they may have little contact with other families with children with disabilities and certainly not with children with the same kind of disability.

Some of the interviewees were in touch with these organisations and had got a great deal of support from them. They provided them with most of the information they needed about services as well as providing more practical and hands-on support.

Of all the groups I've been to they are for me. She goes way out of her way. She takes us to our doctor's appointments because I don't drive and the buses are too much. She takes us to rehab now. It's a big help. Officially I've been in touch with her since the middle of 2005 when she started having interaction with the school. She came in and explained to the class because everybody freaked when Claire had her first seizure. They didn't understand. She did it again last year for the four new students and a number of times with staff and older children in the playground. (Sally caring for Claire aged 6 with epilepsy)

People were glad to have additional information about particular disabilities and conditions and welcomed opportunities to meet other parents coping with similar situations at meetings and camps.

We have just found a support group for parents with kids with Severe Myoclonic Epilepsy of Infancy, SMEI. I had been looking up support groups for parents with epilepsy and wondering why I wasn't getting anywhere. But there is such a broad range of epilepsy. And this will be more helpful, talking to other people in common situations. (Sally caring for Claire aged 6 with epilepsy)

We go on Camp Clayton. They can explain different ways to control the seizures and it's good for us to meet with the other families and get ideas from them. If we pay full price it would be over \$200 but half of it's funded by the Carer Respite Centre so it's \$60 per person and we all go. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

Some organisations will put on workshops and invite guest speakers and experts to present information about aspects of a disability. Fees may be charged. There may also be an expectation that parents participate in organising meetings and speakers. A number of families in the research found that they just did not have the time, the energy or the money to attend meetings and it was impossible to find babysitters.

You have to pay for membership for those things and then have the time and the petrol costs to go there. (Tracey caring for Zoe aged 14 with a hearing impairment)

You need that place you can go to talk to other parents who can offer you support and someone who organises regular meetings. At the moment it's left for us to do it ourselves and we're flat out with our kids. I don't feel like I've got the time to organise a guest speaker to come in, organise venues and all these things. That makes it really, really difficult for parents to meet. If you had a paid coordinator who could do that as part of their job. (Di and Tony caring for Rowan aged 10 with Asberger's)

They bring down professional speakers about the latest research and if you spend \$300 on this package, you can try out this computer program or these visual aids. A lot of it is business based, there's a lot of money in disabilities especially when you have parents reaching for some help. They get trapped into a situation where they think that might be a good investment if I spend \$1,000 on this computer program. It's very hard to pay that money when you don't even know if it's going to work for your child. (Angela caring for Dean aged 7 with autism)

What they found more useful was having other parents to talk to. However as this mother pointed out, being able to join a support group requires parents to have a certain level of acceptance about their child's disability.

You can get quite lonely as the parent of a disabled child. I don't go to meetings because it's too hard but they have a camp and they took him under their wing the last two to three years. They gave me the number but you are always a bit iffish about ringing them, about what they expect from you rather than what you expect from them. What do I need a support group for? In the early stages it's always maybe there's a mistake. You can ring them up about conferences or coffee mornings. A whole group of us were having difficulties getting to these coffee mornings so we started up our own and she helped us to do that. Just getting together and having a coffee and talking about our own experiences, it's invaluable and to know you're not alone. (Kerry caring for Tim aged 12 with autism and Laurie aged 13 with epilepsy)

A national program called MyTime is now expanding support groups for families caring for children with disabilities. During 2007 it is intended to establish 80 local groups across the country in partnership with family and parenting services with 315 over the next four years. Each will have a facilitator, a play worker, and provide information about services. They will be open to all those in receipt of Carer Allowance and cater for the range of disability. As one mother pointed out this would be very valuable:

There's all the support groups, epilepsy, autism and the prem babies have their support group. But it would be nice to have one where no matter what the disability you go through the same process. When you're in hospital you should be given information about support groups who can provide all the information you need, a friend to talk to, someone to cry on. There is none of it and it's not good enough. You have people going home and they can't cope. You need to put people in touch with more people. It would be so beneficial to so many people. (Kate caring for Daisy aged 2 with cerebral palsy)

5.9 Coordinating Services

In assessing the support available to assist families caring for disabled children, both parents and service providers regularly commented on the complex and fragmented nature of the service system and the lack of coordination between services. A failure to address a family's needs holistically leads to a general service system failure where there is no way to link the services they require together to provide a coordinated package of support and up to 80% of families report poorly coordinated services (SPRU, 2004). The onus falls on parents to find out what is available and to access it, to understand the roles and responsibilities of different agencies and the eligibility criteria for services to get referrals for specialists, to arrange appointments and to do the best they can even though they may be worn out by the demands of caring. All of these demands aggravate stress levels sometimes to crisis point and families fall through the gaps.

One family described a lack of coordination even within the same department:

For some reason the referral got lost between Disability Services on the north west coast and Hobart. I was getting hours but they couldn't find anything about it when we moved down here so I actually lost hours. They lost the paperwork about the funding. Realistically we moved from the North West Coast of Tasmania to Hobart but we might as well have moved from the North West Coast to Antarctica. The communication from the top end to the bottom end is hopeless. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

Service providers commented on the wider implications of this lack of coordination whereby, because services were not seen as part of a comprehensive integrated service system, changes were made to some without anticipating the impact of these changes on others. For example Children's Therapy Services in Southern Tasmania have been contracted out to the private sector. This means that they are not involved in any state agency coordination meetings even though they are primary providers of community based care for families. A report by Disability Services (DHHS, 2005) noted 'considerable difficulties are encountered in managing the needs of children with disabilities across the range of programs and agencies and in meeting the expectations of families, advocates and the community.' They suggested that collaborative service models should be developed with the Department of Education and with the Children and Families Division in order to improve the situation.

Research has clearly demonstrated that families with disabled children want one point of contact with services which will provide them with advice and information about any issue they might have, ensure they get the support they need and avoid the endless repetition of information that so many have to endure (Parliamentary Hearings, 2006). Families who have care coordination¹² report better relationships with services and higher satisfaction levels, fewer unmet needs or feelings of isolation, better morale and less stress. Yet very few families in Tasmania can access this kind of support and if they can it is usually only for a short period of time or in an emergency or crisis situation when the family is in danger of falling apart.

Service co-ordination and case management may be available to a small number of families from:

- **Disability Services.** who provide 'service coordination'¹³ rather than case management which does not necessarily build a relationship with the family or offer proactive planning.
- **HACC funded agencies** providing personal care and respite. Yet few are specifically funded to provide case management services which means they perform this role by default.
- **Children's Therapy Services.** Again therapists and social workers will provide short term case management by default and perform a key working function for some families.
- **Association for Children with Disabilities (ACD).** ACD does some short term case management when advocating for clients. It has also started to perform this role for a small number of Motor Accident Insurance Board clients aged under 24 years. This allows advocates to input a significant amount of support over an extended period of time. They would like to see this level of support available to a wider range of families.
- **Support groups** for particular disabilities. Some families are getting significant amounts of assistance from support group staff who have 'taken them on'.

¹² Although there is no precise definition care coordination generally refers to a model in which someone manages the coordination of care and support so that services from different agencies are coordinated, individually tailored and monitored based on an assessment of need.

¹³ Service coordination ranges from one-off advice about where to go for assistance to intensive short-term case management for those with more complex needs.

There is now a DHHS-wide collaboration strategy with key coordinators in each program to coordinate departments, link families into the range of services available to them and identify a primary lead. It aims to promote a culture of collaboration among service providers and is accompanied by a Training Resource Manual which outlines the skills required for effective collaboration work. This strategy focuses on picking up complex clients who require services across different sectors and providing coordination, collaboration, case conferencing and, if the need is exceptional, a referral to the Board for Exceptional Need which is able to establish policy precedents. The main entry point for children with disabilities is through the acute health system; for example if a young child was unable to leave hospital because their support needs in the community had not been met. Since 2004 the Board has dealt with 31 complex cases including children with disabilities and child protection issues.

One service model which has been attracting interest is Local Area Coordination (Disability Services Commission, 2003). This was established in Western Australia in 1988 as a way of supporting people with disabilities and their families in local communities so they could continue to care. Each Local Area Coordinator works in a defined geographical area corresponding to a known number of people with a disability and providing one point of contact with services. The average caseload is 50 families. The Coordinator works with the individual, the family and the community and combines elements of case management, personal advocacy, family support and community development. This might include building the capacity of the extended family to provide informal support as well as advocating with specialist disability services or providing general information. It is a dual role of supporting individuals and families and supporting the development of inclusive communities. Coordinators also have access to a small budget which they can use for discretionary one-off funds as part of a support strategy to meet the additional costs of disability. In 2001-02 this model cost approximately \$3,800 per service user and subsequent evaluations have identified value for money, effective outcomes in terms of service coordination and case management and high levels of satisfaction among service users. The model has now been adopted by Queensland, the ACT and Scotland.

5.10 Adequacy of Support

Families have different capacities to manage stress and sustain care and there are a complex range of interacting factors which influence their ability to cope. These include the severity of the disability, the age, size and behaviour of the child, the availability of informal support, the impact on siblings and access to respite opportunities. Stress levels can rise at times of transition from hospital to home, from Early Learning to school and from school to adult life.

Interviewees were asked how adequate they found the support they got with their caring responsibilities. Although some said they got enough, the majority felt that they were struggling to access adequate levels and the lack of respite and particularly in-home respite was one of the biggest causes of dissatisfaction with service provision. It is difficult to estimate the unmet need for respite because services are usually able, if only in part, to meet the visible demand and they do not keep records of those who may be waiting for a higher level of service. Those who ask will get some level of service but there are many who do not ask, not because they don't need it, but because they anticipate being turned away or have concerns about the quality or appropriateness of care. This unmet need is likely to be significant but because it is not quantifiable it makes it difficult to justify an increase in provision.

I know everyone out there needs respite but I know mothers who just won't send their child there. They need respite really badly but they just won't. And it's getting to that

stage now where I'm just feeling the same way. I like to come home and feel that she's safe. (Viv caring for Tina aged 16 with a chromosomal disorder)

A number of families described instances where their situation had spiralled into crisis due to inadequate help and their inability to cope any longer with their circumstances.

I had a bit of a breakdown, a melt down and now I'm on medication. They put Daisy in hospital for five days because I just couldn't cope. They were all there, my doctor, Daisy's doctor, the Disability Services coordinator, Early Learning, the whole support team that had been helping me. I took her in Wednesday night and on the Friday they got really busy and said I had to take her home but I just said I can't take her home and it was horrible, really horrible. I think at that point everyone started to realise the enormity of what was going on. Sometimes you just don't know who to turn to. Even filling out forms when you're exhausted and you can't think. Who can help you with this? So I had to find this out the hard way basically. It could have been prevented by more support across the board, definitely more in-home support. (Kate caring for Daisy aged 2 with cerebral palsy)

I nearly had a nervous breakdown. He got suspended from school and got brought home. I said I'm going out to the clothes line to get the washing. Well first he took to his little brother with a pair of scissors. I ran in and grabbed the scissors and put them away. Then he got a sewing needle and he was going up and down his little brother's arm so I took the needle off him. Then he went in the kitchen – he was twelve and a half at that stage – and he got a carving knife so I had to wrestle him on the floor to get the carving knife off him. I said we are going to have to do something because you are going to end up killing your little brother. I rang Doug at work and said look that's it, you are going to have to have him because I can't. I brought him down to work and left him there. The doctor wrote a letter to say he could no longer work because he was needed to help care for severely disabled child with challenging behaviour as the mother can no longer cope and is on the borderline of a nervous breakdown. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

As this mother said if she could have accessed help sooner her husband might not have had to give up his job to help:

If there had been support earlier, it wouldn't have happened. It can be very stressful at times and very challenging. If I could have gone and got someone to help so I didn't have to say look Doug you have to give up work but there was no information about where to go. That was the killer. I have days where I just can't cope and where I just have to take off and run. If Doug isn't home I have to ring around and get somebody to have him or be here so I can just go. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

There were also those families who, although they had managed to stay on top of their situation, were very aware of how easily things could spiral out of control. For some people it was about knowing that as a last resort there was some safety net there so they could get a break when they got desperate.

If you've had enough when you drop them off at respite don't pick them up because there is nothing they can do. They can't forcibly or physically make you take them back

and they certainly can't drop them off and take off. When Dan did go to respite there was a little boy there who lived there because his parents didn't pick him up. Then I used to think that was terrible but now I can see why. You do get to the stage – we make sure we don't get to that stage – but you can get to the stage where I've had enough, I don't want to do this any more. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

Some children with disabilities are placed in State care because their parents are no longer willing or able to look after them. As one service provider said, the combination of challenging behaviours, low income and a lack of support can be a recipe for disaster. Disabled children are over-represented in the population of children in care and among those where there is a care and protection concern. There are also cases where children have been abandoned in respite, where the parent has not relinquished guardianship and who then need to wait for a foster family. The disabilities with the highest risk of abandonment are autism and challenging behaviours which are particularly stressful for carers. As of January 2006 about one third (36.9%) or 117 of the disabled children known to Disability Services (approximately 300 children) are also known to child protection services (Jacob & Fanning, 2006). This group includes 25 children on care and protection orders or voluntary care agreements. This number is probably an underestimate as there may be children involved with child protection services that have a disability but who are not clients of Disability Services. A recent review of child protection services in Tasmania suggests that some disabled children taken into care come from families who would have been willing and able to maintain guardianship and custody of their children had appropriate support and respite been available on an ongoing basis. Others perceive the only way to get help is to request that the State care for their child.

A recent project¹⁴ examined the interface between Disability Services and Child and Family Services in relation to these children and developed a policy and protocol for service provision to this group and for departments to work jointly with these complex cases. The project also aimed to disseminate tools to staff about early identification of those at risk and how to work with them.

5.11 Summary

¹⁴ Child and Family Services and Disability Services Interface Project. DHHS 2006-2007. Unpublished.

What families need is on-going, reliable support with their child's day-to-day care and this can be critical to the family's functioning. Without it the additional strain and the impact on jobs and relationships can push a family into crisis. What too many families in Tasmania experience is minimal information about what help is out there and inadequate support levels. National figures suggest that 26% of families caring for a child with a severe or profound disability only have informal help (AIHW, 2006). Extrapolating this figure to Tasmania suggests that there are 1,250 families in the state managing without any assistance at all from formal services. A disability has to be very severe for the family to get five hours support per week and services struggle with a lack of funding and difficulty in recruiting suitable carers. So many families would benefit from having one point of contact with services or a key worker but so few can access this kind of assistance.

Respite in all its forms – through informal help, respite services, childcare and holiday provision – can help to alleviate the strain, particularly for those caring for children with severe, multiple disabilities. Yet all families could do with more respite and there is a need for choice, flexibility and services of a higher quality. As one mother said:

They should offer every family a holiday three times a year just so everyone could have a break and feel more refreshed. People just give up and drive themselves to the grave. (Jane and Mike caring for Lisa aged 4 with cerebral palsy)

An examination of the future of community care in Australia (Allen Consulting Group, 2007) has pointed to the urgent need for reform of community care services across the board and explores strategies to improve the availability, responsiveness, flexibility and quality of what is provided. It advocates for a commitment to early intervention and prevention to prevent crisis situations and increased access to case management, respite, consumer directed care and to information about services. It points out that these initiatives would need to be accompanied by workforce strategies to ensure a sustainable workforce in the community care sector.

There is also a lack of research in this area which can provide concise estimates of the unmet demand, information about the large numbers of people who do not use support services and the costs and benefits of different service models. These gaps in knowledge lead to inaction or inappropriate action by policy makers. Meanwhile families continue to struggle for survival.

When you say 'at risk' people think of abuse and neglect but families are at risk with children who have 24/7 additional needs and those families may not ever come to anyone's attention that they are struggling until a crisis hits and then suddenly everyone is in on them. Everybody is taking the kids away or doing this and that but it's too late then because then what you're left with is a parent who has been struggling and is already feeling bad struggling on their own thinking I must have done a lousy job, they've taken the kids away. A lot of parents have a hidden fear that if they admitted to anyone that they are struggling or they admitted to anybody that things are tough they would be worried that it would be seen as a bad reflection on their ability as a parent rather than a reflection on the additional parenting resources they have to find to support their children. (Gerry caring for three children with autism aged 8, 7 and 6 years)

I would like to see families not give up but if there are no support services out there most people get depression. I've been through depression. If we can look after a

child like this hopefully other families can. We do everything ourselves, 24 hours a day, everyday. We are on our own, no support. It's hard. We just take it in turns feeding her, looking after her. We argue with the stress. Other families out there just give up, their marriages break. They end up in homes or go right down hill. There are a lot of people who are too scared to get what they're entitled to. (Jane and Mike caring for Lisa aged 4 with cerebral palsy)



6. Aids and Equipment

Aids and equipment can support a child's functioning, maintain or restore abilities, improve independence, prevent physical deterioration and reduce the risk of injury to carers. They can also be important tools in promoting the development of children with disabilities and developmental delays and allow them to more fully participate. They can range from wheelchairs and other mobility equipment to hoists for lifting and showering, bathing, toileting and continence aids and communication equipment.

Unfortunately the cost of equipment can be very high and Australian research has identified high levels of unmet need. The majority of families have unmet equipment needs and typically where relatives provide childcare they do it without the necessary equipment (SPRU, 2003).

6.1 Sources of Assistance

There are a number of schemes in Tasmania which provide financial subsidies and help with items which would otherwise be beyond the reach of most families. However the rules and processes involved in applying for assistance can be complicated and services are stretched and under-funded. Sources of assistance include:

- the **Community Equipment Scheme (CES)**. This operates under state-wide guidelines in each of the three regions in Tasmania with the aim of facilitating the discharge of people from hospitals, preventing premature admission into institutional care and promoting integration into the community. Each region has a lending library of equipment including wheelchairs, walking aids, shower stools, minor home modifications, hand rails, surgical shoes and speech aids. It can also provide non-standardised and customised equipment usually for items costing over \$500. To be eligible, families or the child with a disability must be in receipt of a Health Care Card or Pension Concession Card. An assessment is also required from a health professional with applications then prioritised according to urgency of need. There is a \$6,000 cap on any one piece of equipment and the client pays a flat fee of \$50 per annum for the hire of any number of aids. This covers repairs, an annual service on new wheelchairs, parts and all labour costs but it does not cover routine maintenance costs like tyres or batteries. There is a hardship panel for those who reach the cap, require expensive equipment or who cannot afford the charges.

CES also operate a continence service offering free assessment, treatment and management of continence through a continence nurse and outreach clinics. Children over 6 years of age are eligible for assistance providing they have a condition from which incontinence is a resultant disability. Those with an uncomplicated developmental delay or bed-wetting are ineligible.

- the **Equipment and Technology Library**. This is a state wide service which provides equipment to children aged 0 to 18 years who require it in order to access educational programs. It was established in recognition of the fact that inclusion in mainstream schools would generate additional support needs for equipment which had previously been focused in special schools. It provides a service to all schools supporting children with disabilities, is funded by a variety of annual grants from both Commonwealth and State sources and is administered by Cerebral Palsy Tasmania. The service purchases, lends, reissues and stores a wide range of equipment and technologies and can also provide some duplicate equipment for use both at home and at school. Equipment

is lent to the school in the student's name until they no longer need it and then it is returned to the equipment pool. The service cannot supply wheelchairs. The Library also provides assistance and advice in identifying suitable technology. The annual nature of the funding means that there is no certainty from year to year about the level of service which can be maintained.

- **Facilities Services Branch, Department of Education.** This administers a fund which aims to make the school environment accessible. The State Coordinators for Physical Impairment work with schools to ensure that they are accessible to students with disabilities. Principals apply annually to a state-wide committee for works projects which have been assessed by therapists; for example for toilet modifications. Requests can be approved for sums up to \$14,000.
- **Disability Services** which operate an ad hoc one-off funding pool resourced by slippage monies and a bonus. This can cover mobility equipment, respite and one-off personal support and home and vehicle modifications. It does not cover continence services outside an emergency situation or the purchase of vehicles. It can also top up the \$6,000 limit on wheelchairs from the CES. Home modifications are only considered in private homes, not in public housing or private rentals. Applications for assistance require a therapist's report and three quotes. They are then prioritised according to urgency of the need. Disability Services do not have the staff available to maintain a waiting list so if an application is rejected it means reapplying three months after. It is also possible to get equipment through Individual Support Packages as long as a request has been rejected by the CES. If equipment is granted through the fund then ordering, delivery and maintenance is the applicant's responsibility.
- **Australian Hearing Services** which are Commonwealth-funded and supply hearing aids and batteries to concession card holders with an annual service charge of \$50. Aids are provided through four Hearing Centres located across Tasmania which also provide assessments, maintenance of aids and rehabilitation services.
- **Orthotic Prosthetic Services** which provide limb prosthetics, orthotics, surgical footwear and mobility aids. There is a customised seating clinic for wheelchair users. This service is free.
- **St Giles Society** in Launceston which operates a seating and equipment clinic and can provide advice on vehicle conversions. St Giles has also established a pool of mostly therapy-based developmental equipment through trusts and bequests. This can give families speedier access to equipment than through the CES.
- a number of **non-government organisations.** These distribute equipment on a long term or temporary loan basis at competitive rates and some also manufacture their own equipment. Fees for the weekly rental of wheelchairs range from \$20 to \$60 per week. They may also supply continence aids with door-to-door delivery at below market cost. For example the Red Cross have mobility aids to hire, Royal Guide Dogs have adaptive technology services for those with vision impairment and the Tasmanian Deaf Society provide advice on the latest technology for the hearing impaired. A number of organisations also provide some financial assistance to help fund the purchase of specialised equipment or meet other necessary expenses or help families to seek charitable funding. For example the Cerebral Palsy Association distributes up to \$3,000 per month most commonly as top-up payments for wheelchairs. However there are usually caps on how much funding can be provided to an individual family in a 12 month period and this means that they are rarely able to fund large items of

equipment like wheelchairs. In addition the Cerebral Palsy Association runs the Tiny Tots program on the North West Coast. This was established through one off funding from the Tasmanian Community Fund to provide a pool of equipment to meet a substantial unmet need for equipment for children in their homes which was not being met by the CES. The Cerebral Palsy Association also fund the costs associated with some assessments and therapies specific to children with cerebral palsy.

- **Charitable funding.** The Rotary Club, Lions Club and Variety Club all provide charitable funding to meet the specialist equipment needs of children with disabilities. They can be approached by individual families or by services advocating on their behalf.

In addition community nursing services and health centres often have equipment available for loan.

6.2 Experiences of Getting Equipment

Not all the families in the research required aids or equipment but the majority did. Commonly they needed a number of items which might include special seating and shower chairs, hoists, stand up frames, bath boards, elbow crutches, tilt boards and so on. In order to meet these needs they had used a variety of sources of assistance and had met the cost of some items from within the family.

She has a manual wheelchair. I think a fund raiser group fundraised for it and got it for her. It was about \$7,000 and they did the lot I think. I've had equipment through the equipment library and the CES and St Giles. She has elbow crutches which, since she's turned 16, we have to buy ourselves and that's about \$80 a pair. I don't know if there's any help with that, I've not looked into it, we just buy them. Stoppers we buy them ourselves (on the end of her crutches) she goes through a pair a month and they cost \$4 a pair. With her starting at college she was worried about the distance between class rooms and we were looking into getting an electric wheelchair or a mobility scooter but nothing more has happened about that. Her grandmother was going to buy that for her. She has a lap top from Royal Guide Dogs. (Sandy caring for Ellie aged 16 with cerebral palsy and vision impairment)

Equipment needs to be appropriate, suit the individual and the carer and not be too heavy or cumbersome. For children it can be very important to get the right equipment at the right time. Getting appropriate equipment when they need it can facilitate normal development and help to approximate the quality of life of children without disabilities. If they do not it can slow their development, limit their capacity to participate in everyday activities and risk developmental delay.

A major difficulty faced by families was acquiring an appropriate wheelchair for their child. The process involves attending a special seating clinic for an assessment, advice about any special needs or customised equipment and a quote. Clinics are state funded and free and also provide ongoing review and support. Powered mobility is often the most appropriate response to children's needs and allows them to have control over their own mobility and participate in childhood activities. For instance it is much better to be independent in the playground rather than requiring another child to push a wheelchair. Ideally children should have access to both manual and powered mobility and many professionals consider it crucial for their cognitive development. Unfortunately these options are often denied to children and families were having difficulties both with finding sufficient funding to pay for chairs and with the waiting times involved.

Firstly paying for the wheelchair can be fraught with difficulties. Sources of assistance are the \$6,000 available from the CES with top ups from Disability Services, non-government organisations and charitable funding. Children may require very significant seating modifications which can cost up to \$8,000. The \$6,000 available from CES barely scratches the surface for children whose powered chairs may cost as much as \$18,000. For example, a child with cerebral palsy may require a customised wheelchair with body brackets and head control at a cost of \$15-21,000. Neither do the subsidies available keep pace with improvements in technology and rises in costs and the high quality and low cost required by families is not available because of the lack of competition among specialist suppliers in a small market.

It would cost \$13,000 for an electric wheelchair, it's disgusting. You can buy a small car brand new for the same price. These big businesses make massive profits. The government gives you \$6,000 and you have to try to find the rest of it. We are not in with any groups, no football clubs or church groups, no one to support you to raise things. Because my Dad is a veteran we tried to use the Vietnam Vets' Association but they don't have funds for that type of thing and are unable to help. I don't know what we'll do now. Everything we have got is from the equipment scheme. He's in a manual at the moment but he needs a manual and an electric because he's getting bigger and heavier. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

Secondly, unlike adults where a wheelchair can be a one-off acquisition and last for several years, children are growing and their condition may well be changing. This means that any equipment, including wheelchairs, requires constant modification and updating. Nevertheless they have to compete in the same funding pool as adults for priority. If a key criteria for funding priority is to keep individuals out of hospitals or institutions many applications from children being cared for by their families and perhaps requiring equipment to gain community access rather than prevent institutionalisation will never acquire funding priority. The relative scarcity of manufacturers also means that once funding has been acquired there can be waits if the equipment requires customisation. The needs of children can change rapidly between ordering and receiving equipment and they can outgrow a wheelchair in a few months. One child in the research sample had been forced to delay her start at school for three months because she was waiting for an appropriate wheelchair.

We had to wait a long, long time when he had grown out of his other wheelchair. It had fallen to bits, the manual one. We had to wait a long time for the power chair. It was at least 8 to 12 months. We had to wait, it was hard. We couldn't do anything about it. The OT always says we're waiting for funding and we are going to ask Disability Services. That's what they always say, that they will try to get funding from them. (Janine caring for Andy aged 16 with cerebral palsy)

She has a brand new wheelchair on its way and has her first fitting of the chair so they can make sure it's all correct, with the right measurements and comfort for her. Every two weeks she has to go back to get it readjusted before she can go to school. The full cost is \$13,000 and the Cerebral Palsy Association and the State Government are paying. We tried a couple of places but we just got knocked back with the funding. First I went to Cerebral Palsy Association and then I went to Disability Services and then I went back to Cerebral Palsy to see if they would help us. So Cerebral Palsy are putting in nearly \$2,000. She needs the chair before she can go to school, it sits her properly. (Jane and Mike caring for Lisa aged 4 with cerebral palsy)

There were also additional expenses involved in replacing broken or lost wheelchair attachments, maintenance and electricity, courier delivery fees for new items and increased home and

contents insurance. These costs were usually being met out of the family's own pocket and the financial strain and the waiting times for new items could mean that families were managing with outdated or inappropriate equipment.

The cost of the aid and the cost of repairing it whenever it breaks down. Batteries are \$7.50 a packet and each is designed to last up to 70 hours. So we buy them on a monthly basis and most people have \$14 to \$21 per month in batteries. I had to buy her a mobile phone and teletext as she can't hear. My phone bill each month is \$200 of which there would be at least \$60 in SMSs. (Tracey caring for Zoe aged 14 with a hearing impairment)

When he's on his tummy trying to crawl he frogs out so they said buy these for \$6 to stop his legs from frogging out. So there was \$6 I had to have on that day. On Thursday I have to pay \$10 to get a special seat for him to help him learn to sit up. That is only a \$10 deposit but it's \$10 until I take the seat back. (Dot caring for Declan aged 8 months with Down syndrome)

One family had got into debt with the annual service charge on their son's wheelchair:

With the Community Equipment Scheme I didn't pay the \$50 a year so they sent it to Tas Collection Services and another woman said they'd cut me off. They can't take the wheelchair away, then what would we do? I asked someone could they take the equipment away in a court of law and they said no. His chair is okay but I'm at that stage where I can't push him anymore. It's manual but pushing an 11 year old gets a bit taxing. I want a semi one where you both can do it but I was told it wasn't a priority because I can still push. I think that's totally unfair. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

There were also other items of equipment which families had found hard to access. This equipment included other mobility aids, hearing aids and communication equipment like communication boards, speech synthesisers and computer software to assist with writing or access to the internet for use in the home rather than at school. It can be very difficult to access 'state of the art' equipment through subsidised schemes. These shortfalls could have a big impact on children's development and ability to participate generally.

He's supposed to have a standing frame but we can't afford it. The scheme provides it for the school but not for here. They are worth a small fortune. I don't know why, they are only light steel but someone put a patent on it. It means he just sits on the floor and he gets so bored during the school holidays. When we used to have a standing frame he could stand there and be the same level as everyone else. Our neighbour was going to make him one but got into trouble, something about a breach of copyright. He said I could make one of them but the physio said don't, it's copyright. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

We got hearing aids provided by the government but we went out and bought her proper Senso Diva aids. It's very sad that the government doesn't provide them. The other aids aren't as good and she was always saying "what". If you fit within the category and if your parents don't earn too much you get a standard issue but if you want the best you could have a gap of \$1,800 or \$2,000. Each hearing aid is \$3,100. For us to buy her Senso Divas, which is probably why she has done so well, that cost us \$6,000 of which you get nothing back from Medicare. If she loses one we have to buy another one. Standard issue compared to the best on the market, there's no comparison.

I had that money for the hearing aids but a great percentage of parents don't. It's sad that all these kids miss out on so much. They should be allowed to have the best. (Tracey caring for Zoe aged 14 with a hearing impairment)

Escalating costs and waiting times mean that families often have to rely on fundraising to close the gap between the subsidies available and the actual cost and to ensure that the equipment arrives within a reasonable time period.

We did a fundraiser for Meg's wheelchair. We couldn't just go in and say we need a wheelchair and they would say right we'll order one and it would be funded. If you tried to do that you could be waiting literally years. When we found out Meg really needed a wheelchair for kindergarten it was October. We were then told that if she was to wait for government funding she could wait 12 months. Well she couldn't wait 12 months because she started school in a few months. We raised nearly \$4,000. Then the Lions Club said when you want to raise for David, let us know and we will try and support you. They had a corporate golf day. When we bought the wheelchairs all the costs were covered, like the cover, the table, all the initial costs. So unless they grow bigger, the chairs will grow with them although you will have to pay for bigger seating. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

However accessing charitable funding was not necessarily straightforward and there can be administrative difficulties. Although a charitable body may decide to contribute it can take up to two years to confirm the contribution, customise the chair and order it, possibly from America. Some charitable organisations do not commit funds more than twelve months ahead or will not release funds until there is a commitment from the State to provide matching funding. This can involve families and service providers in holding procedures which drain energy and resources. It can be most productive to approach a number of organisations for funding but this also duplicates the service provider's time and energies. Service providers commented that supporting families through the minefield of equipment schemes and fund raising activities was very time consuming. In addition families do not necessarily find it easy to approach charitable bodies for assistance. Parents prefer to concentrate on the positive and they did not want to use the child to elicit sympathy and generate negative stereotypes.

There is that initial thing of putting the kids out there. That was the hardest part with Meg. It was difficult because we have always done everything ourselves. We don't like asking people for money. People say isn't there funding there for them but they don't realise how many children are in need and there's only so much funding. If there are people there prepared to help us with different things then if we go that way it opens the door for other people who don't have that bit of connection. There would be nothing more heartbreaking than to go there and them to say no you have to wait twelve months. For them twelve months probably isn't a long time but carrying a child around from day to day, it's a long time. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

They could also be reluctant to be involved in publicity about any assistance or donations.

The Variety Club are going to fully pay for Dan to have this communication device. It's nearly \$10,000. Rotary Club years ago got me a wedge (they lie on their front and it's to get the gunk off the chest and stretch them out). It only cost them \$150 and they made a big fuss. We didn't want that in the paper. If you give someone something I don't see why on earth you should have a big fanfare. They went to the school to present it and

wanted us there. Variety Club are very understanding and we said we don't want our name in the paper, and they said that's fine. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

Recent research (Hinton, 2006) which publicised both the funding gaps and long waiting lists for wheelchairs resulted in the establishment of a philanthropic fund with a private donation from the Elphinstone William Adams Group in 2007 to provide new wheelchairs to Tasmanians on the waiting list. The fund is administered by Anglicare in partnership with the Community Equipment Scheme and with matching funding from the State Government. However resources are one-off and although they help to shorten the waiting list for wheelchairs they will not be able to meet future demand.

6.3 Contenance

There are two main sources of assistance with continence needs:

- the **State Community Equipment Scheme Contenance Service** provides continence supplies to the value of \$1,000 at half price within a 12 month period. Once the \$1,000 limit has been reached families can still access equipment but at full cost. They can also apply for hardship provision. To be eligible for the service the child must be over six years in age, have access to a Health Care Card and have an assessment and annual review by the Contenance Nurse Advisor.
- the Commonwealth **Contenance Aids Assistance Scheme (CAAS)** provides up to \$471 per year in continence aids to children aged 5-15 years. Eligibility is based on parents' entitlement to the Carer Allowance and a report from an appropriate health professional. The provision of supplies is not linked to assessment or to treatment. When the CAAS subsidy is exhausted families can still access equipment through the CAAS supplier but at a higher cost. There is also a \$12.50 delivery fee for orders under \$300.

Additional assistance may occasionally be available in crisis and emergency situations from Disability Services through their one off funding pool and through non-government organisations. However it is very difficult to get any assistance before the child is five unless there is some kind of renal complication.

Ten of the families who participated in the research had children aged 5 years or older with continence needs and these needs were commonly combined with epilepsy, autism and intellectual disability. There were also those with children who were still in night nappies a long time after most children would be nappy free. Yet these families and those where there were serious continence issues but the child was aged under 5 years were unable to access any assistance with the additional costs.

Families in the research reported considerable difficulties in meeting the continence needs of their children and they often presented as a huge financial cost to the family. Although for some families the subsidy met the majority of their costs for those with a fully incontinent child it can cost over \$100 a month in nappies. This means that the financial subsidies available will run out within four to five months leaving the family to meet the full costs for the rest of the year. These costs can increase if there are also other conditions. For example those with diabetes have excessive urination and may require changing every hour. Irritable bowel syndrome can also mean an increase in soiling and one mother whose 16 year old autistic daughter suffered from this condition could find herself changing her several times in the space of just one hour. Parents commented on the cost of the nappies and other accessories like

nappy bleach, wipes and washing powder, the additional wear and tear on clothing and delivery charges. One mother was spending \$44 a week on nappies and wipes alone without any of the other additional continence costs.

I get the subsidy which is \$500 a year. When I run out of money I have to buy the night nappies and they are \$18 a packet and there's only nine in a packet. If she soils you go through two a night. It's very hard to find enough money to pay for them to deliver a box of nappies. A box is one hundred and something dollars and to find that much money is very difficult. So when I don't get it from the subsidy I buy them from the supermarket because it's easier to find \$18. The day ones, I have to buy those which are the pull ups, and they are \$13 a packet. A packet would do me maybe four days. So the subsidy lasts three months if I'm lucky. With that bit left over I use it to buy wipes and some Napisan for soaking the clothes. You have to have that because she has diarrhoea so that means she soils and it will go on her clothing. Then you have to soak that clothing because it won't be cleaned just by putting it through the wash so you need the Napisan. I buy a packet of wipes every week because when you're out you can't carry washes with you. A big packet is about \$7 and then the Napisan which I get every couple of weeks at least. And then the washing powder and the extra wear and tear. I have to wash daily. She has protection sheets on her bed but the linen gets washed every four days regardless otherwise it smells and the whole house starts to smell like pooh and that's disgusting. She has to be showered everyday twice a day because otherwise she would smell. So it pretty much dominates everything. It's a very high cost, just the water bills alone, the electricity to run everything. You have to wash her pyjamas every day and then they don't last. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

It's \$470 but I use that in a month. She has the diarrhoea and then we try to account for every nappy. I just try and get pads from the op shops. She has to have baby wipes and the cornflour powder because she sweats and cream for her bottom because she gets sores. I didn't find out about the subsidy until she was in her teens. There were many times when I couldn't afford Tina's nappies because we were struggling and things were tight. There was some Sunshine group and they came forward and paid for about five lots of Tina's nappies in a couple of years because we just couldn't do it. We didn't get into debt with the nappies because I would pay for it or my mum would send money up for them. I know we probably should of gone into debt because then it would have been better for our case. But back then I was thinking no thank you, that's the last thing you want, a bad credit rating. (Viv caring for Tina aged 16 with a chromosomal disorder)

The government pay half and we pay half but once I get to that \$500 limit we pay full price and that is a common occurrence with us. It takes us from November through to April and then after that we pay full price. It's worse now because they've changed their delivery courier. It was \$4 when they delivered them so if we got six boxes it was only \$4. But now they've got it through the post office and it's \$5 a box so if it's six boxes we're paying \$30 or \$40 for delivery costs on top of the price. That also covers catheters. If he gets an infection we have to go through one catheter every time and catheters are \$5 or \$6 just for one. It's a big cost but we just pay for it. We could have a good day and only go through four nappies a day or a bad day and go through twelve a day. There are only fourteen in a pack. So on top of the \$500 we are paying probably another \$500, close to \$600 at least. With the Spina Bifida Association they will try to pay 50% or 60% to help us out as well. But we didn't know about that until last year. (Kath and Jack caring for Nick aged 14 with spina bifida)

Not all families were aware of the subsidies available and some had struggled on, in some cases for years, unaware that there was help available.

We only found out a month ago that Meg is entitled to a nappy allowance and she's apparently been entitled to that since she was six years old and she's now seven. There was just no information whatsoever about that, none, and I know there are a couple down there at the school who don't know about it. So we can get her nappies a lot cheaper which for us is \$18 as opposed to \$25 for a packet which is a big deal. \$1,000 a year you're allowed up to and it works out for Meg. \$1,000 at \$18 a go is enough for her for the year. It's good. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

Families did try to economise by buying cheaper nappies or not changing their child so often or changing their diet. Some had also accessed additional financial help from disability organisations. However three families in the research were in the hands of debt collectors because of money owed for nappies.

We had never gone over that \$1,000 in a year until this new principal took over. She was getting them to change him morning tea, lunch, afternoon tea even if they were dry and all of a sudden we were sending a pack of nappies a week. I got a letter for \$3,000 in May 2005. Before that I just never got bills. I rang this lady and they squashed that \$3,000 because it was in his name and he was only 15 at the time. Now it's only \$2,000. What they say is you get that \$92 a fortnight, why doesn't that help pay for the nappies? As we said there are other children with disabilities that don't need nappies and they still get that \$92. It's hard. We just can't afford it. They sent a sheriff out here and I just told them I couldn't pay. It went to court and the bailiff turned up asking for Simon. When he found out he was only 16, he was very upset. We get the debt collectors ringing us, can we speak to Simon please? He can't talk. Why can't he talk? He can't come to the phone right now. They keep ringing and ringing. The best we can do is wait until he goes on a pension and they can take \$20 a fortnight until he's caught up, but he's never going to be caught up. We know others in the same situation. If you have no other income coming in there is no way you can do it and two other children to bring up. It's just unreal. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

Every time I order nappies it costs me \$200 or \$300 and that's a lot of money and I can't afford it. I am in debt up to my eyeballs and I've been getting phone calls from Tas Collection Services saying you owe this. The lady said they'll cut you off but they can't cut me off. I don't think legally they can stop you from having them. I probably owe close to a thousand with Tas Collection. They keep ringing up and hassling. They say if you pay \$5 a week they can't legally touch you. They can yell at you but they cannot take you to court because if they take you to court and the judge sees you're paying something what can they do, they can't do anything. Those collection services use bullying tactics, and sometimes they are illegal what they do. I am going to start next week just sending \$20. This has been going on for a few years. I know I'm not alone, they make out that I am. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

They only give you 14 days to pay it and if you haven't paid it by then they chuck you into Cromptons, into the collection service and you're worried about that as well. So you think if you don't pay that they're going to send you to court and you'll go to jail and then you've got a criminal record. It prays on your mind but you have to laugh and battle through the week. In Cromptons you just pay so much when you can. It's

probably not the best way to deal with it but it's the only way we can deal with it. They don't give you long enough to pay for it. You are struggling to try and make ends meet on the money you do get and then you get a \$150 continence bill and you think I haven't got the money I'll pay for it next week and then next week comes along and you can't pay for it and then the 14 days are up and you get a letter Dear Mr Clark you owe us money, pay up or I'll see you in court. Sometimes you get a nice one and say I can't afford to pay this \$50 can I fix \$20 every fortnight and they say yeah. And then that lady is away and you ring them up and say I can't afford the \$20 this fortnight because something else has popped up and they say you can't do that, if you don't pay you're in trouble. They send you to Cromptons anyway, so you can't win with them. At the moment with Cromptons I've got them taking out \$20 a fortnight out of my pension and it keeps them quiet but the debts are still there. Before that they were ringing up all the time, you haven't made your payment, you said you were going to make a payment. It's something we can't do anything about so we grin and bear it. (Kath and Jack caring for Nick aged 14 with spina bifida)

Debt collection guidelines produced by the Australian Competition and Consumer Commission and the Australian Securities and Investments Commission (ACCC/ASIC, 2005) clearly outline how often collectors can contact debtors – no more than three times a week - and state that recovery practices should make 'reasonable allowance for a debtor's ongoing living expenses'. A large proportion of debt recovery is achieved through on-going Centrelink payments, deductions from bank accounts and wages. However it appears that the families in this research were perceiving high levels of threat in their contact with collection agencies and in circumstances where they were unable to do more than pay small regular amounts off the debt.

What interviewees wanted to see was adequate assistance with continence needs. As one family said:

I personally think that if your child is incontinent and I'm not talking about just wetting the bed at night, I'm talking about severe incontinence like my child has then I feel the government should back us up and at least give us the money to buy the nappies for the year because that is so hard. If you haven't got the funds to go out and buy the nappies, what are you going to do? You are going to cut back, you are going to start not changing the child, or you're going to change them once in a blue moon. Then the child has rashes or irritations or problems because the parent just can't do it. How does that make you feel about your disabled child? If your child is this disabled, which mine is, and there's proof that they are this disabled and they are incontinent, for heaven's sake give us enough money for the nappies if nothing else. What are you going to do, go and squander it on something, hardly? You can only spend it at certain places anyway, so you're not going to go out and spend it on other things are you? You can't go out and buy grog or cigarettes. Just give us the money for the nappies. It annoys me so much because that to me is basic health for someone therefore it should be provided without any questions. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

6.4 Summary

Being mobile and having adequate supplies of continence aids and equipment are basic needs which should be met. Yet many families with disabled children are unable to effectively respond to these needs without incurring substantial financial costs which they cannot afford. Those who are unable to pay experience long waits and emotional strain as they try to find their way through complex schemes and fluctuations in available funding. For some it means the ignominy of charity. For others it means falling into the hands of debt collectors. There are, of course, difficult questions to answer about the balance between public and family responsibility. Many families will have a car and seat restraints. A family caring for a child with a disability will require a particular kind of vehicle and seat restraints which cost three times as much. How should these additional costs generated by disability be met?

What is clear is that the current service system does not meet the acute and basic need for aids and equipment of many children with disabilities being cared for by their families. This is a situation which requires urgent attention.



7. Education

Research demonstrates the impact having a disability can have on educational achievement. It can impact on the ability to complete school or to obtain post school qualifications and is often associated with lower achievement. Although over half (53%) of young Australians complete year 12, this compares with only one third (32%) of those with disabilities (AIHW, 2003). Because the education system can be key in perpetuating or halting educational disadvantage, educational policy, and particularly policies around inclusion and how best to include students with disabilities, are critical.

This section describes the experiences participants in the research have had of educational inclusion for their child with a disability. It outlines the frameworks in place to support inclusion and explores how, through the eyes of parents, these have been implemented on the ground.

7.1 Services

Services provided by the Department of Education (DoE) are currently in transition. In 2005, in order to promote inclusive education and local accountability, state schools in Tasmania were brought together into 27 geographically based clusters across three educational branches. Each cluster had a board overseeing the development of strategies to coordinate learning support particularly for students with special and additional needs and consisting of all principals of schools within the cluster. Clusters also had a specialist support team of guidance officers, speech and language pathologists, social workers and support teachers to support teachers and students within the cluster. From early 2007, whilst maintaining the clusters, the DoE has restructured into four learning service units. Currently the DoE provides:

- **Mainstream schools** attended by 95% of children with disabilities in Tasmania (AIHW, 2004) compared to 89% nationally. This means that Tasmania, together with the Northern Territory, has the highest rates of inclusion in Australia. The principle of inclusion means that every child with a disability has a right to attend their local school and that no child should be excluded because of perceived learning differences. Children with disabilities for whom educational adjustments need to be made should receive an individual education plan (IEP) reviewed at least annually in discussion with parents and addressing any special educational needs they may have. They can also be allocated teacher aides or other forms of support to assist their learning in the classroom.
- **Special Schools** catering for children with severe disabilities. There are currently approximately 130 children attending special schools in Tasmania. It is also possible for children who are not enrolled to access particular programs at special schools, for example hydrotherapy, whilst maintaining their mainstream school enrolment. There is one private special school called Giant Steps in the north of the state attended by approximately ten autistic children.
- **Learning Services** providing a range of support on a regional basis to individual schools. This includes access to support teachers, psychologists, social workers, therapists and guidance officers and supporting the development of inclusive practices in schools. The services also include four full time equivalent (FTE) autism consultants across the state and two FTE physical impairment coordinators.
- **Inclusive Learning Support Services** providing specialist support for students with low incidence disabilities. It includes:

- **Early Childhood Intervention Service (ECIS)**¹⁵ offering a range of educational programs designed to assist children who have a disability or who are at risk of delayed development aged 0-4 years. Children can attend from birth or from when they are first diagnosed or a difficulty is identified. It is a teaching service staffed by teachers and aides and offers home and centre-based programs, baby, toddler and pre-kindergarten groups, therapy sessions, counselling and parent support programs. It also operates a premature babies program working with those born before 32 weeks and at high risk of developmental delay. Services are flexible and family-orientated and combine the expertise of a number of professionals to enhance the child's abilities and development and to build supportive networks for the family. Parents can refer themselves or be referred by GPs, paediatricians, child health nurses and other community services. ECIS has four regional branches providing services to about 400 children state wide at any one time.
- the **Vision Impairment Service** with three offices across the state and ten part time resource teachers trained in the area of vision impairment and working with schools and parents. They also run regular camps. It works with up to 90 families who have blind children and/or complex needs as well as supporting children with moderate needs and any who require access to some form of technology. There is also a Braille Transcription Unit providing special curriculum resources.
- the **Deaf and Hearing Impairment Service** overseeing a specialised service for about 45 children with profound hearing problems included in schools with high levels of extra support from teachers of the deaf and interpreters in class. In addition there are a further 200 children who have some level of hearing impairment receiving varying levels of support. This might include access to appropriate aids and regular review.
- The **Positive Behaviour Support Initiative** promotes positive behaviour in schools by implementing School Wide Positive Behaviour Support (SWPBS) alongside the curriculum. SWPBS assists schools to shift their focus from punishment to teaching and learning. It teaches students 'what to do' rather than getting caught up in what 'not to do'. There are approximately 76 schools across the state involved in a three year program to review what currently happens in their schools and, with their broader community, to refine and implement positive behaviour support approaches. The project provides school communities with professional support and a set of tools to get them started.
- **Distance Education Tasmania** offers an online campus, home visits and educational resources for students who due to isolation, illness, pregnancy, difficulties in travel or inability to work within a classroom are unable to attend a school. Increasing numbers of children with disabilities are enrolled in distance education.

Outside government-run schools the Catholic education system and independent schools are able to access additional funding through the Commonwealth Department of Education, Science and Training (DEST) to provide an inclusive environment for students with additional needs. Some families with disabled children may opt for home schooling if they feel their child's educational needs are not being met. Home programs are inspected and evaluated through

¹⁵ Previously known as Early Learning.

the Tasmanian Home Schooling Advisory Council and home schoolers can also access the DoE's Home Education Support Service for a variety of resources.

7.2 Funding

Funding for children with disabilities in the state education system is complex because it aims to target those who are identified with the greatest needs at the local level. It is provided through both State and Commonwealth funding streams and forms part of a general allocation to all schools with an additional budget for special education that covers all special educational needs. The main sources of additional funding for children with a disability are through:

- the **Register of Students with Severe Disabilities**. There are currently 680 children in Tasmania on the register in one of seven categories of disability – physical disability or health impairment, multiple disabilities, intellectual disability, autism spectrum disorder (in the upper moderate to severe range), psychiatric disability, vision impairment and deaf or hearing impairment. This represents about 1% of the school population. Children are identified according to their primary disability in terms of educational needs but there can be difficulties in categorising some students. Students on the register can be allocated funding up to \$24,000 per annum which is given to the school cluster who then decide how best to provide an individual support package. It might involve aide hours, transport for excursions or professional support for teachers. Students on the register enrolled in regular schools also attract a 0.14 full time equivalent (FTE) teacher. Those attending special schools are funded by a different formula with a notional number of aide hours allocated and also attract a 0.2 FTE teacher per student.
- the **Inclusive Learning Support Service** which manages provision of services to the under fives with disabilities and developmental delays and to hearing and visually impaired children across the state.
- **additional needs funding**. This is a general allocation to mainstream schools for 'special needs' including those with a mild to moderate learning difficulty. Funding, in the form of dollars and teaching staff, is allocated to clusters according to the total student enrolment, educational needs index and educational performance data for the cluster. However the way in which children with special needs are identified can vary from cluster to cluster. Clusters use the special education additional needs resources to meet the needs of students in their cluster.

Students with a disability can also access transport assistance, minor works allocations like ramps and rails, information and communication technology support and consultative therapy.

The funding process has been criticised as clumsy and inequitable. Supporting children with additional needs in mainstream schools can be more expensive than in a special school and there are concerns that the extra costs associated with inclusive practice are not being fully met. Overall there is a general perception among parents that for those children whose impairment is not severe enough to lever resources from one of the funding pots it can be very difficult to access any support at all. There is also the perception that those prepared to make the most noise are likely to get the most resources.

7.3 Early Childhood Intervention Service (ECIS)

ECIS was universally praised by families who participated in the research. They had found them flexible and family orientated. The services had given them access to the expertise of many different professionals and they particularly appreciated the opportunity to talk to other parents. They had seen their child develop new skills and they had been able to pick up information about what other services were available.

He went to early special ed when he was 18 months old till pre-kinder. They are fantastic people because they are specialised in that area and they are trained people who specifically deal with children like him. They do a wonderful job and were very good with him. I was with early special ed for such a long time and I went to every seminar they had, jotted down all the stuff for children like him. If I didn't have this education and all the seminars behind me to back me up in ways of approaching children with disabilities he would be ten times worse and he wouldn't be at school. (Liz caring for Sean aged 12 with multiple disabilities)

The only criticisms were about the social mix of children at ECIS and two parents expressed concerns about their child modelling the behaviour of others less socially skilled than themselves.

The only down side to Early Learning was that I probably should have had her doing something else as well with kids at her same level socially. A lot of them were having tantrums and getting worked up about things and I don't think she was able to build up her social skills with other children. I found it more so with the pre-kinder group than with the toddler probably because the pre-kinder groups were a lot smaller. With the toddler group there was a big variety, and lots of kids more physically impaired so they were on the same social level and she made a few friends through that one. So it was just the social side of things. (Sally caring for Claire aged 6 with epilepsy)

The transition from pre-school into primary school can be particularly fraught for children with disabilities and families may require additional support. Firstly families have to move from a family-centred service to a professional school-based service which has much less flexibility. Secondly, disabilities which are not so apparent in pre-school environments can become more visible when the child reaches primary school. This can mean a growing isolation for families as their experiences increasingly differ from those of other families. ECIS run a transition to school program to develop connections in the year before children attend school and provide support for the first term and families in the research had found this valuable.

It's worked very well and they supported us for him to go into school and to get an aide for him. He's undiagnosed but has an intellectual learning problem and some autistic traits. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

The positive benefits that families gained from their contact with the service suggest that all families should have access to the programs as early as possible. One mother who was not referred until her child was nine months old felt that the support would have been very useful to her at an earlier stage:

It was through the paediatrician when she was nine months old so it was quite late and I've asked a couple of times why that was. They did say that it was because she was so sick and there was so much happening. They have been fantastic, a great support. (Kate caring for Daisy aged 2 with cerebral palsy)

7.4 Experience of Mainstream Schools

All interviewees were very supportive in theory of the principle of inclusion. However in practice their experiences of inclusion differed widely from very good to appalling. There were a number of families who had nothing but good things to say about their child's experience at a mainstream school. These were children living with a range of disabilities including epilepsy, autism and sensory and multiple disabilities of varying severity.

It's a lovely school and they have done whatever needs to be done. They had a whole heap of black poles and we had to paint all those yellow so she could see. It's little things like that. The sight unit go down once a week to check things out, make sure she's okay. She has a tilt board thing she uses and they put bright keys on the keyboard so she can see the letters. She has a teacher's assistant and that's all paid through the sight impairment service. She gets six hours a week. Most of the kids are pretty good with her and try and help her. There are the odd one or two that have their comments but what can you do? Because she's got tunnel vision a boy came up besides her and scared her and because she jumped and reacted he thought that was funny so he kept doing it. I spoke to the school about it and that's all stopped. (Winnie caring for Tess aged 8 with visual impairment)

When I first went up there there was one teacher who looked at me as if to say I hope he's not in my class to which I thought I hope he's not in your class. So I made sure Tim wasn't put in her class. I need a strong teacher. I have to do everything at home and I can't keep going up to the school to sort stuff out and I've been really really lucky to get some great teachers and he's loved every one of them and I've never had to struggle with him to go to school. He has a full time aide. He loves it, the kids love him, they want to be in Tim's class the following year, so it's really nice. We made sure his transition to each class was started in the last month of the year so he knew where he was going and we would arrange for certain toys to go with him wherever he went. They have been brilliant. (Kerry caring for Laurie aged 13 with epilepsy and Tim aged 12 with autism)

The kids down there have been great with her and they've had no problems whatsoever. We have found the aides really easy to work with and the school cooperative. With Meg and David they are visually different, they are in their wheelchairs and the kids accept that. We found with the school from the first phone call and conversation they were fantastic so that put us at ease so there is that mutual respect and understanding. She got an IEP and aide with no difficulties and the process was really easy. They are very easy-going kids and they like being with other children and that makes a difference. They don't have tempers or fly off the handle. They can't feed themselves their lunch or go to the toilet and if a child hits them they can't turn around and say stop because they can't talk. Our biggest worry for a long time was that if something happened to them they couldn't tell us. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

There were comments about the importance of getting a supportive class teacher or concerns about the level of supervision in the playground, but overall these parents were very happy with their child's experience of school.

For other families the experience of inclusion had been problematic and this reflects experiences elsewhere in Australia. According to AIHW (AIHW, 2004) 63% of children with disabilities experience difficulties at school. Commonly these difficulties are with learning, with fitting in socially and with communication. Those whose main disability is an intellectual one have more difficulties than students with physical or diverse disabilities.

From a parent's perspective a perennial problem is not being able to get enough teacher aide time and this can be compounded by misunderstandings about the role of aides and the costs. Parents and some teachers may see aides as an individual resource for the child whereby the aide is 'velcroed' to the child's side rather than being an educational resource for the class room teacher. This can foster a caring rather than an educational response from aides which may restrict disabled children and put up barriers to them engaging with their peers. It can also mean that schools battle for aide hours rather than skilling up teachers to work inclusively. These issues have been recognised by the Education Department who have produced a DVD for teachers with guidance about inclusive practice in the classroom and how to use aides.

A number of parents spoke about the battles they, and the school, had had to fight to get an appropriate level of funding and aide support for their child so they could remain in a mainstream school. This was a battle which often had to be re-fought each year and could drain considerable amounts of time and energy from parents and teachers.

We sent her by choice to a normal school. Basically she's had a very good school experience because I have fought black and blue every year trying to keep her hours of service. That is a real struggle. I just wouldn't take no for an answer. Everything you want that is outside the normal curriculum you have to fight black and blue for. She had two hours' teacher time and two hours' teacher's aide time at primary. That was the maximum we got. (Tracey caring for Zoe aged 14 with a hearing impairment)

The school fought to get the funding and at one point it looked like she might lose it and I'm not sure where she would have been going to school then. She wouldn't have been able to go to school without aide support, absolutely not, not a mainstream school. The principal did a massive job of meetings after meetings, forms, paperwork. Last year we had to fight for it and it doesn't look like we will have to fight for it again at the beginning of this year so it will at least get her through lower primary which is something. I wouldn't want to do that every year and I'm sure the principal wouldn't either. I'm sure he has much better things to do with his time. (Sally caring for Claire aged 6 with epilepsy)

One parent who had fought to get funding for her child through the Catholic education system then had to fight again to ensure that the funding was being used to benefit her own child's education.

As a parent with children with less severe disability you find you have to fight so hard for any tiny thing you get. I know it sounds awful but why should I fight for two years for the funding and get a measly two and a half hours that's not even used for my child. We actually had three and a half hours of funding for her through the Catholic Education office. That was hard fought. My other frustration was that it wasn't used for her and up to the third term last year not one hour had been used. I kicked up a stink, and it wasn't until I plucked up enough courage to make a stink that she got put into a social skills group for two hours a week. When I asked where the rest of the funding was they couldn't tell me and they said you have to have it put into the IEP which I found out was the individual learning plan. Their idea of input was I read it and sign it and give it back. I never got any feedback from that. Presumably she's got funding this year. (Gerry caring for three children with autism aged 8, 7 and 6 years)

Training for teacher aides depends on the needs of individuals and would be identified and met by individual schools. This might be general training or targeting training, for instance in dealing

with manual handling or continence issues. Interviewees were concerned about the skills of the aides employed.

He has to have a minder all morning and all afternoon. One will start with him at 9 and finish at 12 and another takes over from 12 to 3. He went into kinder and we had trouble from day one. Most days I am called down to the school, four or five times a day. I live down there. The staff are just not qualified to deal with children like him. It's not that they can't cope, they just haven't got the skills. School would tell me to go away for an hour to see how he went and he would just scream and scream all the time. (Liz caring for Sean aged 12 with multiple disabilities)

These children should not be just cared for. We want them to get to the best point they can. With teacher aides they hire them because they're cheap or their sister needs a job. Tolerance and patience and understanding is a big thing and that doesn't come out at a job interview. I've picked my child up in rotten states where he's been left in a pool of urine for hours and hours, faeces all down his legs, urinary tract infections from being left in clothes and pull ups with faeces in it. Really basic things, like I don't want to do it so why should I have to, it's not part of my job. (Angela caring for Dean aged 7 with autism)

Families described circumstances where their child was excluded within the school due to behavioural difficulties and/or a lack of funding. These exclusions can be invisible and unofficial. The school may have ten hours of support time per week but find this inadequate to meet the needs and in order to cope might ask a student to come in later or go home earlier or not to participate in excursions. In reality many children with disabilities are segregated because they challenge the curriculum or management strategies in the classroom. Parents also have to cope with bullying and ensuring the school is able and willing to tackle it. Many are grateful for what they get and unwilling to complain or they do not realise it is their right for their child to have a full school day.

He works by himself and isn't included in the classroom at all. He's in a special room on his own. He has never on one occasion said I feel good about myself or I feel good at school. Throughout his life they just put him in a room on his own but when he escalates and lies on the floor kicking and screaming they don't know what to do and I deal with it. I tell them how to deal with it because even after all this time they still don't know. (Liz caring for Sean aged 12 with multiple disabilities)

They did fund cutting last year and Emma didn't get an aide because she had speech even though her speech doesn't really mean anything. We were really disappointed with that. In the playground they are just not watched enough, there is not enough supervision. We are thinking about going to see the principal because when her other friends go to the Oval she's not allowed to go because the teacher over there doesn't have an aide. We just don't want her bullied. The aides are very good and the school has done everything in their power but they can't get the funding. But Emma does need more help than she's getting. If the teacher has to take time out for Emma the other kids miss out. You want to incorporate them into the school but they don't make the funding available for it to happen. (Jill and David caring for Emma aged 7 with autism and Rosie aged 2 with cerebral palsy and epilepsy)

As he got older and his needs got more the school found a way to try and get rid of him or they couldn't afford an aide or they didn't give him an aide. I used to go up there

every morning and afternoon to catheterise him and toilet him, give him his medication. A couple of times when he did get sick and had to go down to Hobart he missed a lot of schooling so they started carrying on about that. A couple of kids in the school were very cruel, you wear nappies and all that sort of stuff. He was about 8 or 9 then and it just got worse. I said to them he needs an aide for going down steps so he doesn't fall. We had doctors' letters saying yes please support Nick, he needs an aide with him all the time and please excuse him from classes when he's not well. But they carried on and we had teachers saying he's going to be kept back, his school work is suffering. (Kath and Jack caring for Nick aged 14 with spina bifida)

He was being locked in by himself. He was being excluded from activities like music and art. This was in a state school. He had a one on one aide for the 30 hours he was at school but the aides are untrained. They don't know what they're doing, they are babysitters really. I had a lot of problems with the school last year. My son still has continence issues and if I hadn't got the continence under control over the last school holiday period they said they would consider he would not be allowed back into the education system. It is completely outside the policies for schools, what they did. (Angela caring for Dean aged 7 with autism)

Families also commented on a lack of information about what supports are available within the education system and a lack of awareness among teaching staff about the implications of particular kinds of disabilities. Even if schools are aware of supports only some will call them in while others feel they can do it themselves. All children on the Register of Students with Severe Disabilities have an individual education plan (IEP) which is reviewed annually but others who are not on the Register are dependent on a decision by the school and cluster that this is appropriate and that the child has personalised learning needs. This means that some parents have difficulties in getting an IEP for their child and in getting it reviewed.

At school he's treated as a behaviour management problem. They don't understand the depth of Asberger's and think these kids make a choice to be naughty. They set up systems which they think help him but they don't really and then he has to cope with the teasing of the other kids because he's so different. When you have a child with special needs I think they should take you aside when you enrol in the school and say these are the support services that we've got and introduce you to the guidance officer. We didn't even know there was a guidance officer for a year or more. And then once we found out we asked whether we could see the guidance officer. We thought that in talking to them they would actually put something in process and we were waiting and waiting and nothing happened. When we asked they said you have to fill in a blue form. So we filled that in and then the guidance officer contacted us and said you're on the bottom of the waiting list and we will get to you. When we got to him he didn't provide much support for the teacher. Basically the teachers never even took the time to talk to him on a one to one basis. We asked for an IEP to be done. We were promised it would be done at the beginning of this year. Half way through the term we then decided we would home school because the school wasn't doing it. We didn't find out about the autism education consultant for this region until I went to an Autism Tasmania meeting in the middle of last year. She said she was going to organise the meeting for everyone to put together an IEP. She wrote a report to be put forward at the meeting and we had approached a child psychologist and he was going to write one. But then I think the support teacher took it over at the school and was organising it. She's overworked and has far too much to do, she's a regular classroom teacher and I don't think she really understands the need and eventually communications broke down. Nothing happened and we never heard from her again. (Di and Tony caring for Rowan aged 10 with Asbergers)

We didn't get an IEP until we hit the roof because they had never done one while we were there – 18 months. They did it just before we left to come down here. We ended up having a really big meeting with teachers and doctors and the headmaster and they did it then. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

Families and schools also struggle with issues around medication, seizures and meeting continence needs. Although it is the responsibility of the school to ensure that aides are trained to meet the needs of individual students and should feel comfortable with this role this does not always happen. This may mean that parents are on constant standby during the school day and making numerous visits to the school to meet their child's basic care needs and to help deal with their behaviour. Obviously this impacts negatively on parents' employment opportunities.

We have a really strong continence program to toilet train him properly. They refused to do it at school all last year. He was beaten by a carer at the school because he wet his pants and it started a terrible ordeal for him where he was traumatised. He would stop drinking at school, wouldn't let anyone help him, wouldn't take off his jumper. He wouldn't go into the toilets whatsoever and the second he got home after holding on all day he would wet his pants at the front door. They would only accept him being put in pull ups which are completely age inappropriate. (Angela caring for Dean aged 7 with autism)

Although a number of parents in the research may have been reasonably happy with their child's experience of inclusion at primary school, the experience of secondary education was mixed and achieving a level of inclusion can become more complicated. A disability that might not be so visible in kindergarten can become much more apparent as the child moves through the education system and the child themselves increasingly feels different to their peers. This can introduce or worsen behavioural problems and make the move into high school difficult. Although this transition can be planned for, planning often does not happen well.

For me as a parent with a child with a disability I need to know that he will be safe or I won't send him. You need to know that someone is watching and monitoring him. It is very difficult to get high schools to that way of thinking for any child with a disability. The headmaster said that Sean would have to shape up or he just wouldn't be able to come to high school. It is very difficult when you get that kind of response from a headmaster. Next year will be sheer hell because I'll have to start all over again telling them what to do. His mind is that of a 4 to 5 year old and when he gets to high school he will feel it, he's feeling it now because the other children are succeeding and he is not. There is a big meeting with him and Disability Services down at the high school to decide his future. Disability have an active role in the plans and the transition and they will have to be really careful about the way they plan for him. Being such a big high school they may not have the minders there to be able to supervise him on a daily basis. Because he isolates himself they will have to look at that and whether they have somewhere for him, not just in the hallway which is what we're looking at the moment. They will have to be very flexible in their management plan. He will still need a minder all day and be supervised at all times. It all depends on the high school now. (Liz caring for Sean aged 12 with multiple disabilities)

Lastly attendance at a mainstream school can also impact on the disabled child's siblings in a negative way. For one family this had resulted in a severe psychological impact on one of their children which had only been resolved when her brother had been moved to a special school:

Our daughter also went to the school and she was constantly teased that she was the same as him. If you went into the school with him no one spoke to her, they only spoke to him so she was this non-existent child. She's been having counselling for two years now because of all the effect on her. She's much happier now that she goes to her school and he goes to his school. It was awful. She was coping with this every day and the teasing. Kids are cruel. She's a different child now. When they did this inclusion program they should actually look at the effect it has on the siblings going to the same school. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

Inclusion depends on every teacher taking responsibility for educating every child in the class and where necessary having access to other resources. It has been shown to be very dependent on attitudes and values and requires constant re-interrogation. As one provider said 'inclusion is a minefield'. What was clear from parents' experiences of inclusion was the lack of consistency in implementation and concerns that mainstream schools are unable to provide a fully inclusive environment due to poor resources and lack of training for teachers and aides. Although the policy is to include children with disabilities, schools maintain autonomy over the way in which they provide for disabled students and this means that not all will get the same welcome. The reception parents got was dependant on the principal, individual teachers and the level of disability awareness in individual schools. This meant that in one school a pupil might be suspended due to challenging behaviours whereas in a neighbouring school which had fully adopted inclusion they were able to fully integrate them and maintain control over any difficult behaviours. Experiences could also vary from year to year as children changed classroom teachers. Some parents reported very favourably on support systems in other states where funding is easier to acquire at lower levels of disability, where support services in schools can be more holistic and better coordinated and where there is much more awareness about and commitment to providing an inclusive student-centred environment.

However families in Tasmania find themselves in the middle of a maze surrounded by class teachers, principals, aides and other learning supports where, as one provider said, 'Everyone has an opinion but it's the families themselves who have to make it work'. It means that inclusion can become a major stress in family life particularly when children may require a more protective environment. As one parent said:

They have this inclusion policy but they don't back it very well. Inclusion for some students is good but the staff have no idea what they're doing. The teacher aides were single mothers whose kids went to the school. They had never been aides before, no formal training, no nothing and they are sticking them with the highest needs students that are non verbal, with behavioural issues. They have no idea what they're doing and there is nothing in the guidelines that they have to be trained. Anyone can go and do it. The government need to look at that if they are going to give the holiday pay. They need to take on training. Last year I sat in a meeting with the autism consultant, the support leader from the cluster, the class teacher, the teacher aide and a few others from the Education Department. The teacher said I don't know why you put so much emphasis on Dean being able to write. As if he is ever going to need that skill. I burst into tears and I could have strangled her. How do you battle attitudes like that? (Angela caring for Dean aged 7 with autism)

The DoE is aware of many of these difficulties and it is one of the reasons why they fund the Association for Children with Disabilities to advocate for parents involved in inclusion issues with schools. The Department has also convened a task force of principals to advise about educational provision for children with disabilities and access to special schools.

7.5 Other Options

A place at a special school is only available to children on the Education Department's register of students with severe disabilities but although a child may be profoundly disabled a special school is not necessarily the best place for them. On the other hand the range of difficulties and behaviours associated with some disabilities can become problems to be solved in mainstream education, whereas in special education the child is not seen as 'different'. This can be a big relief for families. Among families in the research there were those who had always used special schools, those that had moved from mainstream to special education, those that had moved from special to mainstream environments and those who had combined the two. These experiences highlight the need for a range of educational options to be available to families.

Some interviewees were very happy with special education and compared it favourably to their experiences in mainstream schools. They particularly appreciated the caring environment and the ability of the school to meet the individual needs of the child.

He went to the local primary school until Grade 2. It didn't work at all. The first year I gave up work they wanted to suspend him from school for good and we said no he needs an education. We had to fight to keep him in school. All he needs is a one on one aide all the time but they said there's no funding for an aide. We had a big fight to get this aide for him. He got assaulted and he had a lot of problems there. It wasn't suitable for him, not the right environment and he had no help at all. We went to the doctor and I said I'm so scared because no one patrols the toilets and if he got bashed in there, had a seizure in the toilet, he would be there for lord knows how long until they found him. The doctor said I'll get back to you in two hours, he starts (at the special school) on the Monday. He was about five or six years behind in his learning. He loves it there. He has a one on one aide all the time. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

School is fine. I'd be lost without it. There are only five in the class. She did go to local kindergarten with an aide but they wanted to keep her in kindy and I said no. Because she was too big, she has always been tall and she was like the gentle giant. You couldn't put her in with all these little kids. But the special school I can't pick a fault in them. Tina has done well there. (Viv caring for Tina aged 16 with a chromosomal disorder)

The major criticism voiced by those with experience of special education were concerns about children's safety and picking up difficult behaviours and this could operate as a barrier for those unhappy with mainstream options but unwilling to move their child to a special school. One family whose son was experiencing high levels of exclusion in his local mainstream primary school would have preferred having access to a school more appropriate to his needs but they were also unhappy with the special school options.

In Simon's class there are one or two in wheelchairs and the rest are mobiles and you have to watch them all the time. We were worried about Simon being the only one who wasn't mobile and some were head butting walls and windows and throwing lunch boxes across the room. We were not impressed with him being in that class. You won't know if he's hurt or anything because he just won't make a sound. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

Sean picks up on bad behaviours very quickly. You have children there of 14, 15 with that broad spectrum who have really bad behaviours who he would pick up on so that's not an alternative either. So actually we haven't got any special schools where he could

go. He would love to go and has always wanted to go to somewhere else but finding a place (is difficult). They should open up another school for children like Sean. (Liz caring for Sean aged 12 with multiple disabilities)

And another family wanting to combine special and mainstream education had been unable to find a mainstream school to take their son:

He goes to a special school. He loves getting on the bus in the morning. He gets really upset when he doesn't go to school. The school is really, really good but when we moved he was going to spend half the week there and then a couple of days at a normal school. But they couldn't find a normal school that would take him. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

There was also one boy with multiple disabilities who had been successful in using both special and mainstream education, although there had been some problems:

He started at the special school when he was four. There were some lovely people there. In grade 5 his work was going too good and he was finishing his work before the others so they put him into primary for two days and special school for three. In grade 6 he went to the primary full time and then started in high school until grade 10. We had a bit of trouble there with boys being awful to him in the chair, he would run over people in his chair. They would expel him for a week and he was home for a week and he would go back for a couple of days and then they would send him home for another week. He was just trying to get into trouble to get out of school. Now he's at college, he started last week. He's doing wood work, practical maths and English, cooking. (Janine caring for Andy aged 16 with cerebral palsy)

If a child is having bad experiences at school or is being picked on parents can also choose home schooling. Three families in the research had resorted to home schooling and were now much happier about the education their child was getting.

The principal there said there's a program called distance education, open learning and he can do it at home. We found out about it and said to them this is Nick, these are his medical problems and they said yes we'll try him. Since he's been on the home schooling he's learnt more than at school. He does his work but if he gets into trouble he says Dad how do you do this and we are there to help him. Since then, and he's been doing it for four years, he's shined like a star. It's his own work. He can get on the internet and go into his classroom. His teacher comes up twice, three times a year to see how he's going. They have activity days where they come up from Hobart and have a sports day or socialising day. It's been great. He loves it this way because they treat him one-on-one and they don't look at his disability. It's fantastic. I wouldn't put him back up at the school now. (Kath and Jack caring for Nick aged 14 with spina bifida)

7.6 Leaving School

School for many families offers some respite from the demands of caring. Leaving school therefore raises a host of issues for parents about what their child will do, where they will live, who will care for them and their future financial security particularly as many may be unable to gain employment or participate in study or training. This transition to adulthood has been described by both families and service providers as a 'black hole' with limited options for the

young adult with a disability, combined with a drop in the levels of support available to families. At 16 children move onto the Disability Support Pension or onto the lower levels of Newstart Allowance if they are not in full time education and are assessed as being able to undertake part-time work. At 18 they move from paediatric health services to adult health services. There are few supported accommodation or day support options. It means that although families might cope while their child is at school leaving school can precipitate a crisis.

Parents in the research were very anxious about what lay ahead and concerned to line up support once their child was no longer attending school. These anxieties can be particularly acute for those parents who are trying to maintain a working life for themselves and they may also face having to give up or reduce their own employment.

I did ring up the other day to see what other options I might have. I am getting really scared knowing Tina is going to be 18 and what do I do with her? Do I stay home with her every day and night? I need my bit of break. It's very touchy. I think by the end of this year I am going to have to really think hard about it. I like the idea of a group home where she can come home as many nights as she likes but still have a bed there but apparently there's a very big waiting list. I dread having to think I will have her home 24/7. Then I won't have any time and I need it. She's very, very demanding. (Viv caring for Tina aged 16 with a chromosomal disorder)

Parents might have been resigned to the fact that their child would be dependant on them for years to come but facing the years of caring ahead and the impact on their own employment opportunities and income was a deep concern to many interviewees. As one mother said, 'You have to take it as it comes. If you look too far into the future it's depressing'.

There are times when things get a bit on top of you and you start to think how can I do this for the next sixty years? Anything I've learnt with Tim is always different and not like the text books so you have to treat these things individually and as they come up and not get too far ahead of yourself because that can draw you into not a nice place, how things might develop. If Tim wants to live here then I'm quite happy to be his carer for the rest of my life. That's part of having children. But if he wants to be independent I am quite happy for him to do that too. Sometimes it can get a bit overwhelming on your own. All of the responsibility is on me. (Kerry caring for Laurie aged 13 with epilepsy and Tim aged 12 with autism)

I try not to think too much about it. The future may be better but financially I can't see it improving and as the children get older there is less financial support available as a family for them and yet they may well be dependant on me for some time to come. My husband may not work so we may be reduced to one income. We are not going to have our house paid off, we are not going to have superannuation. His superannuation, because his work has fluctuated so much, is minimal, mine's minimal. We don't have any family that will leave us any inheritance, we don't have savings. We live from week to week. (Gerry caring for three children with autism aged 8, 7 and 6 years)

Although young people with disabilities aged 16-18 years require a planned transition a questionnaire survey of 283 families in Glasgow (Heslop et al, 2002) found that despite legislation and guidance a fifth of those with learning difficulties left school without a transition plan and with few post school options around housing and employment, a lack of information and difficulties in moving from paediatric to adult health services. This situation is reflected among young people with disabilities in Tasmania. Even those who have been in contact with Disability Services for most of their lives have not necessarily been involved in forward planning.

She is coming to the end of the time when she will be full time at school and I don't want her to have nothing. She can go part time until she's 20 so she will be going to the day centre part time as well so she still has something to do. You couldn't have her home all day because I would be booking myself into a loony home. We just can't cope, physically, mentally can't cope. It's too much to ask of a person. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

The Government does acknowledge that the transition of children with disabilities through childhood, schooling and into adulthood requires effective management. There is some assistance available through the Supporting Individual Pathways Program funded by Disability Services which provides support to young adults with disabilities to make the transition from school to adult life. The Government has also developed a web based resource to support the transition to post school life including transition planning, planning guidelines, information leaflets and curriculum links with examples of post school pathways. It has implemented the Post School Options Project to improve coordination, development and provision of options by identifying the service gaps and establishing a mechanism to identify students who may require earlier support. All students – both with and without disabilities - are now also required to do pathway planning and this means that transition planning should become an integral part of the curriculum.

Another key concern of families is how best to financially plan for the future care and support of a child with severe disabilities and how to ensure that they benefit from a parent's estate. Changes have recently been introduced to the rules governing Special Disability Trusts which provide relief from social security tests for both the beneficiary of the trust and family members contributing money into the trust. In essence the first \$500,000 of assets contributed to the trust is excluded from the asset test for social security of the person with a disability. For the family members donating capital up to \$500,000 is excluded from their social security gifting provision. These changes may benefit families with assets but for low income earners who are not home owners they have little relevance and many parents felt bleak about the future.

Personally I've got to the point where I've felt quite drained and been quite sad at the whole thing, where I don't know whether this is how I want life to continue for a long time but there seems to be no happy end to it. You will always be stuck in this daily grind of lots of work with a person with all these needs and you get so tired and there's no happy in there at all. We all love our children but it's very hard. I've sat down and had a really good cry. I'm always the optimist and there are a lot of people out there with a lot more issues than what I've got. (Angela caring for Dean aged 7 with autism)

Ensuring family assets are managed for the benefit of children with long-term care needs involves complex legal and financial decisions. The Australian Government has recently produced two booklets¹⁶ which outline the options available to families in planning for the future financial security of their disabled child.

¹⁶ Department of Families, Community Services and Indigenous Affairs, 2007. *Planning for the Future: People with disability* and *Special Disability Trusts: Getting Things Sorted*. Commonwealth of Australia.

7.7 Summary

Supporters say that just because there may be challenges involved in implementing inclusion, this does not mean that the principle should be thrown out. Parents generally agreed but were keen to emphasise that what was needed was a range of options to fit the spectrum of educational needs. They wanted to see teacher aides who were trained and able to provide high quality support not just care. They wanted to see appropriate levels of funding available to support children with disabilities in mainstream schools so that they did not impact negatively on the education of other children and so that parents and teachers did not have to engage in an annual battle to secure support. As one parent said:

If you're going to put all these children who are very high maintenance and require round the clock care in the mainstream you have to have a back up plan and without the specialised teachers will he succeed? No, he won't. He is just slipping through the system because people are just sick and tired of him. The educational system is letting him down miserably because they just don't know what to do with him. You have to push and it is hard, pushing every day for something better for him and getting the school to recognise it and schools don't. They need to put people down there that work with children with disabilities in the broad spectrum. For children with spina bifida, Down syndrome, Asberger's, they look after them fine but those children who really do need a lot of help they don't get it, they don't get the care or the time. It's a form of abuse really and neglect on the government's part in not giving children what they need. I feel they have failed him terribly. (Liz caring for Sean aged 12 with multiple disabilities)

As well as meeting the gap between the rhetoric of inclusion and families' actual experiences, parents also wanted to see a planned transition into adult life for their disabled child which provided options for the young person and support to families.



8. Access to Health

There is little data on the access that children with disabilities have to mainstream health services (AIHW, 2004) and having a disability does not necessarily indicate poor health. However what data there is suggests that children with disabilities use health services more frequently than others. This section explores the access that children have to generic health services and to specialists, therapy and medication.

8.1 Primary Health Care

For children who are born with a disability or who have acute needs paediatricians and hospital-based specialists provide the initial link with the health system. For those whose disability is identified later and for parents who have concerns about their child's development child and family health nurses and GPs are a common first point of entry into the health system.

Regular development checks are undertaken by family and child health nurses during the first 18 months of all children's lives and these will pick up a number of developmental delays and disabilities. However concerns have been raised by service providers about the recent eradication of the routine check at three and a half years. This means that many developmental delays which would have been picked up at this stage remain unidentified until the child reaches kindergarten. This is particularly true for first time mothers and for those children on the autism spectrum where difficulties may not be apparent until a child is three years or older. It has led to a drop in referrals over the past twelve months of children with developmental delays to the Early Childhood Intervention Service and to Children's Therapy Services.

There is no mandatory training for GPs about disability. This can make it difficult for them to keep up to date with the wide range of services patients can be referred to, manage the relationship between disabilities and other health conditions and commit the time it takes to deal with complex needs. Some of these difficulties manifest themselves in doctors' difficulties in correctly completing 'treating doctor's reports' for the purpose of accessing Carer Allowance or Carer Payment from Centrelink (see page 46). However most families in the research reported reasonable access to GPs and satisfaction with the service they received. Although their doctor might not know that much about the child's disability they were efficient in referring on to a paediatrician when necessary. The importance of having a GP who had some understanding of the disability was a high priority for a number of families and meant they were prepared to travel some distance to remain with a GP who knew the family, knew the child and who bulk billed.

The GP we've got down here is fantastic. He's brilliant with special needs children. He's a popular doctor with millions of patients to see. You can wait a long time to see him. A lot of the other doctors won't deal with Nick or the kids with big medical problems so you are limited to which doctors will deal with it. You get the locums coming in and they don't know what's going on and won't treat him anyway. It's better to stick with the same doctor. (Kath and Jack caring for Nick aged 14 with spina bifida)

The GP is pretty good. She says she fails me but they don't have any training on disability services. I've trialed a few doctors to see how they cope – and they don't know how to coax him and find out what's wrong. Autism people can have a lot of gut problems, digesting food and they have sensory based issues like being touched. It presents a lot of problems when seeing a doctor. They also have a higher than average pain threshold and unless you can physically see it it's very hard to see it. I've stuck with her because she knows me. (Angela caring for Dean aged 7 with autism)

However although those caring for children with more severe disabilities might take their child to the GP if it was a question of a cold or an ear infection, they would commonly bypass the GP and take their child straight to the paediatrician.

He's fantastic but we're a bit beyond a GP. Every time I take her in she says bring her back tomorrow and she'd ring the paediatrician anyway so it's easier for me to go straight to the paediatrician. (Kate caring for Daisy aged 2 with cerebral palsy)

Some recent initiatives in primary health care provide new opportunities to offer a more comprehensive service to those with complex needs. They include access to funding for GPs to formulate care plans with nominated carers. Plans can include allied health services. They also include funding for GPs to attend case conferences and to conduct comprehensive health assessments for people with disabilities which can include prevention programs. GPs are now paid \$200 for each assessment.

8.2 Specialists and Acute Care

Having a child with a disability often means being in regular contact with a paediatrician and a range of other specialists both in Tasmania and on the mainland. Mostly families were very happy with the services received and had nothing but praise for the medical care.

She has the GP, a paediatrician and the ophthalmologist over here. In Sydney she has three eye doctors and an immunologist. So we do the rounds and see everyone. The government pays for the airfare and the accommodation so it's fairly good. We stay at Ronald McDonald House in Sydney which is right behind the hospital and volunteers make meals. (Winnie caring for Tess aged 8 with visual impairment)

They have been absolutely fantastic the doctors at the hospital. We go back every week and it's great. We are on first name terms. Because we live so close he is classed as an in-patient. We are just waiting for the test results. You cannot fault them, they have done everything in their power to help us. They have sent us to Melbourne. Hobart has been great. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

However families also identified a number of barriers to accessing good medical care. These were shortages of specialists, difficulties in getting a diagnosis, financial costs, the quality of emergency services and links with community services.

Firstly access to specialists was certainly an issue for some families. It can vary from region to region and interviewees particularly commented on the shortage of paediatric neurologists generating long waiting lists in the south of the state. They were very appreciative of specialists from the mainland who were prepared to run regular clinics in Tasmania to improve access for Tasmanian patients.

Where her back and her hip are concerned it's all the Royal Children's (in Melbourne). Up until three or four years ago we had to go to Melbourne for everything, even just a day visit or an hour visit. But now they've started to bring the specialists to Hobart or to Launceston for the day so we get to see them for half an hour instead of flying over for the whole day. (Sandy caring for Ellie aged 16 with cerebral palsy and vision impairment)

For those families where the diagnosis was unclear or where there was disagreement among specialists about treatment it was very difficult. A constant dilemma for some families was wanting to explore all avenues and reach some kind of solution or diagnosis but having to do so without support from their doctor. This meant that some were going it alone and paying privately for paediatricians and second opinions if they could afford it.

With the paediatrician you get that feeling that they just rub their head in dismay and haven't got a clue about what to do. He just says there isn't anything I can do for him. Everyone chucks him in the too hard basket. I would love to get the specialist to work out what is going on in his brain but you have to have the money and the funding and the paediatricians say what is the point in getting any more diagnoses, it's already there. I disagree. I would like to know it's been done. You find they can get to know him too well and they are not looking for anything. What one doctor won't pick up another one will. (Liz caring for Sean aged 12 with multiple disabilities)

We've been having fighting battles with doctors. Since they put this other shunt in we've had trouble. We want to get his problem fixed so he can lead as normal a life as he can but then we have doctors saying yes he needs an operation to fix the problem and the other one overriding saying he doesn't need it. This has been going on for years. I took him back to the family doctor the other day and the doctor here reckons he's got a trapped nerve but they don't do anything about it. Nick is getting moodier and moodier with the shunt, you can't touch him, he's in pain, so we're putting up with his anger and mood swings. The doctor reckons that when they put the new shunt in they put in a smaller reservoir and the amount of fluid that is trying to escape is greater than the reservoir can hold. So it's draining the fluid out but probably not as quick as it should be and it's building up pressure on Nick which gives him pain. It must be a burden on him to have all that pain. He does ask for Panadol when it gets really bad. My doctor reckons we should get a referral and go and see someone else but when you look at Tasmania there's only two neuro-surgeons so we would have to go outside Tasmania. (Kath and Jack caring for Nick aged 14 with spina bifida)

Families identified financial barriers. A number commented favourably on the Patient Travel Assistance Scheme (see page 120) which had assisted them in meeting transport and accommodation costs. However there are often considerable costs involved in seeing specialists.

Tom goes to specialists and it will be \$80 or \$90 and Medicare will only cover half. If he has a scan or anything that's \$400 or \$500 and they will only cover half. It's very, very difficult. We got a loan and we couldn't pay it back. My girlfriend lends us money. It's just scratching and we have to ring around and borrow and then pay it back on pay day. We are supposed to go back to the doctor at the end of last year but we haven't paid the bill yet. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

There had been difficulties for families who had used emergency services and they commented on the lack of disability awareness among staff in emergency departments.

We sat in a cubicle for eight hours and after a while the doctor came in and asked if we could keep him quiet because he was just screaming. The paediatrician also worked at the hospital and he came in and seen us sitting there and made them send us straight up to the ward and said we were not to be kept waiting. How can you keep a child like that quiet? He wasn't very happy with them. All these doctors walking around saying can you keep him quiet? They had no idea. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

Other studies have found regular 'diagnostic overshadowing' where physical illness is missed because it has been attributed to the child's disability. This was certainly true for one of the families in the research sample who had used emergency services.

That emergency department is terrible. If it's a disability they don't want to know, get them away. He fractured his arm and shoulder last year and six hours they made him sit in the waiting room because he wasn't screaming in pain and then they told me he was fine. Then when we get into the x-ray they found he had a fracture. We tried to explain these kids don't always cry in pain. He doesn't talk much at all. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

Lastly there can be difficulties in coordinating acute and specialist medical services with community based services for children with disabilities. One parent commented on the completely inadequate support she had received on discharge from hospital with a baby with profound disabilities:

The community nurse came three times. She popped in to say how are you going which was lovely. I'm trying to say no I haven't got post natal depression, yes I'll come to the mothers' group if I can. But with a kid going home for the first time I needed a nurse to come every day and make sure I was confident in tube feeding. Not just coming two or three times but coming every day until you're confident in a nursing role which you've never done before, let alone looking after a brand new baby for a first time mother. So definitely there should have been someone who came with me when we went home. (Kate caring for Daisy aged 2 with cerebral palsy)

Peak organisations for particular conditions or disabilities regularly complained that hospital staff and specialists did not inform patients about their existence despite the fact that they could provide high levels of support to newly diagnosed children and their families. In some cases they had also been omitted from directories of services that are available in the community. They put this down to a lack of commitment, a lack of an appropriate framework for effective discharge procedures and high levels of staff turnover in acute settings which meant that information was continually being lost.

8.3 Therapy Services

An integral part of the service system for children with developmental delays and disabilities is therapy. Therapy can provide an early assessment of needs and provision of coordinated support which can maximise developmental opportunities and avoid or minimise secondary health issues. It can reduce demands on carers and on service systems and early intervention can reduce longer term costs. Therapy aims to develop, improve and maintain wellbeing (AIHW, 2006) and is seen as a broad range of interventions to reach individualised goals which embrace the family and the community. It can include:

- physiotherapy to maximise mobility and quality of life;
- occupational therapy to maximise independence, self care and the effective use of aids and equipment which are often a component of therapeutic interventions;
- speech therapy for the diagnosis and treatment of communication difficulties and to maximise the ability to communicate;
- psychology to assist with better functioning; and
- social work providing advocacy, assistance in accessing services and personal support.

There are also alternative and complementary therapies like acupuncture, recreational and music therapy and sports and art therapy.

Therapists can assist under-fives to develop physically, cognitively, emotionally and socially. They can prepare children for school and assist them in accessing education, maximising their participation in the classroom and improving their ability to sit, perform tasks, engage socially and use aids effectively. They can work with classroom teachers to provide ideas and strategies and work outside school hours to provide counselling (AIHW, 2006). They can help to improve confidence, provide general support to the family and reduce the need for hospitalisation.

Therapeutic services in Tasmania are provided in a range of settings which can make it confusing for services users. A recent review of children's therapy services in Tasmania (Evolving Ways, 2006) mapped service provision across the state. It showed that services have evolved differently in each region. Both the DHHS and the DoE provide funding for paediatric therapy in specialist clinics, schools, ECIS, hospitals and other community settings. Within the DHHS therapy is funded through three different divisions which each manage different contracts and with services provided by departmental staff, NGOs and private organisations. The DoE directly employs speech therapists, psychologists and language pathologists and purchases physiotherapy and occupational therapy services from the same providers who deliver DHHS funded services. Families can access therapy through:

- **Children's Therapy Services** who accept referrals from any source including self referrals and although there is a strong focus on the 0-5 age range they can provide for children up to the age of 18 years. In the south these are available through the Children's Therapy Service run by Calvary Private Hospital on a three year contract from the government. It employs a range of allied health therapists including a psychologist, social workers and two part time paediatricians and provides access to assessments and reports, counselling and information. The service has formal arrangements with the podiatry clinic at the Royal Hobart Hospital and with orthotic and prosthetics services. It also has a language program operating in three local authority areas which picks up many 'non-disabled' school aged children and provides help with handwriting, communication disorders and other conditions which affect access to education. In the north similar services are available through the St Giles Society. They also include access to psychologists and to social work support. In the north west paediatric therapy services are provided through the North West Regional Hospital (NWRH).
- the **Early Childhood Intervention Service** which provides access to speech therapy on site and can facilitate access to other therapies through referral to Hobart Therapy Services in the south, St Giles in the north and the NWRH in the north west.
- **schools** which provide the main point of access to therapy for school aged children through a referral from guidance officers to Children's Therapy Services or to therapists employed by the DoE. The DoE employs speech therapists and psychologists. However this service is not well resourced enough to meet the speech therapy needs of all school aged children and they are then unable to access speech therapy through Children's Therapy Services as it is considered to be 'double-dipping'. The DoE do not employ occupational or physiotherapists so school aged children with these needs are referred to Children's Therapy Services or community paediatricians. In the south there is also the Targeted Schools Program providing physiotherapy and occupational therapy to children not eligible for Children's Therapy Services, for example for those with minor equipment needs like a writing slope.

In non-government schools therapy is provided by Children's Therapy Services and they are funded to purchase speech therapy from private providers.

- Clinical Support Services in **hospitals** which can provide occupational and physiotherapy following assessment and treatment for post-acute care. This can include home visits and trials of assistive equipment including wheelchairs. There may also be assistance with additional respite services to children following surgery at the Royal Melbourne Children's Hospital. Hospital social workers can also provide information and support prior to discharge.

In addition there are **Community Health Centres** which provide some speech and language pathology services but with services differing between centres. **GPs** can provide access to a number of alternative therapies for children with a disability and there are **private therapy services** offering a wide range of options for those who are in a position to pay. These costs can be substantial.

Once children turn 18 they lose access to therapy through children's services and become reliant on a GP referral. Service providers described this as a big issue for families as it commonly involves a reduction in access and can create considerable stress.

Some therapy services can offer help with travel costs. If families access speech therapy through the DoE they can apply for a petrol reimbursement. However this is not available for other therapies accessed through Children's Therapy Services.

There are well documented financial and administrative difficulties in accessing therapeutic services for children across Australia (AIHW, 2006). This has generated a significant unmet need for therapies which support social activities, for social work and for family support interventions. Shortcomings identified in the access Tasmanian children have to therapy services have led to a series of reviews in the last decade. The most recent review (Evolving Ways, 2006) was jointly funded by Disability Services and the DoE and aimed to identify ways of improving equity in access state wide. It has highlighted a lack of a policy framework for children with disabilities within which therapy services could operate, no single point of information or referral for parents, on-going problems with recruiting and retaining allied health staff and an inability to focus on early intervention. Overall the system has been described as lacking in collaborative planning mechanisms between agencies which has fostered a lack of consistency and coordination. As one provider said, in essence it is a multi-disciplinary team spread across two or sometimes three different agencies. This does not facilitate good coordination. It means that although access to therapy can be good in special schools and in the early years, there can be a big reduction in the amount of therapy available once children reach school age and families, particularly those in mainstream schools, can fall through the gaps. It means that social workers spend time trying to coordinate services. It also means that therapists employed by Children's Therapy Services are funded to work with education staff and are involved in assessing school environments for modifications but have no control over how budget decisions are subsequently made. This can cause high levels of frustration.

8.4 Experiences of Accessing Therapy

For the families in this research access to therapy had typically been good for younger children. Families had found services very helpful in all sorts of ways and had been impressed with the difference it could make. However for school aged children it was more problematic and families

commented on the acute shortage of some allied health practitioners, particularly speech therapists, and especially in the north west region.

There are no speech therapists now and he needs it desperately. He had no speech therapy for a year, all the way through kindy and then last year she did see him a few times but he's in the hard basket and she's got all the Meander cluster to do, one girl. Now she's pregnant and will be away for 18 months. Where do all these kids get their therapy? It's wrong but there's no one to take her place. He's got to go next week for more orthotics to see the OT and the physio. But once this OT leaves there is no one to take his place, no one. The other girl, she refused to pay her holiday pay so she went to the mainland. The girl after her was just as nice and they refused her too. What's wrong with this system? This young bloke, he's finishing his apprenticeship and then he's gone. It's a battle for everyone, it's shocking. He needs occupational and physiotherapy all the time. (Jackie caring for grandson Jake aged 6 with multiple disabilities)

I had an excellent speech therapist through the Community Health Centre who had him right through prep and that year he started speaking much clearer. That was the most vital year. He was mixing with other children at school and not able to make himself understood. He was very frustrated and just having that regular input once a fortnight. Sadly she left and the Department of Education were hopeless and wouldn't do anything because the children were going to a Catholic school and there was no support. There was one person who finally saw my son once at the school he was at. Her job was to do an initial assessment whereby she gave us a report and said we needed to do this, this and this and follow it up at our own expense. We are on a really low income and at \$50 an hour get real, I have to put food on the table more than get speech therapy. I utilised some of the knowledge I had over five years of speech therapy to implement what she was doing. They have a wonderful service at Calvary and he went through the OT and physios there. They didn't do the speech because they don't double dip. If you have speech in one place you can't have it in another. (Gerry caring for three children with autism aged 8, 7 and 6 years)

Lack of assistance with behavioural issues was a key issue for many families, particularly for those caring for children with autism or ADHD/ADD. These children do not necessarily develop any functional language and their ability to communicate may be severely impaired. This can result in frustration and aggressive or violent behaviour in their efforts to communicate. The community and service providers can attribute these kinds of behaviours to bad parenting or an absence of discipline and this can impose severe stress on families in their efforts to cope with minimal support. Children's Therapy Services do have psychologists as part of their teams who are able to assess the child but not able to provide interventions. Social workers are not supposed to do behaviour management although they may be able to offer coping strategies. Disability Services offer a challenging behaviour program but it is mostly delivered to adults in group homes. The DoE do employ psychologists but shortages mean referrals impose long waiting times and few have particular expertise with conditions like autism. This means that families often embark on a long search to get access to a psychologist who can advise them about behaviour strategies and support them through implementing interventions.

You have to pick up therapy through school and that's difficult. The psychologist is only up there one day a week and she's got heaps and heaps of people to see. Tim has not seen a child psychologist since he was diagnosed. (Kerry caring for Tim aged 12 with autism and Laurie aged 13 with epilepsy)

In South Australia we had the child psychologist through the community health centre. When we had problems he helped us try different things which helped us to cope. We could actually talk to him about what we were feeling as parents, when we would go out and our child would be unmanageable. We had that support there. But down here the system doesn't seem to have that at all. There is no medical support system that understands autism. We haven't found a psychologist in the system that would talk to us, or just someone we could get some help from with how we should be disciplining him. We've searched all over the place trying to find somebody, but we haven't found anyone. Perhaps we've looked in the wrong places. We tried to access somebody in Hobart and they said no you've got the services in the north, we provide services for the southern area. She was a paediatrician and we found out through one of the other mums in the school that she had a particular expertise. I think a lot of the time the doctors don't know who they can send you to or even if the expertise exists. We also hooked into a lady who did home visits and came and observed you. She was in private practice in Hobart. We thought we could afford it, it didn't seem too bad and she said she could come and see us. It sounded excellent, really good. We had her all set up to come but she got ill so it fell through. And at that stage Rowan was really quite violent, kicking us and head butting us. The biggest thing that would help us now is some kind of psychologist support who we can go and talk to and work out what it is we should be trying. We are very much on our own coping with his behaviour. (Di and Tony caring for Rowan aged 10 with Asberger's)

Many parents desperate to get information about how to deal with particular behaviours had used the internet. This could make things worse as parents read about the worst case scenarios and panicked. Some had accessed private therapy to supplement what they were getting or to access treatments not available elsewhere. For instance trying to get two physiotherapy appointments a week can be impossible in the public system and would require families to pay privately. These costs can be substantial and combined with the additional travel costs to get to and from services (see page 121) place them outside the pockets of most families on low incomes.

That's where he gets his physio. It's not as regular as we'd like as all the funding has been cut back but we go up there every three or four months for assessment and see how he's growing and his physio needs. They do their assessments, give us our exercises to do at home and then we go again six months later. Really he needs more physio. He's getting a lot bigger and taller and the exercise he was doing when he was younger needs updating. (Kath and Jack caring for Nick aged 14 with spina bifida)

There are things like accessing psychologists to get a report done, accessing speech therapy to get some ideas, accessing any services once they get to school age. There suddenly becomes a cost involved in doing that. For example my children have low muscle tone so I need them to be doing something like swimming or dancing to improve their coordination and muscle tone. On my income I would not normally be able to pay for that, it's an extra cost that we can't afford. But my dilemma is that I want to do everything for my children to give them the best possible start because there's no going back. But there are costs involved because you can't just put them into any swimming class because they couldn't cope so you have to pay the extra to get them in there. They have doctor's appointments, specialist appointments. There's the cost of paying for the specialist appointment because I'm not in a health care fund. I can't afford it. There's the cost of transporting them there and then the added cost of prescriptions. (Gerry caring for three children with autism aged 8, 7 and 6 years)

One family had employed private therapists to implement applied behavioural analysis (ABA). This provides individualised programs designed by autism specialists with parents as partners and is considered to have very positive outcomes for children with ASD. However these therapies can be extremely expensive and time consuming for the family to implement at home.

ABA is considered to be the only therapy which has any significant intervention with children. To do that it comes at an amazing cost. At the time it was putting me back about \$600 a fortnight so at least \$1,200 a month. So if you had to register your car every week that's what you'd be looking at. I did that for two and a half years from when he was three. I got ten hours a week of one to one intervention therapy at home or at the child care centre because I was at work trying to pay for it. On top of the \$600 you would also be looking at speech pathology which is \$130 an hour and at that time you couldn't claim it on Medicare. With private health you get about a \$20 rebate on \$130. If you work you can't access any of the services because they are only offered between the hours of about 9 and 12 so you are in a catch 22 about what you can actually do. Your choice is do I keep working and have some services that I can provide and it nearly runs you into the ground or do you stop working and try and access these tiny bits of service that you can and also be running yourself into the ground by having to do this really full on intervention program as well? So there's not a bright outlook on either side of it really. There is a half an hour appointment once a week to once a fortnight for speech pathology and then next week you might have a half an hour appointment for OT but the responsibility there is on the main caregiver to put any of those programs into place. So not only have you got the behaviours that you're trying to deal with, the autism and the fact that he couldn't dress, couldn't feed himself, was not continent, plus trying to put in these intervention programs on your own as well. So I employed private health for these ABA therapists. They recommend the child needs 30 to 40 hours a week and I can only put in 10. So although he only made small gains along the way it was nothing compared to what he could have had if he'd had a good, strong intervention program for a couple of years and we wouldn't be where we are now. (Angela caring for Dean aged 7 with autism)

Some families, coping with behavioural issues, had tried to access mental health services but this had been problematic. Child and Adolescent Mental Health Services are delivered through three regional centres, Oakrise in Launceston, Bourke Street Clinic in Burnie and Clare House in Hobart. Although in theory they also offer assistance to those experiencing behavioural and emotional problems, in practice and given the demand on services, priority is given to those with mental health problems. They will only assist if there is a diagnosed mental health problem and if the children referred are cognitively functional. This means that most on the autism spectrum would be excluded unless there were additional problems like depression, anxiety and obsessional/compulsive disorder. It would also exclude those with an intellectual disability and challenging behaviour. Services described situations where they had referred to Child and Adolescent Mental Health Services and the referral had been passed back because the child had a disability and it was therefore considered inappropriate for Mental Health to deal with it.

She went to Clare House and saw the psychologist and psychiatrist there who frustrated me. The psychiatrist was probably very experienced in dealing with people with mental illness. The difficulty is that Asberger's isn't really a mental health problem, it's a disability. I needed strategies to deal with her behaviour, deal with the fact that until 12 o'clock at night she was kicking the wall and I couldn't get her to go to sleep. I needed those sorts of things from the psychiatrist but she said she didn't believe in labelling. (Gerry caring for three children with autism aged 8, 7 and 6 years)

Sean was with Clare House and they discharged him because they couldn't work with him, they just give up. I had to get in touch with Sean's coordinator at Disability Services and ask for a psych referral. I felt it was something that really needed to happen and so did Disability Services but there was no money. I rang the school this week to ask them to give permission for Sean to have a psych referral and Disability would provide their psychoanalysis person who specifically deals with children like Sean and works with the psychologist at the school and gives him strategies about how to work. The school's budget is very limited and he just doesn't get what he really needs unless you're prepared to push and push and push. (Liz caring for Sean aged 12 with multiple disabilities)

There are also gaps in social work support and access to counselling to help cope with the emotional strain and the burden on relationships. The Commonwealth Carer Respite Centre does provide a counselling service offering emotional and psychological support to carers but most services do not have the funding to be able to provide anything beyond someone to listen and a sympathetic ear.

What was clear was the pressure on parents to feel they had done the best they could for their child and their main concern was that they were missing a 'window of opportunity' to help them be all they could be (SPRC, 2003). This struggle to do well by their child and the involvement it required from parents to implement therapeutic regimes at home took its toll and it was easy to get caught up in a circle of goals and targets rather than allowing their children to just be children.

We have hearing appointments and appointments at St Giles, at the doctors, or the OT. With Meg she got it a bit rough early on. It was almost like it was physio all the time. You would go to St Giles and they would say work on this and we were almost fanatical about it. You can't be educated all day, you can't pump them 24 hours a day. When they are with us it's with mum and dad, it's not physio or school. Our job is the fun side of things. With Meg and David you learn to appreciate the little things they do, the eye contact. You might talk to them ten times and once they might look at you so you really appreciate that. So you focus on that rather than on the fact that they're not doing it. All everyone worries about these days is the kids walking and talking. Meg is seven and she doesn't walk. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

This pressure is particularly acute in the autism field where a range of private providers offer services for autistic children often at a substantial cost. There is also convincing research evidence to suggest that high levels of therapeutic intervention early in life can have a big impact on later outcomes. Families are prepared to sell their house, access funds from grandparents or to move state to access these treatments or to make contact with 'experts' in the field. Because so many were unable to afford these costs it left them with a burden of guilt that they had let their child down.

He is now in grade 6 on a grade 2 book and you would have hoped for a better outcome than that. I think that if he had had the proper teachers at the right time or had people with expertise in that area who knew how to work with him he would be in a different place. (Liz caring for Sean aged 12 with multiple disabilities)

8. 5 Medications

Not all the children in the research were taking medications, beyond occasional pain relief, and some parents described their children as very healthy. For those who were on regular medication their Health Care Card meant that they had access to financial assistance through the Commonwealth Pharmaceutical Benefits Scheme. This subsidises the cost of commonly used medications and means that while general patients pay \$30.70 per prescription up to a safety net threshold of \$1,059 in a calendar year holders of concession cards pay \$4.90 for each prescription up to a threshold of \$274.40 beyond which any scripts are free until the end of the calendar year. This subsidy meant that for most families the cost of medication was not a big issue.

The medications are all on the PBS and with a Health Care Card they are not overly expensive. I think if you ran out of all of them in the one week you would be in a bit of trouble. So they are only \$5 a hit for each one but you can have four or five boxes going at the same time. If you're on your last few dollars and all four ran out you would be in trouble. (Sally caring for Claire aged 6 with epilepsy)

However for those taking many different kinds of medication costs could be significant especially when not all drugs are covered by the scheme. It could not only impose complicated medication regimes on families where they might be visiting the school several times a week to administer tablets or eye drops, but there might also be difficulties in accessing the medication from different sources as well as unscripted medications to pay for.

We have to give him 28 tablets a day. You have to try and get these tablets down this little boy's throat. The only way we can do it is to open his mouth up and give it to him like a puppy dog. At the moment it's all supplied by the hospital. We pay for it but we have the card. Melatonin we pay for which is \$75 a bottle. When you're not going through the hospital it's a bit of a pain because you've got half of them the GP can write a script for but other things you have to go to the paediatrician. So we will be looking at \$100 a time to visit and then to Medicare to get your rebate. It's the mucking around just to get a script written. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

We have to pay \$50 for his Melatonin. Meg's epilepsy is cheap but it's ongoing. There's constipation so you have to have laxatives which then leads on to the nappies. Laxatives are not on scripts. They do have a lot of ear infections so you are forever buying scripts there. It is \$5 a script and we can have up to three or four scripts a month. He's on iron at the moment because of deficiencies. It's up to \$70-80 a month. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

She's on a lot. She takes this three times a day and then she has her tablets in the Webster pack and then there's the Panamax when she's looking a bit off. If I had to get her drugs from the chemist and they're not on the free list, just for her calming down tablet it would have been \$33 for a pack of four. So I get them through the hospital for \$4 something. And also the Movicol which makes her bowels open which again is about \$30 but I get it for the \$4.90 or whatever the scripts are now. I would be lost without that and of course I didn't know about that either and I used to pay. I think Tina was about 14 when we realised that you could get help with it. Now I don't have trouble. I just ring up and go in the next day and it's there ready for me. (Viv caring for Tina aged 16 with a chromosomal disorder)

He gets a lot of urine infections so there's a lot of antibiotics and usually by August we get to the threshold. Some of Nick's antibiotics we can't get them for the \$4 and it's \$7. You get an antibiotic that's cost \$7 and he just gets used to that and then the doctor rings up and says he's got this sort of infection and that antibiotic I prescribed for him is no good so we have to get another one that's worth more than \$4. You are constantly changing antibiotics, spending the money. It's a pain in the backside forking out that money. (Kath and Jack caring for Nick aged 14 with spina bifida)

What was particularly difficult for many families was trying to find the most appropriate medication for their child's condition. This could involve them in a long journey where they were testing different options and coping with what could sometimes be negative results. This could be especially fraught for medication which controlled behaviour.

Doctors have always been saying try Ritalin. A paediatrician suggested that maybe stimulants would wake him up enough to listen to signals so after years of saying we wouldn't we tried it for a while. He lost weight on it and his anger became much greater when he was not on it. So at school he was perhaps more reasonable, but at home when he was coming off it every day he was terrible and it was destroying our family life. At that stage we were seeing a private psychologist and he supported us in taking him off it. (Di and Tony caring for Rowan aged 10 with Asberger's)

She was started by a paediatrician on a full dose straight away at the age of two and her regression plummeted. When I saw another paediatrician for a second opinion we cut that down and she started to build up her development skills again. We don't like being guinea pigs and I'm sure that was going on because it was reasonably new at the time. (Sally caring for Claire aged 6 with epilepsy)

For the last three years he'd wake up at two and stay awake until five or six and then go to sleep just before breakfast. He was very aggro all the time. He would slap himself in the head, refuse to wear his hearing aids, off the show. But three months ago the doctor put him on Melatonin. We put him on it just before he started school and it's been amazing. He still gets us up two or three times in the night but he's a totally different child, more mellowed and he can be educated. Without calming down he would have been too disruptive to the other children. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

8.6 Summary

In interviews with families what was striking was the extent to which they themselves were having to push for their children to get the health and therapy services they felt they needed. There were few certainties or final solutions. Instead there was always the promise of a second opinion, more effective therapy, better medication, or a more experienced specialist to tempt families. Families often lived with an overwhelming sense of having failed their child if they were unable to access these interventions. The problem was that they often came at a considerable cost which was beyond the means of many families who were already struggling to survive financially.

You have to do it yourself and push, push, push. St Giles I saw on the TV when he was six months old and wasn't attempting to sit, roll or do anything. They used to come out three times a week with manipulating, massage. I am so grateful to them that he is where he is. If it had been left to the doctor he would still be in a wheelchair. If I hadn't gone to Sydney and found a lovely surgeon he wouldn't be walking. (Jackie caring for grandson Jake aged 6 with multiple disabilities)

9. Affording The Essentials of Life

This section looks at how far families with disabled children were able to access the essentials of life – housing, transport, food and clothing. It explores the ways in which they managed on limited budgets and whether or not they could pay their bills.

9.1 Housing

Given that a key policy objective is to enable families to deliver intensive home based care to their disabled children the quality of housing is a major concern. The difficulties low income households face in accessing affordable housing in Tasmania have been well documented and many commentators describe it as a crisis (Cameron, 2002, Gabriel, 2004). For families caring for a child with a disability who have additional support needs and special requirements these difficulties can be particularly acute. Fully accessible housing is only a tiny proportion of the total housing market in Australia and traditionally only provided by public housing authorities who manage less than 10% of the stock. Inappropriate and expensive accommodation at a distance from services and/or in difficult neighbourhoods can mean that families do not gain the support they need, have increased stress levels and run the risk of isolation and social exclusion. This impacts negatively on their ability to care for their children.

Families who participated in the research were living in the range of housing tenures with ten families buying their own home, nine living in public housing, four renting in the private rental sector and one family who were currently homeless and staying with relatives. Interestingly six families had moved to Tasmania from the mainland because of issues related to their child's disability; for instance to be nearer to family and informal support, to be in a climate which better suited their child's condition or to be able to access a particular service or school.

9.1.1 Home owners

Owning a home can provide an important cushion against the impact of disability and offset some of the costs of care. Home owners can borrow against their house or downgrade by selling, buying somewhere cheaper and using the proceeds to fund disability related expenses. How far were those in the sample able to use their advantage as home owners to get the accommodation they required?

One family had sold their house to free up money to pay for expensive therapy:

I had a house and I had to sell it when he was first diagnosed to get the ABA therapy. Unfortunately it was just before the boom so I only made \$20,000 out of it and it didn't go very far at all. I am renting here now. This house is actually pretty good but it is quite expensive, it's \$260 a week. (Angela caring for Dean aged 7 with autism)

Certainly most families had found that considerable modifications were required to meet the needs of their disabled child and that this could require significant investment. They had had to improve security and storage and upgrade bathrooms and kitchens.

We have adapted our house for Chloe. We put in fences to stop her climbing out of the back yard and we have to have a child proof gate so she can't get out. Then we childproofed the inside of the house which entails locks on certain things and putting a food cupboard in which is lockable because we have to keep the food away from her. Garbage bins have to go in there too because she will eat from the garbage bin. All

other things, dangerous things, I have to lock away like poisons and detergents and we have to have the power points covered because she sticks things in power points. Inside the house we have to have the security of being able to put her in a room and lock the door to secure her for her own safety during the night. In the bathroom, it's an issue with the taps. I can lock the bathroom door otherwise she turns on all the taps and can scald herself. The same with the laundry, it's locked so she can't get in there. The door to the front of the house is always locked as it's too near the road. We put a bigger shower in because a carer has to be able to get in there and help her shower. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

Unfortunately there is very little assistance available to home owners to meet the costs of any modifications. The sources of assistance are:

- **HACC funded home modification and maintenance services** where users pay a \$10 maximum service charge and pay for the cost of materials. This is available to HACC eligible families (or those families caring for a child who has difficulty performing everyday tasks and where without assistance they may require admission to residential care).
- the **Community Equipment Scheme (CES)** which can undertake minor modifications like grab rails and ramps. Again installation is free but the user pays for materials.
- **Disability Services** who can fund minor modifications if funds permit.

However none of these schemes can fund major works like bathroom or kitchen modifications. This means that either families waited for windfalls or they had approached charitable bodies or they lived in substandard housing which did not meet their needs. It meant that in situations where the cost of adaptations or their feasibility was prohibitive families were forced into contemplating a move.

We have had the physio come out but our biggest problem is the stairs. To put a ramp in it would be outside the window. We have three lots of stairs and I don't know what we'll do about that later on. So adapting it will be impossible, to make the bathroom and toilet big enough. So it's not really possible to change the house. She said people do move. (Jill and David caring for Emma aged 7 with autism and Rosie aged 2 with cerebral palsy and epilepsy)

9.1.2 Public housing

A number of families had good experiences of public housing. They might have had to wait for a period of time to gain access or fight for priority but once they moved in they found it suited their needs and they had been able to get the adaptations they required.

When we first moved down here we were put on category one for a house. They lost our files and mucked us around for months and months. Someone told us to ring this advocate service. We had the house about a month later. They moved us here about five years ago because the other house we used to live in they would have had to replace all the doors. Every door in the house was too narrow and it would have cost them too much. So they bought this house for us. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

Before we were in a two-bedroomed flat and they were sharing a room but with him having night seizures his brother wasn't getting much sleep and it wasn't appropriate.

That was private rental. This is actually a wheelchair accessible house. We moved in three years ago and St Giles, the Housing Department and Disability Services worked together and organised this house for us. It was empty and we got it in a few days. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

For one family it had been a question of reaching crisis point before they became a category one applicant and were able to access a public housing tenancy.

It was only last September when someone suggested I go on the list. No one had suggested it before that and in hindsight I find that quite odd. We were in private rental, a tiny one-bedroomed place with no laundry or off street parking so that was part of the meltdown because I wasn't sleeping. We waited five months and then I wasn't coping or sleeping and I couldn't function. Then everyone got on the bandwagon and helped and rang and rang and they found this place. We did jump up and down. We now have a great little unit. It's adaptable with wheelchair access and we can modify it as she grows. It's so nice, it's sunny and Daisy has space to grow and develop and we can fit in her equipment. I can take her for a walk and go to the supermarket. (Kate caring for Daisy aged 2 with cerebral palsy)

Housing Tasmania has a modifications service to make existing properties more accessible. It is free and there are no costs for tenants although the budget is limited. Applicants require a therapist's report and if the changes to the property will be too expensive or not feasible there are options for transfers to other properties. Although most families were happy with the way in which the Department had meet their needs for housing modifications it can also be difficult to get modifications done in Housing Tasmania properties.

We have been trying to get a rail out the front. He hangs onto the window sill going down the steps. Sometimes he loses his balance in the wet and he falls. We've had hassles after hassles with it, trying to get one. We went to the Housing Department and the doctors to try and get a rail put up and it's just been a battle. We've been here eleven years and more or less for ten years we've tried to get a rail. If I had spare money I'd make one myself but then we would probably get in trouble for it. They've put rails in the bath so he can get in and out. The Housing Department say they haven't got enough money for a rail and the funds aren't there. We'll try to get it next year and they say the funds are not there still and they pass the buck. The physio will have to do up a new report and we will have to push a bit more. (Kath and Jack caring for Nick aged 14 with spina bifida)

They ended up offering us this house. It wasn't wheelchair accessible, there was no ramp and steps at the back, the bathroom was awful but we took it because it was four bedrooms. Four months down the track and Dan's physio said we better get them to do a ramp. They ended up doing it and said that's it, nothing else. Two years later they did the bathroom for us but only because they were hammered again by Rehab. We were going to get one off funding to do it from Disability Services but then Housing said we'll do it but nothing else. But then last August they pulled up all the carpet, repainted it because it was unhealthy and the paint was peeling off the walls in big chunks. They gave me a sliding door for the wheelchair and rounded these edges. So they are good but they keep bumping the rent up - to \$200 a week by the end of the year. It's up from \$153. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

A number of interviewees did comment on the rent levels in public housing particularly on how any increase in income was eaten up by an increase in rent.

9.1.3 Private rental

Families appeared to be finding life most difficult in the private rental sector and they struggled to access appropriate and affordable private rental housing. This is also the experience of other low income groups where the highest levels of housing stress are in private rental properties and there is an acute shortage of affordable housing stock. The interviewees commented on high rents, difficulties in finding rental accommodation in the areas they wanted close to services and instances of discrimination against families with disabled children by private landlords.

It's a bit annoying that we have to pay a fortune to get so close to the school. It feels like dead money sometimes. What I understand for kids with special needs the high school is just as good as the college so I don't see any need to move from this area at all. We have everything we need here mostly within walking distance. (Sally caring for Claire aged 6 with epilepsy)

To get a house for a reasonable price that met our needs was nearly impossible. This is not a reasonable price. It was really, really hard to get something in a reasonable location near to schools at a reasonable rate. However we did but there wasn't a lot on offer. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

We rented off my parents but they wanted to sell the house but we couldn't get a house to rent and as soon as the landlords saw the wheelchair they didn't want to know. They never come out and said but they had excuses. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

Again it is difficult to get any assistance with modifications in private rental accommodation. Although some landlords might be happy to install modifications there can be a reluctance by others to allow or provide necessary fixtures and fittings like grab rails and ramps to their properties and most people get no assistance at all to help with the cost.

There are three steps at the back door and we must put a hand rail on to make it a bit easier for her. I think soon we may need to talk to the landlord or see what's available for showering because I don't know how much longer I can put her into the shower myself because it's over the bath. But I don't think the landlady is going to change the bath around, I can't see her doing that. So maybe a shower chair, maybe we can look at one of those. I will just ask her whether it's all right to do it (the hand rail). I wouldn't expect her to pay for it. (Sandy caring for Ellie aged 16 with cerebral palsy and vision impairment)

One large family currently homeless and staying with relatives described the difficulties they had had in finding affordable housing:

I'm not waiting for government housing simply because it just doesn't work out any cheaper for us because of all the kids. The rent goes on how much you earn. If I'm through Housing and paying \$130 or \$140 a week I don't get any rent assistance whereas if I was doing that privately I'd be getting rent assistance for it. We've been out looking this morning. We've been looking for eight to ten weeks. I don't want to have to change his school. We see ads for a four-bedroomed house which sounds perfect but it's professional couples only and no families. Then you find a three bedroomed place and the bedrooms are too small. They have approved us for the bond assistance but we still have to pay for where we're living and make sure the kids have everything they need plus pay the bills and try and save as well for a new house. We can't find a place for under \$200 a week and then we have to pay three weeks so if we go for a place

for \$200, \$250 it will cost us a fortune. All my furniture is in storage and that's \$125 a month for storage and then removals fees. (Dot caring for Declan aged 8 months with Down syndrome)

9.2 Transport

Having affordable and accessible transport can be crucial for families caring for children with disabilities and impact on their ability to access services and participate in the community. Some assistance is available for families through financial subsidies for the cost of transport and through improving the accessibility of services. These schemes are:

- the **Transport Access Scheme** which reduces the cost of standard taxis by 50% and wheelchair accessible taxis (or WATs) by 60% for holders of concession cards with a permanent and severe disability. There is a maximum concession of \$25 per journey in a standard taxi and \$30 in a WAT. Eligibility requires a statement from a qualified medical practitioner. WATs are available in the main urban centres but not in regional areas.
- the **Patient Travel Assistance Scheme (PTAS)** which provides assistance with transport and accommodation costs to all Tasmanian patients who have to travel more than 75 kilometres intra or interstate to access specialist medical services. The scheme also assists with the costs of an escort accompanying a patient under the age of 18 years. In exceptional circumstances approval may be given for financial assistance for more than one escort. Health Care Card holders are required to contribute \$15 to the cost of each return journey and in any one year the maximum contribution is \$120. Travel in a private vehicle is subsidised at 10 cents per kilometre with a maximum of \$30 per night for accommodation per person. Applications must be lodged before the date of departure through forms provided by GPs or specialists. Reimbursement is claimed on the return home.
- **Disability Services** which will cover some transport costs in limited circumstances, for example, funding the purchase of a vehicle if there is more than one person with a disability in the household.
- the DoE's **Transport Assistance Program**. Although the responsibility for conveying students with disabilities to and from school lies with the parents or caregivers, some assistance is available when the use of private or public transport is not practicable or possible without assistance. Those who are attending their nearest appropriate school or ECIS program may be eligible for special transport assistance from a single nominated residence. This is provided in the form of a conveyance allowance for the use of a private motor vehicle, or contracted bus transport or taxi travel or public bus transport or a combination of all of the above. Contract bus or taxi services are only considered when parents demonstrate that they are unable to provide transport or arrangements cannot be made on public transport or other forms of community travel. Applications for assistance are considered by a Transport Committee. Students enrolled full time in a special school can access contract bus services to and from school without having to make a special application.
- a **Disabled Parking Authority Card** which is available to access designated parking spaces and provides for an additional 90 minutes in metered spaces. The scheme has been criticised for inconsistencies in allocated timeframes and the quantity of disabled parking zones for peak access.
- the **Vision Impaired Travel Pass** which entitles the holder to free travel on Metro services and concession rates on other services if they are legally blind (as defined by

the Social Security Act 1991) and hold a concession card. It is issued for a five year period.

- the **Red Cross** who provide transport to and from medical appointments for people with disabilities for a fee of \$5 per journey. However the routes are limited and the service does not cover all areas. Usually siblings cannot be transported. This makes using the transport very difficult for single parents.
- **Community Transport Services** which provide a state wide service with 72 vehicles and a minimum fee of \$4 for a door-to-door journey to people with disabilities with the aim of promoting social integration and access to community services. Smithton to Hobart would cost approximately \$65. Those eligible for HACC services are also eligible for Community Transport. However the service is very dependant on driver and vehicle availability and there is no weekend or evening provision.
- some **non-government organisations** which receive HACC or charitable funding to purchase vehicles for transporting service users. These services however tend to be ad hoc and are not coordinated with Community Transport.

In addition there is a push to make mainstream transport services more accessible for people with disabilities. Metro aims to have a fully accessible bus fleet by 2020.

9.2.1 Experiences of using transport

It was striking that the majority of families who participated in the research had transport issues. The care demands generated by their child's disability meant that there was a constant round of medical and therapy appointments, often some distance from where they lived or in Melbourne. The difficulties they had in using public transport meant that being able to maintain a vehicle was of topmost priority to them. Only two families in the sample did not have access to a car and for those who could not drive or did not have a car gaining a license or a vehicle were considered to be major priorities.

Suzanne was going to two appointments every day. She would put the kids in the car, drive to an appointment, drive back, unload the kids. Two hours later put the kids back in the car, drive to another appointment. A normal child you wouldn't have to do one of those. There are all these extra petrol costs involved so when the price of petrol goes up we can't say oh we'll only do one trip, we still have to do two trips and you always do what's in the best interests of the kids and if they need that they have to have it. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

Although there is help available to attend specialist medical services more than 75 kilometres from the home through the Patient Travel Assistance Scheme, there is no assistance for those accessing services within the 75 kilometre radius. Many medical and therapy services expect families to travel to a weekly appointment which is very costly and involves the family in a regular financial struggle. Travelling to urban centres from outlying areas for these services can not only require petrol and a three hour round trip but also involve the cost of a meal and care for siblings. Although some assistance is available through ECIS for pre-school children to cover the costs of attending therapy during the school day this subsidy is very limited and for most families there is no assistance at all. As service providers commented, it might be possible to organise a holiday program with additional support for the child with a disability but it was then impossible to organise transport to get them there and back again.

We don't fit in because we're not far enough away from Burnie, it's about 20 kilometres. We try to get a lot done so we don't have to go in again but we find we go in a lot, not just for Rosie's medicines but for other things and Rosie won't last a long time in the

car. We go into Burnie three or four times a week. Fuel is a huge thing and the time in the car when you're tired. When we had Rosie in hospital for three weeks it cost us over \$2,000 just with fuel. David was coming home, it was the middle of winter, it was three trips a day. So he was buying a lot of take-aways because he was too busy to do any cooking. The teacher at the school enquired about the cost and got us \$200 from the Sunshine Foundation which was really nice. But it's not taken into consideration the times when the wheel bearings go, lights get smashed. They think as long as they're paying for fuel everything is fine, but you take the car in and it's \$800. (Jill and David caring for Emma aged 7 with autism and Rosie aged 2 with cerebral palsy and epilepsy)

I used to go every week to the orthopaedic clinic where he was having the plaster changed here at LGH and they wouldn't give it to me (the PTAS) because I'm about two kilometres out of the map. Even the doctor tried to get it for me and they said we can't because the map finishes. So every week there was 80 kilometres I was doing there and back. And then he would have to go to his therapy and there was nothing there for that. The only time we can get reimbursement is if it's for the speech therapy. (Jackie caring for grandson Jake aged 6 with multiple disabilities)

Even when families are eligible for the PTAS there are additional costs which can be difficult to meet. A number of Tasmanian children with disabilities require regular treatment either at the Royal Hobart Hospital or at the Royal Melbourne Children's Hospital. Although PTAS covers some of these costs there is very little subsidy to cover living expenses and there are the additional but hidden costs of maintaining a household in Tasmania while a child is elsewhere. Subsidised accommodation is available at some medical facilities; in both Hobart and Melbourne families have access to Ronald McDonald House providing free accommodation for children and their escorts. However families still have to cover the cost of meals.

We've been to Melbourne once and I got a bill for \$15¹⁷. We were there for a week. It didn't cover food and you have to still run your house at home for everyone and cover the cost of that. It cost us a bit of money going over there and having to buy the food and everything, the phone bills, trams. Luckily with the Health Care Card the trams weren't as expensive as they could have been. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

We stay at Ronald McDonald house so that's covered through the transport system. We drive down. The subsidy for the petrol is not much. Down and back it's \$53. We were down there for four days once and we left the car in the park and by the time we left it cost us \$50 in parking tickets. We have been told that if he does go to Melbourne the government will help one parent go and then we have to find our own money. Well we have kids here to look after as well. It's all right to pack up and go to Melbourne but you're doing double living. You have to buy food in Melbourne or Hobart and still have food here for the ones who stay here and a family friend or relative staying in the house to look after the house and the animals. We've managed but it's been a burden as well. It's something we had to do so we've done it. (Kath and Jack caring for Nick aged 14 with spina bifida)

He goes every six months to Melbourne to his orthopaedic surgeon. When we go it costs me a fortune. I have to have somewhere near to stay to the hospital and I can't

¹⁷ \$15 is the maximum contribution payable by Health Care Card holders for any one return journey.

get anything under \$80 a night. That's all my pension gone and I can't get any help there. They apologise but they can't do anything. They pay the airfares and the taxi fare if I have the chit, so that's good. They did say they would pay a certain amount of the accommodation and I've kept all my receipts but the only way they will pay all the costs is if you stay in Ronald McDonald but they only like people to stay there if their child's having operations. They think he's just having a consultation one day but it's too much for me so I have to stay somewhere. If I've got an appointment to be there eight in the morning I have to get there the night before. If they had the surgeons here it would save all that money and we wouldn't have to go. (Jackie caring for grandson Jake aged 6 with multiple disabilities)

More generally interviewees described problems in using public transport and problems in maintaining private transport. All families using private transport were concerned about the costs involved. It impacted significantly on their ability to use the services they needed and to maintain some kind of social life.

Buses tend to over-stimulate her and I don't drive. To go to Calvary Rehab it takes two bus trips to get there and by the end of the second bus trip we literally got off the bus and down she went. I hadn't even made it to the rehab. So buses can over-excite her. Any form of over-excitement, panic, worry are a trigger. So with not driving and no buses, that's a big one and it tends to be a bit of the four walls closing in. (Sally caring for Claire aged 6 with epilepsy)

There is never enough money and sometimes I have to cancel an appointment because I just haven't got enough petrol. There is not even a place where you can take your car, get it fixed and then pay it off so much a fortnight. They want cash there and then and it's \$50 an hour for a mechanic and that's without what they have to do. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

It is very difficult to get any financial assistance for buying or modifying vehicles and many families spoke about the difficulties they had in keeping a car on the road or getting access to an appropriate vehicle or one which could transport a wheelchair. There is no help available to purchase wheelchair accessible vans. This means that families have to rely on charitable funding.

We have to get a new car because it's too low to get him in and out of. It's urgent. To get him in and out someone has to get down and in and put him in and then pull him out again. We have a harness for the car because he doesn't like sitting in a seat belt and he gets out of that. We will probably go back into fundraising to help us buy a car. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

We had to buy a new car to accommodate the two wheelchairs. You cannot put two wheelchairs into a boot so we figured if we had to buy a car we might as well get something reliable which would last us a long time. So we bought a new car. We can't afford to be stranded somewhere with two children. Then there are the insurances on the two wheelchairs which are an extra \$120 dollars on top of everything else. Just little things like that, things you don't really think about. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

We used to have a car but it kept breaking down. Then someone lent one to me and that broke down on me and we haven't had a car since. The church give cars sometimes to the needy and we have our name down but there's a 12 month waiting list. So at the moment it's just catching buses or taxis. Tom can't do any of those by himself, he hasn't

got the skills. Not having a car makes things very difficult, getting around. There are no buses after six o'clock, you have to walk everywhere. If he has a seizure now we can't just take him in the car, we have to call an ambulance. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

Parking can also be an issue. There can be difficulties in negotiating the process required to get parking concessions and in accessing parking when it was required.

Someone said to me you might be able to get a disability sticker for your car. I went and enquired and they said oh no you're unlikely to get one of those because you have to have severe mobility issues. But the person I know her daughter's got no mobility issues. But with children with autism or epilepsy and ADHD the further you park away from something they are always running into the road and it's totally dangerous parking some way away from where you're going. I decided not to try because there's so much red tape to go through. You have to go to the doctors and have an appointment. I have to ring the paediatrician who promised me she'd write a letter and hasn't done so. You have to always chase people up. (Gerry caring for three children with autism aged 8, 7 and 6 years)

My last straw was trying to get a car park at the Royal. Every other day we would be rushing to get to the hospital. The tube feeding took two hours and then she would vomit and you would rush to the hospital, find a car park. Someone would be driving up my bum or giving me the horn. They should have a carer's sticker on the car just because it's so stressful and life could be a bit easier. (Kate caring for Daisy aged 2 with cerebral palsy)

Lastly families spoke about difficulties in getting any assistance to transport their children to school from respite facilities (see page 65). Unless transport to respite is available within the existing transport schedule and budget allocations parents have to make their own arrangements. This was having a major impact on their ability to use respite services during the week.

9.3 Managing the Budget

How far were families in the research able to manage on their incomes and provide a basic quality of life for their children?

9.3.1 Additional costs

This research has detailed the range of additional costs facing families caring for a child with a disability. These include the extra costs associated with acquiring appropriate aids and equipment and meeting continence needs, additional expenditure on transport to access the range of services and on housing to be able to live in appropriate and accessible accommodation within a reasonable distance from support. There are also the longer term costs of being unable to invest in superannuation and of savings being compromised because of parents' inability to work. This meant that many families had no disposable income to invest in their children's future.

Many families also faced extra costs related to food, clothing and heating. A number of the children in the research had special dietary needs. Either they required a particular kind of food or the way in which they ate was very wasteful of the food provided. Several children on the autism spectrum were described as being compulsive eaters who, left to their own devices,

would consume large quantities of food. Or they would only eat certain brands, usually the more expensive brands, or they had particular disorders which meant they could only have some kinds of foods. All this added to the weekly grocery bill.

He doesn't eat our food and there is separate food for Simon. He doesn't eat what the other kids eat. He has to have puree type foods, mashed. If he finds a piece of corn he'll spit that out. He doesn't like anything hard because his tongue fills all his mouth. We try and keep soft stuff and he lives on a lot of stews. He will eat sandwiches every now and again. Anything cold, sometimes he eats it and sometimes he doesn't. Or you will just get something prepared and he'll hit it and then you'll have to start again, it's all over the floor. He does it all the time now because he's getting so strong and he's knocked the bowl clean out of my hand. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

She has to have gluten free food because she's celiac. She has special bread, special biscuits, rice cakes. Her bread alone costs me \$20 for three loaves and they only do me a week and a half because it's wheat-free bread. It's never easy with her with the money side of things. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

He only eats yogurts, only certain types of yogurts. He doesn't like the cheap ones only the more expensive brands. He only eats certain flavours of vanilla ice cream. So you have to have certain foods in the house for him because he doesn't eat what everyone else eats. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

Rachel tips things out. She's tipped out cartons of milk. There used to be sliding doors there but they took them out especially for Rachel because I need to lock the doors at night because otherwise she is in the kitchen eating things. She pours milk into the sink which is really annoying and there are no shops around so you can't just go and pick one up. (Marge caring for Rachel aged 5 with autism)

There were also additional costs with clothing, shoes and bedding because of particularly heavy wear and tear and special requirements.

You have to keep buying clothes because he's on the ground all the time wearing out the pants. His shoes he rubs on the floor and wears out the sides. His socks too. He's growing that quick at the moment so you have to keep buying bigger and bigger. You have to be careful with trousers because they are too long in the legs and too short around the waist and they have to fit a nappy. Even some of the tracksuit pants don't go up high enough. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

He's a huge kid and the clothes he wears are never on sale because it's always the biggest sizes. He's really hard on mattresses, on beds, on shoes, furniture. Mattresses are expensive – he's gone through three in ten years. (Kerry caring for Laurie aged 13 with epilepsy and Tim aged 12 with autism)

Heating was also an issue where the child might require a particular temperature because of a lack of mobility. One child refused to cover himself at night which meant his family had to keep the house warm 24 hours a day:

You have to keep the heat up in the house and wood is up to about \$150 a ton at the moment and that's a killer. Even buying small amounts of wood you are still going through \$30-40 a week of wood just to try and keep it warm in the house. He's got a

giant cot for a bed and he just sits there and shakes it and won't cover himself. We've tried electric, oil and an old doctor told us you have less problems with wood heaters because it doesn't do as much damage to the air. Other heaters dry it right out and it makes him more prone to chest infections. You have to keep the heat up in the house and with wood when you shut it down at night it's still there. Once you shut hydro off it's gone straight away. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

Parents were also having to compensate for damage to furniture and fittings because of the child's behaviour. This could be especially difficult in public or private rentals where they were unable to live with the damage until they had enough money to repair it.

Before Christmas he was kicking windows and we would have to replace doors. We've repainted entire walls and it costs a lot of money to do that. \$200 for a window a time. One of our requirements for a house is not so many ground floor windows. (Dawn and Gary caring for Tony aged 8 with multiple disabilities)

I can't replace some of the things he breaks. We can repair some and save up. Probably he saves me money because I stay home. (Kerry caring for Laurie aged 13 with epilepsy and Tim aged 12 with autism)

The combination of all these additional costs was very draining on the family budget.

9.3.2 Managing on the money

All of the families described difficulties in managing on their incomes. Those who said they were able to manage, also said they were very careful about how they spent their money and they lived in a way that many other people would find unacceptable. They never went out, never went to the movies or out to eat and never had a holiday.

We are not big spenders and we are very, very careful with what we do. I only have a change of clothes so we don't spend money on clothes. We have enough but we don't live like other people live. We tend to take our kids to things that are free. We shop for Christmas in the middle of the year when the sales are on so we can make things go further. We always shop for cheap food and buy things when they are on special, so we save a lot of money that way. I do all the hair cuts in the family. (Di and Tony caring for Rowan aged 10 with Asberger's)

You get enough to manage but not comfortably. You get enough to pay your bills or your day-to-day living but you don't get money to save. Today I thought I had \$20 left in the bank but because it's the second of the month the bank charges have come out and I've only got \$3 in there. So that was the kids' tea for tonight. With him I have to have money for the doctor's tomorrow because the doctor is going to give him antibiotics and then I have to pay for the doctor's as well. It's just crazy. You just have to try and have money every day in case any hidden expenses come up. Heaps of little things pop up. I dropped a full tin of formula and you can't scoop it up, you have to go and buy more and that's not cheap stuff. (Dot caring for Declan aged 8 months with Down syndrome)

Some people said that if they were careful they were just able to scrape by and manage from week to week but were forced to utilise high interest credit for household bills.

Sometimes you manage, it's not easy but you manage to get by and then other times you get a few bills in and they all seem to come in at once and you have to get prescriptions and then it can be a bit difficult. I have a credit card. Thank God for my

credit card. When I get my rego if I can't afford to pay it I put it all on there and then pay \$50 a fortnight or whatever I can. That's my one debt, everything goes on that and it's been a God-send. I'd be lost without it. But everything I own is like where you can pay it off because you just don't have the money to pay for things. (Winnie caring for Tess aged 8 with visual impairment)

You can manage your fortnightly but it's when the hot water cylinder goes bang. We have no savings. You seem to save a bit of money and then something goes wrong. What keeps us going is that there are plenty worse off. If you only had to go from fortnight to fortnight you'd manage but once you have a car and the gear box goes it's just where are you going to get that money from? We are able to heat the home because the farmer down the road drops off firewood. (Jill and David caring for Rosie aged 2 with cerebral palsy and epilepsy and Emma aged 7 with autism)

We live day to day, you have to make do. We are going backwards with me not working at the moment. When I was working we never went without and clearly if the children were regular children we would have just gone ahead. We were managing quite well, we were managing to save a bit. Now we are behind this year. There are a lot of things we do without. We don't go out a great deal. You notice the petrol bills. We don't go out to eat and apart from family days we don't do anything. We don't go out just for a drive to get out of the house. We can't do that now. Visiting friends you don't tend to do that as much. We don't eat bananas. It's the small things. We never go away. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

Several interviewees commented on the impact of the rising of the cost of living in Tasmania which had hit them hard and was making it increasingly difficult to manage.

Even though we're getting that little bit extra money the price has gone up on everything so I'm not actually coming out in front because everything has gone up. I get \$150 a fortnight for looking after Tina but I usually spend that on bread and milk alone. Petrol for the car as well because we always have to make sure we have a full tank in case we need it. I did go into City Mission and that was the lowest thing I've ever done. I went in there, I was crying and I said look I just need some help. They gave me some nappies, gave me a couple of bags of food. I couldn't get the Health Care Card because we'd be on it for six months and then Darren would go over it by a dollar and we would lose it again. I'd come out feeling really bad and thinking I don't like being in here, this is where people who really need help go. I would make sure it was just the basics, just bread and milk, toilet paper, washing powder. I used to say I just need a couple of things to get me through. (Viv caring for Tina aged 16 with a chromosomal disorder)

9.3.3 Living in Hardship

There were many things families had to do without. As well as holidays, outings and the ability to participate socially, they were cutting back on expenditure like insurance, pocket money for their children, clothing and heating. Although they said that their children were always fed there were times when they cut back on food for themselves and were forced to rely on food hampers from Emergency Relief providers.

I have gone without meals but my kids have never gone without meals. I just had a coffee and said to my husband if he said anything I'm just not hungry tonight and that's not true. I don't ever have meat because I can't afford it. You make sure your kids and your husband eats well. (Viv caring for Tina aged 16 with a chromosomal disorder)

We have struggled to get meals at times. We had help with food hampers and they put us on a budget. They've even cut back on funding for hampers and they don't give them out any more. So if we get stuck again we won't be able to go and get help. The fellow next door he gives us things out of his garden. We do have times where we don't have any money and then we wonder where we're going to get food from. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

They had accessed help from family and some had at times used Emergency Relief services to supplement their income. They had delayed paying bills or negotiated repayment arrangements with creditors.

I have found it hard and my parents have helped me. With the shoes if I couldn't buy them my mother would pay for them and I'd pay her back or I would just have to put them on lay by and pay so much off each fortnight – about \$10 a fortnight. It's the only thing I could ever do. I've never had big money. We have had to ask for an extra couple of weeks for the rent. (Janine caring for Andy aged 16 with cerebral palsy)

We owe Housing and now they are taking more off us. I haven't used emergency relief yet but the lady is coming out to see if I can get some on it. I am already paying \$180 a week on rent and then they want an extra \$70 on top of that to pay off the debt. Power bills and all my bills I get taken out otherwise I couldn't manage. I couldn't pay the telephone bill. I can't really not pay the rent as it's direct. I've sold things, a few things. I've had to get help from Mum, she's had to give me money. (Marge caring for Rachel aged 5 with autism)

Several families had gone into debt to meet their basic needs and to pay for disability-related services.

The first week, the pay week, is fine. The second week is when we hit trouble because that's when I start to run short of money. I have to buy food, nappies, food for Chloe and run the house, try and pay the bills, put petrol in the car every day. I can pay maybe two bills out of each pension but sometimes I can't pay more and if you get more than two bills come in you have to look at which you pay and which you don't pay. At the moment I'm in debt to (a service provider) for \$122 for last Christmas's holiday care because I haven't had the money to pay it. They are very good about it but I'm still in debt to them because I haven't had the money. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

At the moment I am stuck in an extremely bad cycle of debt. I have put the rent on credit cards, paid the therapists with credit cards. I am about to have to go bankrupt I think. I have taken out loans for credit cards and run the credit cards up again. It's not a huge amount of money but I won't be able to pay it off in the next year or so. It's been really hard in the last six weeks where I've diminished all my savings to pay off the remainder of the speech pathology and the remainder of the ABA therapists that I hired last year. It's a very strange position to be in where you have no money to go and buy essentials like food. I've never really been to the point where you're scared you can't provide essential food. That's a really worrying fact for me and I have too much pride to go to the Salvation Army and get the food vouchers although I know you can do that. I feel really embarrassed to do that and I know you shouldn't be when you're stuck between a rock and a hard place. (Angela caring for Dean aged 7 with autism)

One family was borrowing money at a very high rate of interest in order to survive:

I've gone to and got a card to say I can get pay day loans, so instead of having to take my phone or my camera in to them they actually give me a loan and \$50 interest on top of whatever I borrow. But if you need money, you need it. My mum is not in a position to be able to lend money and Doug's mum I wouldn't like to ask her. No one in our family is in the situation to be able to say well here's \$50. So if I do just need \$50 I go to them and just get it but I have to pay \$100 back over four weeks. So if you do need money it's good at the time but once you don't need that money any more you're paying out big time. I had to go and get money before pay day one time. It was only the next day until I needed it but I still had to pay all the interest back and everything. I've borrowed twice on it. (Dot caring for Declan aged 8 months with Down syndrome)

All families who participated in the research were asked whether, over the last 12 months, they had experienced a series of difficulties due to a shortage of money. The results are listed in Table 5. It shows that three quarters of the families had sought financial help from friends and from family and had difficulties in paying power and phone bills on time. One third had delayed payments on their rent or home loan and a third had also had difficulties heating their home appropriately. Over half of those who owned vehicles had difficulties paying the registration and insurance and half also had not sought health care when they needed it due to a shortage of money. Over 40% had pawned or sold something in the past year to make ends meet. It also shows that those families caring for a child with a disability and in receipt of a Health Care Card were doing considerably worse than Health Care Card holders generally.

Table 5: Proportion of families reporting experiences of financial hardship in the previous 12 months

Type of financial difficulty or hardship	% of families in sample reporting hardship	Tasmanian population#	
		% HCC holders	% all population
Unable to pay electricity/phone bills on time	71	25	15
Unable to pay rent/home loan	33	6*	4
Unable to pay car registration/insurance on time	55	20	11
Pawned or sold something	42	20	7
Gone without meals	4	11	4
Unable to heat the home	33	10	4
Sought financial help from friends or family	75	22	14
Did not seek health care when needed	54	20	10
Did not fill a prescription ordered by the doctor	38	14	9

Note: Questions adapted from Household Expenditure Survey.

Figures taken from the Tasmanian Community Survey. See Madden & Law, 2005.

** Estimate has relative standard error of between 25% and 50% and should be used with caution.*

A number of research participants commented on the inequities in the state concession system which mean that those with a Pension Concession Card can get assistance with the costs of car registration and a heating allowance while those with a Health Care Card cannot.

I get a Health Care Card, I've got that and that helps. But we want the pension card for car registration. I know people who get heating allowance, I don't even get that. It seems so unfair. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)

What was very hard for families was to think about the things they were unable to acquire for their children because they could not afford it. These might be expensive therapies or they may just be outings which would make their children's lives more pleasant. It was the fun things in life which families had to do without.

It's hard and we are limited in what we can do for the children. We would like to be able to do more for them but we can't because we just can't afford it. There's a lot we go without and that the kids miss out on. (Doug and Simone caring for Tom aged 15 with cerebral palsy, spina bifida and epilepsy)

There would be a lot more costs involved if I could afford them. Ideally if I had the money my son would be going to weekly speech therapy because he is hard to understand and people call him a retard and that breaks my heart. My two daughters would be accessing the physio because of their low muscle tone and their balance problems. One of the biggest ones is if I had the money they would be accessing applied behaviour therapy. But at \$30 to \$40 a session and at least two sessions a week there's no way on this earth so you don't even get to go there or get them assessed. So you feel like a lousy mother because you can't access the service because you can't afford to. So in terms of their disability what I spend is much less than I would ideally like to spend to support my kids. All parents have demands but for parents with children with disabilities you have the added thing of the guilt factor, of wanting to give the best you can to your children, but because of financial constraints, or time constraints or just the fact that one person can only do so much you can't. (Gerry caring for three children with autism aged 8,7 and 6 years)

9.4 Summary

Families were very concerned about their difficulties in managing day-to-day on a low income, their inability to save, insure themselves or provide for their own or their child's future. Although grateful for the income support they did receive and the Carer Allowance they did not feel it was enough to meet the additional costs of coping with their child's disability or to allow them to provide a quality of life for their children which equated to that of other families. They emphasised how much they were saving the government by caring for their children at home and the inadequacy of the current subsidies available to begin to meet what could be the overwhelming expense of providing in-home care.

I am very grateful for my \$90 a fortnight but personally I don't think \$90 a fortnight is a great deal. They are getting away with it quite easy. If we had to put the children into care it would cost ten times that. We can accept that they are our children and we take responsibility for them and it's great that people will support us with wheelchairs and stuff. We accept we have to buy nappies and drive extra for appointments, buy

certain foods but what really bugs us is that with everything going up at what point, what do we do, do we share one nappy between the three of them? We joke about it but it really puts a strain on you. We don't expect the government to turn around and say because you have a child with a disability we should fund that child. We are grateful for the fundraising. Is there a different way they can go about subsidising? (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

The government wants you to look after children like this. If you put Simon into full time care and then tell me how much it's going to cost to look after him. I heard it was something like \$300,000 a year. But we are expected to bring him up on minimum amounts. You give your life up and you can't do nothing. Everything is a waiting game. We just have to wait and see what happens. That's all you can do. (Sheila and Des caring for Simon aged 15 with multiple disabilities)

Families were struggling to access and maintain affordable housing which met the needs of their disabled child and it could require a crisis to make families eligible for public housing. The cost of home modifications for home owners and those in private rental accommodation was daunting without assistance. Transport was another big issue with inadequate subsidies for health related travel, a lack of assistance with buying and modifying vehicles and a reliance on charitable funding to maintain the private vehicles which are so necessary for many families. What they wanted to see was more financial assistance available that that did not tar them with the 'welfare' brush.

A \$50 voucher to spend at the supermarket on some good essential foods but without having that thing of going to the Salvation Army. Getting something nice in the mail, not something that you have to beg for. A bit of a boost without having that whole blanket that you are solely welfare recipients. That is hard for people. I have always worked and now to be stuck in this position where you have no money at all, for clothing, to move, for anything nice, not extravagant but just nice. (Angela caring for Dean aged 7 with autism)

If they are on a special diet maybe they could have a little bit extra in their pension for the diet. You can prove these things if you have to so maybe their pension could be a little bit more than someone else's. If you can prove that your child needs extra care, has these problems why couldn't they have a little bit more, maybe an extra \$100? What a difference it would make to the quality of life they have and the quality of life we'd have as parents. It would make life so much easier. (Doreen caring for Chloe aged 16 with severe autism and Sam aged 6 with behavioural disorders)

The extent of additional costs faced by families caring for children with disabilities and by people with disabilities generally has led to calls for a universal disability allowance to meet them (Community Affairs Reference Committee, 2003). The policy dilemma is to provide assistance to those who require it in proportion to their needs but in a way which is readily accessible, non-stigmatising and reasonably efficient to deliver.

10. Conclusions and Recommendations

Families in Tasmania play a pivotal role in providing secure and caring environments for children with disabilities who require support. Yet as this report has shown, although overwhelmingly they want to care for their child at home, they do not necessarily receive the support they need in order to perform this role effectively. Their efforts to balance work with care responsibilities, manage tight budgets and low incomes and cope with strained relationships and the impact on any siblings mean that significant numbers have difficulties in meeting the additional challenges. Too many are on the brink of disaster, particularly when they are coping with profound disability or behavioural issues like autism.

There is a general failure to deliver appropriate services at the right time and a considerable unmet need for information about support available, financial resources and help with day-to-day care. Children move through developmental stages but the way in which services are planned and delivered imposes long waiting times for treatment or equipment which mean by the time it arrives it is no longer appropriate. What is available in one part of the state is not available in another and collaboration between agencies is limited. This imposes enormous strain on families in trying to manage the many health professionals and government departments whose support they need. Overall the service system is inherently discriminatory so that costs and barriers impact especially hard on low income families. Those who can fight or pay get services while others who are more socially and economically disadvantaged and unable to advocate for themselves lose out. This service system failure means that living at home is not a reliable indicator of quality of life or of positive outcomes for the child or the family.

A major issue in challenging the inequality that families experience is the low political priority given to services for children with disabilities and their families. The current attitude is one of sympathy rather than a commitment to providing higher quality services. As this report has indicated investment in families which allows them to avoid crisis situations and family breakdown offers direct benefits for the community and for the economy. Yet government pursues policies which limit the costs whatever the impact on the families might be.

If families are to continue to provide unpaid care for their disabled children it has to be made doable so that they do not have to give up their entire lives to meet caring responsibilities or struggle to survive on the poverty line. How should this be done? Tackling poverty amongst these families means both addressing their access to the essentials of life – a reasonable income, health, education, employment and affordable housing – as well as providing a service system which assists them to continue to care for their disabled child.

10.1 What Families Want

What do families themselves feel is the way forward? Those who use services are best qualified to judge them and all those who participated in the research were very clear about what kind of support had been most useful to them in dealing with their situation and what could work better. They gave numerous examples of good quality support where services were working very effectively as well as examples of bad practice and service failure. They were all asked what they felt the government should do to improve the situation. Their key priorities were:

- more **financial assistance** with the additional costs generated by their child's disability; in particular with equipment like wheelchairs and continence aids.
- **information** about services and assistance available and access to information about particular disabilities and conditions.

- **one point of entry to services** anchored by a centralised assessment system able to assess a family's support needs holistically.
- **respite services** (including personal care and support in the home) which provide a range of options, are reliable and regular and where parents can be confident about their child's safety and wellbeing.
- **a wider range of educational options** and a funding system which can fully resource inclusive practices.
- **Centrelink services** which are promoted and publicised and where application processes recognise the issues facing families caring for children with disabilities.
- an **equitable state concessions system** which acknowledges the difficulties created by differential access to concessions for Pension Concession Card and Health Care Card holders.
- a **comprehensive therapy service** including early, prompt and expert assistance with behavioural issues.
- **timely access** to services, supports and interventions which recognises the impact of waiting on children's development.
- **support for siblings** of disabled children including specialist counselling and social and recreational opportunities.
- **support for parents** through opportunities to participate in parent support groups and social opportunities for the whole family.
- **social outlets for children with disabilities**, particularly teenagers.
- **improved access to mainstream services** including employment, childcare, accessible and affordable housing and transport services.
- **better collaboration** between acute/specialist services and community support services, between sectors like health and education and geographically across regions.
- **an ability to plan and save** for their child's future.
- **more understanding and awareness** about the situation of those caring for children with disabilities from politicians, policy makers, service providers and the community generally.

Overall what families wanted was more support across the board to assist them to keep their heads above water and prevent a descent into crisis.

I don't think the government is doing enough for kids with disabilities. It's very slack on that. They spend millions of dollars on a football club thing, millions of dollars on the Elwick Showgrounds. They build the new hospital but they just don't think of disability people so they get shoved to the side. (Jane and Mike caring for Lisa aged 4 with cerebral palsy)

10.2 Recommendations

Getting the system right is a question of equity and the urgency of the situation is growing as families compete for already inadequate resources. Solutions for families are complex, and spread across different sectors. The Review of Disability Services currently being conducted under the auspices of the Department of Health and Human Services is an opportune time to implement appropriate and effective responses for families.

Different families have different needs and it is vital that this individuality is recognised in any service system. The scale of the need also means that getting sufficient resources has to be accompanied by more efficient ways of meeting needs. Improving services does not necessarily mean wholly new approaches and as families have demonstrated there are examples of good practice and services getting it right everywhere. This suggests that there may be a range of service enhancements and relatively small scale or low cost initiatives which could be made without enormous additional resources but which could have a big impact on the quality of life of families. These include a single point of access to services, better coordination of support, increased availability of individual support packages for families, reducing waiting lists for equipment and improving subsidies for continence aids. It is also about mainstreaming good practice and promoting an attitude which sees the social exclusion of children with disabilities and their families as unacceptable.

10.2.1 Policy framework

Every child with a disability should be given the best possible start in life by supporting them and their families. There should be easily accessible services at key transition points which are delivered in a coordinated and timely fashion. Yet although there are many policies and initiatives across different sectors which impact on children with disabilities and the families who support them there is no overarching framework within which to address the issues they face. This means fragmented services and inconsistencies across the state. The Disability Framework for Action 2005-2010 identifies some of the issues faced by families caring for disabled children but it does not currently provide a basis for developing a comprehensive support system for families.

Recommendation 1: That the Department of Premier and Cabinet develop a Tasmanian framework for specialist support to children with disabilities and developmental delays and their families from birth through to adulthood. This should:

- acknowledge that supporting families improves a child's wellbeing;
- be developed and integrated into the Disability Framework for Action during the review process in 2008;
- provide a vision of what supports families should expect and be entitled to;
- be linked to a comprehensive early intervention strategy which can promote the early identification of problems and the timely provision of appropriate support; and
- be linked to universal childhood services available to all children and families and inclusive of the needs of families with disabled children.

Recommendation 2: That the Department of Premier and Cabinet require government agencies to prioritise the needs of disabled children and their families in Disability Action Plans and any related targets and benchmarks.

10.2.2 Dealing with unmet need

A considerable on-going financial commitment is required to enable services to meet basic needs and provide consistent, high quality services with appropriate staffing levels. Current resource levels have not kept pace with demand or with complex medical and behavioural difficulties. There are now considerable shortfalls in basic community support services. Families are unable to access a range of respite options and adequate respite hours, sufficient levels of personal support hours, a range of equipment, particularly wheelchairs, and subsidies for continence aids which cover the actual costs. At the same time the evidence for the positive impact of regular respite, personal support and appropriate equipment delivered in a timely fashion is overwhelming.

However it is difficult to measure the extent of this shortfall. No waiting lists are maintained for people needing respite care or personal care and support and there is no duty placed on service providers to record unmet need. For example, waiting lists for group homes are based on those who are in crisis, in hospital or prison rather than reflecting the true extent of demand for accommodation. Much of the shortfall in respite care and personal support is under-met demand where services can meet some but not all of the support that families need.

Given the current lack of data on levels of unmet demand it is difficult to estimate the true extent of need which is not currently being met. This is complicated by the fact that many families do not know what they need or what their options might be. This creates a pool of hidden needs which do not translate into a demand for services. At the same time ABS projections (Disability Services, 2005) estimated that increased support requirements nationally for people with disabilities across the age range will result in a growth in demand of 3% to 8% per annum. This means that on top of an unknown level of need, disability services will need to expand in order to keep pace with growing demand levels. Given the high proportion of the population in Tasmania with a disability the following recommendation adopts the 8% projection.

Recommendation 3: That the Minister for Health and Human Services must include in the Review of Disability Services the urgent need to upgrade the support offered to families caring for children with disabilities including:

- ensuring that routine data is collected about unsuccessful requests and under-met demand for respite and holiday care, personal care and support and other disability services in order to monitor levels of unmet need;
- ensuring that budget provision is made to meet levels of unmet need; and
- committing to funding increases to Disability Services of 8% per annum from 2009 to improve the quality and quantity of services and meet the projected growth in demand. Within this funding increase the following should be prioritised:
 - development of a range of accessible and appropriate respite options for children with the goal of achieving a legal minimum entitlement to respite with a benchmark of four weeks' annual leave and ten days' sick leave for primary carers by 2020;
 - increased access to domestic assistance and to personal support; and
 - increased funding to the Community Equipment Scheme to meet current demand and allow for an increased limit on expenditure for individual items.

10.2.3 Income support

Many families caring for children with disabilities do not get the benefits that they are entitled to. They may not know that they are available or, despite providing high levels of care, are refused payments. The recent Welfare to Work measures introduced in 2007 have introduced further barriers and despite the introduction of temporary exemption from activity test requirements for parents of a child with a disability many families are unaware of the exemption. They also encounter complicated application processes with a constant demand for information about the extent of the care provided that often does not recognise the pressures involved in caring for a disabled child or the life-long nature of many disabilities and the impairment and care needs they generate. Applicants can find this intolerable. Ensuring families get all the financial help available is fundamental.

Recommendation 4: That the Commonwealth Government through the Minister for Families, Community Services and Indigenous Affairs establish a universal disability allowance to meet the additional costs associated with disability.

Recommendation 5: That the Minister for Families, Community Services and Indigenous Affairs direct Centrelink to conduct comprehensive disability awareness training with all Centrelink staff annually.

Recommendation 6: That the Minister for Families, Community Services and Indigenous Affairs commit to a review of the way in which Centrelink benefits are provided to people with life-long disabilities and their families in order to provide a consistent approach which recognises support needs and which eradicates unnecessary demands for information.

Recommendation 7: That the Minister for Families, Community Services and Indigenous Affairs direct Centrelink to publicise more widely the benefits available to carers and how to claim them and operate as a signpost or gateway to other services for families caring for children with disabilities.

Recommendation 8: That the Minister for Families, Community Services and Indigenous Affairs direct Centrelink to routinely provide information to doctors required to complete 'treating doctor's reports' about the application process and what is required in terms of recording the impact of any disability or condition on carers.

The state concessions system has the potential to have a significant positive impact on low income earners by lowering the cost of some of the essentials required for a reasonable standard of living. However, it is currently inequitable. Aged pensioners, disability support pensioners and single parents are able to access a Pension Concession Card which allows them a rates remission, motor vehicle registration concession, heating allowance and the driver's license fee concession. The Health Care Card available to other low income groups excludes them from these subsidies. For home owners not having access to the rates remission can mean a cut of \$9 per week. Inequities in transport concessions hit families caring for children with disabilities particularly hard given the reliance so many have on having access to private transport. This research showed that 55% of families with access to a Health Care Card had been unable to pay their car registration or insurance on time. Many were also struggling to pay their electricity bills.

Recommendation 9: That the State Government review the concessions system to ensure that it offers an effective mechanism for providing low income Tasmanians with a reasonable standard of living. This involves equalising eligibility for concessions between Pension Concession and Health Care Card holders, especially for the heating allowance, vehicle registration concessions, the licence discount and private bus concessions.

10.2.4 Support in the community

Access to effective and coordinated community support is vital in order to assist families and prevent the escalation of situations into a crisis. At present, although most families rely on informal and community based support networks, most resources are directed to formal service systems and residential care. What is required is community supports which are flexible, responsive and family-centred in order to provide the best possible start for children and allow families to continue to care. Common to all families and to adults with disabilities is the urgent need for information about the kind of service they can expect, how to access it and one point of contact with services. This should be available from the point of diagnosis, injury or identification of a developmental delay. The Children's Therapy Services Improvement Project (Evolving Ways, 2006) proposed that an integrated service model for children with disabilities and developmental delays and their families be developed. This would include clear points of information and referral, consistent eligibility criteria, a common assessment framework, service coordination and access to services on the basis of need. This integrated service model should grow out of the development of a comprehensive framework of children (as in Recommendation 1).

Western Australia has for many years successfully modelled 'local area coordination'. Each coordinator works in a defined geographical area corresponding to a known number of people with a disability and providing one point of contact with services. Local area coordinators (LACs) can provide a range of information about financial and other benefits, the child's disability and what help is available and continue to provide information as the child develops and entitlements change. The average caseload is 50 people and the coordinator combines elements of case management, personal advocacy, family support and community development with access to a small budget for discretionary one off funds to meet additional disability related costs. This model has an annual recurrent cost per service user of approximately \$2,427 (Disability Services Commission, 2006) and numerous evaluations have identified value for money and positive outcomes in terms of service coordination, service take up, case management and satisfaction among service users (Bartnik & Psaila-Savona, 2003). Versions of this model have now been adopted in Queensland, the ACT and Scotland for people aged 0-64 years living with severe and profound disabilities.

One way to test the appropriateness of the LAC model in Tasmania is to operate a pilot program in a small number of locations. The pilot would test how best to fit the model into existing infrastructure, who should operate the service (government or NGOs) and role definitions. At a minimum LACs would operate as service coordinators rather than service providers and have a proactive role in contacting families and assist in managing the package of support they require. They would also advocate for their needs, boost the capacity of informal support networks and provide case management for all higher care needs clients. The system would facilitate prompt referral to support services.

Recommendation 10: That the Tasmanian Minister for Health and Human Services commit \$500,000 to pilot local area coordination in three different locations in Tasmania with a commitment to ongoing recurrent annual funding and expansion state wide if outcomes are satisfactory.

The above costing would also cover action research to monitor and evaluate the model and feedback into its development.

The research identified a pressing need among families for access to information about services, support networks and particularly disabilities and conditions.

Recommendation 11: That the Minister for Health and Human Services establish a broad communications strategy for families with disabled children which includes:

- short directories of local services and support networks which are regularly updated;
- more in-depth and informative booklets covering local and national services; and
- a resource centre with information on disabilities and conditions which can also subsidise the cost of bringing 'experts' into the state.

The research clearly demonstrated how a break from caring is a key factor in allowing families to continue to care. There is an urgent need to increase the range of respite options available and their quality so that families feel confident in using them. The current review of respite services being carried out by Disability Services should contribute towards this goal and Recommendation 3 prioritises a legal minimum entitlement to respite and increasing the range of respite options. Many families prefer family-based care as opposed to centre-based facilities. One popular option among parents was using host families. Statewide however the host family program is under-utilised. There are host families in the south waiting for a match and many families with disabled children in the north and north west who are waiting for a host family.

Recommendation 12: That the Minister for Health and Human Services increase the availability of hosted respite by funding the further promotion of the scheme and the realities of hosting to potential host families.

As the research has demonstrated parents need to be able to trust and rely on support workers especially with non-verbal children. Reliable and consistent support workers can have a significant positive impact on family life by providing support and empathy, spending time and having a willingness to work flexibly.

Recommendation 13: That the Minister for Health and Human Services develop strategies to professionalise the disability workforce to ensure they have good interpersonal and communication skills, are reliable and consistent, have access to good quality training about disability awareness and family-sensitive practice and have clarity around their duties including flexible work practices.

10.2.5 Social participation and support networks

All the families in the research commented on the value of contact with others in the same situation and their difficulties in participating socially in the community. This was true for children with disabilities, for their parents and for their siblings. Barriers to participation included a lack of time or energy, coping with difficult behaviours and the financial cost. The MyTime Program recently introduced nationally by the Australian Government is setting up local support networks for parents with young children who have a disability or chronic medical condition. It brings parents together to socialise, share ideas and information and provide mutual support. It is targeted at families with children aged five years and under.

Recommendation 14: That the Australian Government through the Minister for Families, Communities and Indigenous Affairs commit to an expansion of the MyTime support group program to all families caring for children with disabilities up to 16 years.

The research has identified the difficulties siblings of disabled children can experience and the positive impact of contact with and support from others coping with similar situations. Yet Tasmania, beyond one-off holiday camp and day activities for young carers, has very few opportunities for siblings to gain this kind of support. This is a national issue and the

Commonwealth Department of Health and Ageing (DoHA) has provided Siblings Australia with financial support to employ a project officer to develop partnerships with other DoHA funded programs to increase the availability of siblings groups and explore school support strategies. They are currently establishing a national reference group to help guide the project.

Recommendation 15: That the Tasmanian Minister for Health and Human Services ensure full participation of Tasmania in the Siblings Australia National Reference Group to promote a network of sibling support groups across the state.

10.2.7. Aids and equipment

The lives of families can be transformed by having access to appropriate aids and equipment to assist with mobility, communication and continence yet many cannot meet these needs without incurring substantial financial costs which they cannot afford. This means that they either do without or are forced into the ignominy of fundraising. This is despite the fact that access to aids and equipment can reduce expenditure on health and social care in the longer term.

Recommendation 16: That the Australian Government extend the Medicare Scheme to ensure that people with disabilities can claim the cost of essential equipment less other funding sources like community equipment schemes.

Coping with continence needs is a major issue for many families and the current subsidy does not begin to cover the costs of those who are doubly incontinent where, on average, the cost of nappies is \$100 per month. These costs represent 10% of the Carer Payment (child) and 51% of the fortnightly Carer Allowance (child) and mean that too many families are forced into debt. Paying for nappies also has a major impact on families' ability to fully participate in community life. The provision of nappies for those on a low income with continence issues is a basic and essential health need and should be fully funded.

Recommendation 17: That the Australian and State Governments commit to fully funding the cost of disposable nappies and associated continence aids for Pension Concession Card and Health Care Card holders for individuals with disabilities over the age of four years.

10.2.8 Health services

Many families have difficulties in moving from hearing a diagnosis to accessing supports in the community and there is no structured transition from the acute hospital setting to community based services. This is true even when children are discharged with acute medical needs and where parents are having to provide intensive nursing care and supervise complex medication regimes.

Recommendation 18: That the Minister for Health and Human Services establish procedures to ensure a planned hospital discharge for children with disabilities. This should include:

- assessing the parent's capacity to care;
- ensuring community support arrangements are in place;
- informing relevant service providers in the community; and
- distributing information to parents outlining the disability service system and all appropriate support agencies.

One of the main referral pathways into services for families with disabled children is through Family, Child and Youth Health Nurses and most families will have some level of contact with these nurses. However the eradication of the routine developmental check at three

and a half years has impacted on their ability to refer on pre-school children with later-onset developmental delays. This means that some children will not be identified as having difficulties until they reach school and opportunities for early intervention are compromised.

Recommendation 19: That the Tasmanian Minister for Health and Human Services restore the later developmental check undertaken by Family, Child and Youth Health nurses and ensure that it is available to all children when they reach three years of age.

Access to timely and appropriate levels of therapy, particularly for school aged children, was an issue for many families. This research fully endorses the outcomes of the recent review of Children's Therapy Services which recommends a comprehensive therapy service for children across the state.

Recommendation 20: That the Minister for Health and Human Services establish a comprehensive state wide therapy service linked to the proposed Tasmanian framework for specialist supports to children with disabilities and developmental delays and their families from birth through to adulthood.

Families need skills and strategies to cope with challenging behaviour and a lack of sleep that can impact on the whole family and threaten their ability to cope and sustain caring responsibilities. Yet the research identified major issues for parents in accessing support to deal with these problems. This is despite the fact that behaviour management and sleep programs are both early interventions which can greatly improve outcomes and the family's ability to manage.

Recommendation 21: That the Minister for Health and Human Services ensure that behaviour management and sleep programs are available to families caring for children with disabilities and/or developmental delays.

10.2.9 Mainstream services

Social exclusion of the whole family is fuelled by the barriers parents face to economic participation and their concerns about housing, limited childcare options and limited recreational and social opportunities. There is a need to make mainstream services more inclusive.

Transport

One of the main keys to inclusion for families caring for children with disabilities is accessible and affordable transport which allows them to access services, social activities, education and employment. However they encounter many practical difficulties including the costs involved in purchasing, adapting and maintaining private transport, accessing affordable transport to health services and barriers to using public transport. Modifying a vehicle is very costly and beyond the reach of most families. All these difficulties impact on families' ability to access the services they need and to participate in the community.

Recommendation 22: That the Minister for Health and Human Services increase funding to the Patient Transport Access Scheme so it meets the actual costs of transport, accommodation and living expenses while away from home and ensures that concessionary rates and subsidies are based on real economic modelling relative to the incomes of concession-eligible people accessing specialist health services.

Recommendation 23: That the Minister for Health and Human Services commit to an extension of the current Patient Transport Access Scheme so that concession card holders can access transport and accommodation subsidies to specialist medical services within the 75 kilometre boundary and that the scheme covers both access to specialist medical services and allied health practitioners when referred by medical specialist.

The Victorian Government has recognised the importance of private transport in promoting community participation and has recently made funds available to assist with the cost of vehicle modification.

Recommendation 24: That the Minister for Health and Human Services increase funding to the Community Equipment Scheme to provide assistance to people with disabilities to modify vehicles.

Housing

Access to suitably adapted housing improves the quality of life of children and makes it far easier for families to care for them. However people with disabilities do not have the same choices and opportunities in housing as others. They may have to devote large amounts of discretionary income to living in more expensive areas so they can access services or be near family support. They may also have to modify their accommodation so it is suitable for their child but, for those who are not public housing tenants, current opportunities for getting assistance with adaptations are very limited.

Recommendation 25: That the Minister for Health and Human Services develop a model to improve access to home modifications for those buying their home which incorporates waiving of state government duties on loans, provision of low interest loans to contribute towards the costs of modifications and free advice on and/or brokerage of the design and management of proposed modifications.

Recommendation 26: That the State Government direct funding to Housing Tasmania to increase the supply of affordable housing stock which is constructed according to universal design principles and located close to services.

Employment

Services currently fail to support economic inclusion. Limited childcare options and inadequate support with caring responsibilities mean parents may have to leave work. Appropriate assistance is required for parents to protect their ability to enter or remain in the workforce, avoid the risk of poverty and to improve outcomes for children. Although all families should have the same access to appropriate, high quality childcare provision there are currently a number of barriers in accessing childcare for families with disabled children. These include affordability, accessibility (and especially the lack of affordable and appropriate transport) and a lack of disability awareness among the childcare workforce. In addition parents may also have to combat inflexible employment environments which do not take into account their caring responsibilities.

Recommendation 27: That the Minister for Health and Human Services commit to ensuring the expansion of high quality affordable child care services for children with disabilities which also give priority access to the siblings of disabled children.

Recommendation 28: That the Commonwealth Minister for Employment and Workplace Relations commit to programs to increase awareness among employers about the need for flexible workplace environments and family workplace policies to increase attachment to the labour market.

Education

Since 1995 the Tasmanian education system has demonstrated a strong philosophical commitment to the values of inclusion. However implementation of these values, in the absence of a clear accountability framework for inclusion and a lack of resources, has not been consistent across the state and this has raised uncertainties about the future of inclusive practice in Tasmania. The lack of clarity and confusion among parents about how children with disabilities are identified, about what they are entitled to in terms of additional support and the reliance on individual school principals to ensure they get that support leaves many parents fighting battles in order to gain what they feel their child needs in school. In particular suspension, or the withdrawal of access to education, is not an appropriate educational response to disability. At the same time inclusion is not the best option for all children and although there are special schools the current configuration of provision does not necessarily fit the needs of children who cannot be effectively included. Many parents would like to see more enrolment options available to their children, including learning centres or additional needs units attached to high schools.

Recommendation 29: That the Tasmanian Minister for Education reiterates a clear commitment to inclusion values in Tasmanian schools so that all children with disabilities have an unequivocal right to be enrolled in mainstream schools.

Recommendation 30: That the Minister for Education ensures the establishment of a clear accountability framework for schools in implementing inclusion values and educational outcomes. This should include accountability for ensuring individual education plans and transition planning are in place.

Recommendation 31: That the Minister for Education commit to adequate resourcing for professional learning, training and support for inclusion including awareness raising among all school staff and for inclusion support for extra curricular activities.

Recommendation 32: That the Minister for Education promote a wider range of educational options for children with disabilities, including additional needs units in high schools.

Recommendation 33: That the Minister for Education increase the Transport Assistance Program budget to ensure that families using weekday centre-based respite options are able to access assistance with transporting their children between school and respite.

10.2.10 Consultation and representation

The research highlighted a lack of consultation and representation mechanisms for families caring for children with disabilities. Disability issues tend to only get onto the political agenda when major negative incidents occur yet it is important to listen to families on an ongoing basis to understand the most effective ways to provide support to them. The public, service providers and professionals should be educated about the impact of disability on the lives of families.

The Premier's Disability Advisory Council focuses on the individual with a disability rather than families as advocates for disabled children. At the same time the Parent Reference Group which

operates in the Education Department is an information-giving rather than a consultative body. These shortfalls have led to a neglect of the issues facing families coping with disability, like the impact on siblings and the family as a whole. This in turn has led to an inadequate response to their needs where parents are seen as potentially troublesome rather than experts who can contribute towards the development of services. There is a need for a true commitment to user participation and a consultative mechanism representing families in the broader context.

Recommendation 34: That the Department of Premier and Cabinet establish a Family Advisory Committee as part of the Premier's Disability Advisory Council to ensure ongoing consultation with families.



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