ANGLICARE
TASMANIA

My Life as a Budget Item: Disability, budget priorities and poverty in Tasmania

Teresa Hinton
Social Action and Research Centre
Anglicare Tasmania

My Life as a Budget Item: Disability, budget priorities and poverty in Tasmania

Cover artwork by Mathew Oakes

ISBN
PB: 1-921267-00-3
Web: 1-921267-01-1

For further information contact:
The Social Action and Research Centre
Anglicare Tasmania
GPO Box 1620
Hobart 7001

Tel: 6234 3510
Fax: 6231 9589
Email: t.hinton@anglicare-tas.org.au
Web site: www.anglicare-tas.org.au

Acknowledgements

This research was funded by Anglicare Tasmania. The author would like to thank the members of the Project Reference Group, Mandy Clarke (Anglicare), Jo Flanagan (Social Action and Research Centre, Anglicare), Ingrid Ganley (Disability Services), Mary Guy (Ministerial Advisory Council on Disability), Ken Hardaker (Advocacy Tasmania), Seda Harding (Carers Tasmania), Margaret Reynolds (ACROD) and Robin Wilkinson (Tasmanians with Disabilities) for their advice on the development of the research and their valuable input on the final report.

The research findings, conclusions and recommendations of this report are those of Anglicare and should not be attributed to any members of the reference group. Any errors in the report are the responsibility of the author.

The author would also like to thank the community service providers who helped with the research for their assistance in advertising for participants and talking to the author about their work.

Most importantly the author extends an enormous thank you to the research participants who generously gave up their time to share their stories. Without them this research would not have been possible.

CONTENTS

EXECUTIVE SUMMARY

This report describes research which explored the circumstances of the working age population of people with disabilities living on low incomes in Tasmania during 2005/06. The aim of the research was to contribute towards the development of policy and services in order to improve the quality of life of people with disabilities. It involved collating information about the daily lives of 48 people reliant on the Disability Support Pension (DSP) and 20 carers in order to explore the relationship between disability and poverty, investigate how this might impact on access to support services and detail unmet needs and gaps in service provision.

Key Findings

- There are currently over 24,800 people aged 18-64 years reliant on the Disability Support Pension in Tasmania. It is estimated that 22,100 have a profound or severe core activity restriction which means that they sometimes or always require assistance with daily activities in order to live a reasonable lifestyle. It is this group who are the main consumers of disability support services. As the likelihood of disability increases with age and Tasmania is projected to age more rapidly than other jurisdictions the state faces a significant increase in demand for services for people with disabilities.
- There is a strong correlation between poverty and disability in Tasmania. Living with a disability is too often associated with serious financial disadvantage due to lower workforce participation rates, low incomes and higher living costs related to disability related expenses. This is compounded by an inequitable two-tier system of income support which divides people with disabilities into those who are compensable under insurance schemes and those who are non-compensable. This means that those with similar medical conditions get very dissimilar treatment and the compensable have access to significantly better levels of replacement income, on-going support and a better quality of life.
- Some of the additional costs of disability are met by government subsidies and services but overall living with a severe disability and being reliant on the DSP typically means having very little disposable or discretionary income once the basic costs of living have been covered. Many are living in hardship and cutting back on essentials like food, heating and health needs as well as social and community participation. This means that disability commonly leads to a constrained existence where living standards, opportunities and life chances are substantially poorer than for the rest of the population.
- Some research participants had good things to say about their experiences of services, particularly when they had been able to form positive working relationships with providers. For others accessing and using services had been problematic. The divisions between Commonwealth and State government responsibilities, inadequate financial resources and contracting out of services to a broad range of non-government organisations has resulted in a complex and fragmented maze where agencies have their own administrative and funding

arrangements and target different groups. The outcome is duplication, gaps and confusion with no integration of information or care planning across disciplinary boundaries. This has generated a substantial unmet need for a range of services and difficulties for consumers in finding their way through the system.

- Personal care and support services which enable people to remain in their own home are currently delivered through different programs and a range of providers. Success in accessing support can depend on how a disability was acquired, skills in navigating the system and an ability to advocate for yourself. For those who are successful the outcome is commonly a minimum level of service which is about survival rather than the amount required for a quality of life and there are particularly shortfalls in the amount of domestic assistance available and in the support required to promote social participation. The result is a service network which allows many to lead impoverished lives while at the same time pushing the few into situations of acute need.
- Improvements in assistive technology are increasingly able to change people's lives and revolutionise levels of independence but the costs involved can be high. Assistance available to meet costs is fragmented and provided by a range of services where eligibility differs according to type of impairment, how it was acquired, age of the applicant, where they live and in what sort of accommodation. No one is responsible for monitoring or coordinating schemes to provide a comprehensive service. The research identified major gaps and shortfalls in the assistance available to meet mobility, communication and continence needs.
- The quality and availability of housing is a major issue for the delivery of home based care and although there is no shortage of housing models or of demand for them the lack of accommodation options in Tasmania has a profound impact on people's ability to manage as independently as possible. One factor is the lack of assistance with home modifications for both home owners and those in private rental accommodation. This means that people with disabilities are forced into making do or in having to meet the additional costs associated with modifying their environment or in ensuring that where they are located has reasonable access to the services that they need. At the extreme end of this spectrum are those young people with high support needs who have no alternative to being housing inappropriately in nursing homes.
- Accessing health care means a heavy reliance on the public health system for those living on the DSP. Many research participants reported difficulties including long waiting times for acute services, high transport costs, a lack of awareness about disability issues among health staff and an absence of planned discharge from hospital care. They also reported difficulties in accessing preventative health programs, oral health and alternative treatments as well as having to cover the additional costs of medications and medical supplies not included in the Pharmaceutical Benefits Scheme safety net.
- Varying degrees of social isolation are the norm rather than the exception. Overcoming the physical, financial, attitudinal and psychological barriers to social and community participation is a constant battle for many people with disabilities which drains their energies. There are limited day options and barriers to accessing mainstream recreational and leisure facilities. In addition a lack of affordable transport imposes severe restrictions on people's lives reinforcing the social isolation that so many experience.

- Home based care relies heavily on the availability of friends and particularly family as carers. For carers themselves acquiring caring responsibilities can be a life changing experience bringing with it restricted employment options, extra costs, low levels of financial assistance and a high risk of poverty, hardship and poor health both physically and emotionally. Despite the fact that the value of their work if it was replaced by formal services is enormous most carers felt that they needed more support in their caring role and many considered that they were unsupported and exploited.
- Having access to employment, education and training can have a big impact on income levels and self esteem. However research participants faced major obstacles including direct discrimination and the additional costs involved particularly with transport and technical aids. Despite a big increase in the numbers of students with disabilities this is not reflected in a rise in the numbers of people with disabilities in the workforce.
- People with disabilities want a one stop shop providing information about what is available, full recognition of the additional costs of living with a disability, a person-centred holistic approach, and a more coherent service system with access based on entitlement not whether individuals have the energy to fight for what they need. The recent Disability Framework for Action launched by the Tasmanian Government is welcomed but change requires action at number of levels - legislation, policy reform and attitudinal change in community. The lack of a well resourced consumer lobby which can represent the views of Tasmanians with disabilities has hindered collective action and operated as a barrier to achieving a higher profile on the political agenda.

Recommendations

Recommendation 1
That the Commonwealth Minister for Family and Community Services and the Tasmanian Minister for Health and Human Services ensures that the Commonwealth State/Territory Disability Agreement provides a planning framework for the provision of disability services across Australia which takes into account demographic changes, future service needs, changing expectations of service users and carers, the capacity of service providers and other relevant factors including the need for improvements in the quantity and quality of data collected.

Recommendation 2
That the Tasmanian Minister for Health and Human Services and the Treasurer ensure transparency in the allocation of monies to disability support services by itemising funding and “outputs” in State Budget papers as has previously been done for Children and Families and Housing Tasmania and by establishing a communications strategy to inform stakeholders about what money is available and how it has been spent.

Recommendation 3
That the Tasmanian Minister for Health and Human Services and the Treasurer allocate one-off funding of $3.1 million to build seven new group homes for people with disabilities.

Recommendation 4
That the Tasmanian Minister for Health and Human Services and the Treasurer provide an additional $9.8 million per annum to meet the ongoing support needs of those removed from the waiting lists.

Recommendation 5
That the Tasmanian Minister for Health and Human Services ensures that routine data is collected about unsuccessful requests for respite care in order to monitor the levels of unmet need for respite services.

Recommendation 6
That the Tasmanian Minister for Health and Human Services and the Treasurer commit 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 and the needs of an ageing population. Within this funding increase the following should be prioritised:

- development of a range of accessible and appropriate respite options with the goal of achieving a benchmark of four weeks annual leave and ten days sick leave for full time primary carers by 2020;
- increased access to domestic assistance and to personal support to promote independent living and social and community participation;
- increased funding to the Community Equipment Scheme to meet current demand and allow for an increased limit on expenditure for individual items;
- provision of a range of day options for people with disabilities which are appropriate to their needs in terms of age, type of disability and geographical area; and
- increased range of long term supported accommodation options.

Recommendation 7
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 8
That the Commonwealth Government through the Minister for Families, Community Services and Indigenous Affairs restore provisions to backdate the Carers Allowance for 12 months from the date of the claim.

Recommendation 9
That the Tasmanian Premier direct the Department of Premier and Cabinet's Social Projects Unit to research the effects of the welfare-to-work reforms on people with disabilities and other groups affected by the reforms to assess outcomes in terms of gaining sustainable employment and the impact on Tasmanian community and health services.

Recommendation 10
That the Minister for Families, Community Services and Indigenous Affairs direct Centrelink to conduct comprehensive disability awareness training with all Centrelink staff annually and produce clear guidelines about working with people who advocate for people with disabilities.

Recommendation 11
That the Minister for Families, Community Services and Indigenous Affairs direct Centrelink to develop an information kit outlining the support available for those transferring from compensation payments to Centrelink benefits.

Recommendation 12
That the State Government through the Attorney General require the Department of Justice to produce information about the options available to people with disabilities and their families to plan for their future financial security.

Recommendation 13
That the Commonwealth Minister for Employment and Workplace Relations secure funding to improve employer incentive schemes, assistance with disability-related employment costs and disability awareness programs to encourage employers to employ people with disabilities.

Recommendation 14
That the State and Commonwealth Governments act as role models by reviewing their own employment practices so that people with disabilities are employed in the public sector at a similar rate to their numbers in the working age population.

Recommendation 15
That the State Government commit to ensuring that a quota of 10% of new traineeship positions in the public service is targeted towards people who are long-term unemployed and within this broad definition a quota is identified for people with disabilities who are long-term unemployed.

Recommendation 16
That non-government organisations review their employment practices to ensure that they do not erect barriers to the employment of people with disabilities. This should include reviewing the administration of pre-employment medical checks and the requirement for driving licenses.

Recommendation 17
That the Tasmanian Minister for Health and Human Services introduce a streamlined service system which addresses multiple entry points to community care for people with disabilities, uses a common assessment tool, has a common approach to data collection and can provide case management services to those who require them.

Recommendation 18
That the Commonwealth Minister for Families, Community Services and Indigenous Affairs and the Tasmanian Minister for Health and Human Services abolish the co-payments for HACC services in order to remove financial barriers to accessing services.

Recommendation 19
That the Tasmanian Minister for Health and Human Services ensure that all workers in the disability sector, related services and health service staff have access to good quality disability awareness training conducted by trainers with disabilities.

Recommendation 20
That the State Government immediately amend the Disability Services Act to ensure that cognitive impairment is specifically identified in order to ensure those with acquired brain injury have equal access to services.

Recommendation 21
That the Tasmanian Minister for Health and Human Services put strategies in place to ensure that those population groups with high needs enjoy the same level of access as the general population to disability services and that barriers to Indigenous and culturally and linguistically diverse communities are removed.

Recommendation 22
That the Tasmania Minister for Health and Human Services establish a disability support information service within Service Tasmania which can provide a one stop shop about rights and entitlements to support and assistance across the spectrum of services.

Recommendation 23
That the Commonwealth and State Governments ensure that younger people with disabilities currently living in residential aged care have access to the Community Equipment Scheme and to the range of other disability services.

Recommendation 24
That the Tasmanian Minister for Health and Human Services fund the No Interest Loans Scheme (NILS) to undertake a 12 month pilot offering loans to people with disabilities for items of equipment not available through the Community Equipment Scheme to assess demand and cost.

Recommendation 25
That the State Government fund the capital cost and operating budget of a core and cluster housing model in each of Tasmania's three regions for people with disabilities with low to moderate support needs.

Recommendation 26
That the State Government fund Housing Tasmania to develop shared equity models specific to the needs of people with disabilities, including those with ageing carers who possess assets.

Recommendation 27
That the State Government fund Housing Tasmania to conduct research to establish how far the needs of people with disabilities are met in the public housing environment in terms of access, affordability, a modified environment and the promotion of social participation.

Recommendation 28
That the State Government develop a model to improve access to home modifications and independent living for people with disabilities or carers who own or are 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 and/or brokerage of the design and management of proposed modifications

Recommendation 29
That the Tasmanian Minister for Health and Human Services reviews the charges and fees in supported accommodation and group homes to ensure that they are uniform across the State.

Recommendation 30
That the Tasmanian Minister for Health and Human Services define wheelchair accessible vehicles as 'equipment' to allow individual support package recipients to use the funding for support hours they have not used (banked support hours) to contribute towards the costs of modifications to vehicles.

Recommendation 31
That the State Government fund two pilot projects to explore ways of better co-ordinating Community Transport, wheelchair accessible taxis and non-government organisations to provide a more effective transport service. It is recommended that these pilots should be located in a rural/remote area and in a metropolitan area.

Recommendation 32
That the Tasmanian Minister for Health and Human Services increase funding to the Patient Transport Access Scheme so it meets the actual costs of transport, accommodation and meals for people with disabilities accessing specialist health services.

Recommendation 33
That the Commonwealth Government restores the Medicare safety net threshold to $300 for Disability Support Pensioners.

Recommendation 34
That Medicare is funded to subsidise the costs of prescribed medical items such as neck braces, surgical stockings and bandages for Disability Support Pensioners.

Recommendation 35
That the Tasmanian Minister for Health and Human Services abolish the co-payment for general treatment in the public dental system.

Recommendation 36
That the Commonwealth Health Minister and the Tasmanian Minister for Health and Human Services ensure that patients attending GP surgeries have access to adjustable height examination beds.

Recommendation 37
That the Tasmanian Minister for Health and Human Services establish procedures to ensure a planned hospital discharge for people with disabilities. This should include:

- ensuring accommodation arrangements are adequate;
- confirming transport arrangements;
- assessing the carer's capacity to care;
- informing relevant service providers in the community; and
- distributing an information kit to patients and carers outlining the disability service system and appropriate support agencies

Recommendation 38
That the Premier through the Minister for Health and Human Services immediately commit $200,000 per annum to ensure the existence of a peak state-wide consumer organisation which is funded to represent the interests of consumers of disability services and covers the concerns of people with all types of disability.

1. INTRODUCTION

The circumstances, experiences and attitudes of Tasmanians with disabilities have, until now, been inadequately documented in the published literature except as part of a broader picture of social disadvantage. Despite the fact that a substantial proportion of people with disabilities are reliant on government benefits, what it means to live with a disability on a severely limited income is not well know or recognised by the general population. This report sets out to remedy this gap by collating information about the daily lives of 48 people with disabilities and 20 people caring for sons, daughters and spouses living with disabilities on low incomes.

1.1 Background

There are approximately 111,700 people, or 23.5% of the population, living with a disability in Tasmania (ABS, 2004). This means that, together with South Australia, the State has the highest proportion of people with disabilities in Australia.

There is a strong correlation between disability and economic hardship caused not only by low incomes, low educational attainment and restricted employment opportunities but also by the additional costs imposed by the disability. In Tasmania 24,824 people are reliant on the Disability Support Pension (DSP)[1] which means they are living on a low income. In addition social factors like the accessibility of the physical environment, the availability of transport, barriers to accessing specialist disability and generic services and discrimination deepen the disadvantage that people face and severely limit their participation. This has led some commentators to identify a continued institutionalisation within the community where low income and poverty have served to limit choice and restrict opportunities. As the experiences of people with disabilities and their families are largely unpublicised this virtual re-institutionalisation remains invisible and out of the public gaze.

Things are likely to get worse. The welfare-to-work reforms introduced in July 2006 mean significant reductions in income for many with disabilities exacerbating the financial and social disadvantages they face.

It is not only people with disabilities themselves who suffer financial and social insecurity but also those caring for them. These include family, friends and ageing parents and almost half of all carers are dependant on income support (Carers Australia, 1998).

With almost a quarter of the Tasmanian population living with a disability, assumptions are made that there is a coordinated response from all levels of government - national, state and local - to provide comprehensive disability services to meet their needs. Instead there are regular media reports of long waits for disability services, funding running dry, mismanagement in residential accommodation and individuals who cannot be discharged from hospital because of a lack of services in the community. The disability service system in Tasmania has been described as a system in crisis (Coalition of Disability Advocacy Groups, 2005).

---

[1] Source: Centrelink monthly statistics May 2006.

These concerns have not gone unrecognised by the Tasmanian Government which has launched the Disability Framework for Action 2005-2008 (DPAC, 2005). The Framework outlines what the Government intends to do to promote the full participation of people with disabilities across state government agencies. A comprehensive system reform agenda has also been advocated by non-government organisations to promote a more holistic approach to service delivery across Tasmania.

Yet many disabled people consider that the realities of living with a disability would surprise people. Unless it has impacted on them personally politicians and the community at large do not have a good understanding of the issues people with disabilities face. Neither do those involved in managing disability services have an adequate idea of what is like to be at the receiving end. It is this lack of understanding and awareness which this report sets out to address.

1.2 Definitions

What is disability? It is a heterogenous term describing people in a wide range of circumstances but who are generally considered to have a condition which hinders them in their ability to carry out day-to-day activities. It is defined by the Australian Bureau of Statistics (ABS, 2003) as the presence of a restriction, limitation or impairment 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. 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 need assistance; and
- profound when the person is unable to perform these activities or always needs assistance.

A medical model of disability associates the impairment within the individual with a medical illness that has to be treated at an individual level to allow the person to become a more ‘normal’ functioning citizen. A social model suggests that, although individuals may have serious impairments, society creates disability through structures, norms and attitudes (DPAC, 2004). The degree of disablement experienced is therefore a result of society’s ability or inability to support their social, economic and cultural participation. In the UK (Prime Minister’s Strategy Unit, 2005) a social definition of disability has been adopted and it is described as ‘the disadvantage experienced by an individual as a result of barriers that impact on peoples’ impairments and/or ill health’. This implies that a disabled person is anyone who is disadvantaged by the way in which the wider environment interacts with their impairment.

This research took the approach that the limitations imposed by disability and the level of socio-economic disadvantage people face is as much the result of physical, social, cultural and geographical barriers as the individual characteristics of the person with the disability or the nature of that disability.

Whatever the definition, ‘disability’ describes a range of conditions, effects and consequences and every person with a disability will face a different combination of attitudinal, physical and socio-economic barriers. This means there is no one way to address needs although there are themes common to all groups.

1.3 Aims of the Research

This research aimed to provide an improved understanding of the characteristics and circumstances of people living with a disability on low incomes in Tasmania and contribute towards the development of disability policy and services. It was carried out over a ten month period from October 2005 to June 2006. Using qualitative research methods it documents the experiences of low income earners with disabilities and their carers, provides a forum for their stories and puts people with disabilities at the centre of discussions about how to improve the security of their lives. In particular the research aimed to:

- explore the relationship between disability and poverty and provide a qualitative account of the daily living experiences and quality of life of people with disabilities living on low incomes;

- investigate the way in which living on a limited income affects access to the range of support services and explore unmet needs and gaps in service provision;

- collate the views of people with disabilities, carers, service providers and other stakeholders about poverty, disability and access to services; and

- formulate recommendations for improving the stability and security of the lives of people with disabilities and their carers in Tasmania so they can best manage their disability.

The Social Action and Research Centre (SARC) at Anglicare has previously explored the issues faced by people living with severe mental illness and their carers (Cameron and Flanagan, 2004). This population was therefore excluded from the research.

1.4 Research Methods

The study was designed as a qualitative piece of research and entailed a number of strands. These were:

- **in-depth interviews with people with disabilities.** The researcher interviewed 32 people living with a disability using a piloted semi-structured questionnaire. Potential interviewees were contacted through service providers, advocacy groups, peak organisations for particular kinds of disability and community organisations and invited to participate. The criteria for involvement was:
  - being of working age (18-64 years)
  - being in receipt of the Disability Support Pension (DSP)
  - living with a physical, intellectual, cognitive or sensory disability

  The sample was not random or strictly representative but constructed to ensure good representation across key variables, (age, sex, nature of the disability, household structure and living arrangements, level of participation in the workforce, geographical location and indigenous or non-English speaking background).

- **interviews with 20 carers** using a piloted semi-structured questionnaire. Fifteen interviewees were contacted through Carers Tasmania[2] who provided names of carers in each region who were looking after a person with a disability who met the above criteria. Five additional carers present at interviews with people with disabilities were also interviewed.

- **interviews with service providers** to map the service network and explore the barriers encountered by people with disabilities in accessing services (see Appendix A). This included the range of support services - Centrelink, disability and health services, housing and supported accommodation, education, employment and community services and NGOS - providing advocacy and support for people with particular kinds of disability. Interviews were conducted both face-to-face and on the telephone.

- **collation of research, policy and statistical information and documents** in order to review the research literature on poverty and disability, provide a policy and statistical background and offer a contextual framework for the qualitative research. This included tapping into already existing data about the prevalence of disability and the characteristics of people with disabilities as well as data about the use of services and unmet needs.

In addition to the semi-structured questionnaire participants were also asked to complete adapted versions of the Australian Unity Wellbeing Index[3] (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. They were taped and transcribed. Interpreting and advocacy services assisted in conducting interviews when there were any hearing or comprehension difficulties. All interviewees signed a consent form for the release of information and were also remunerated for their participation. As far as possible verbatim notes were taken during interviews with service providers.

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

1.5 Profile of the Research Participants

The research explored the experiences of 48 people with disabilities either first hand or second hand through their carers. This included five people with disabilities and living on the DSP who were also operating as primary carers. The sample picked up a broad range of both men and women across the age spectrum and living in a variety of different kinds of households. Three interviewees identified as being of Aboriginal origin.

---

2 Carers Tasmania promotes the role and interests of carers in Tasmania and provides carers with specialised carer resources, education, counselling, carer support groups and a young carers program.

[3] 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.

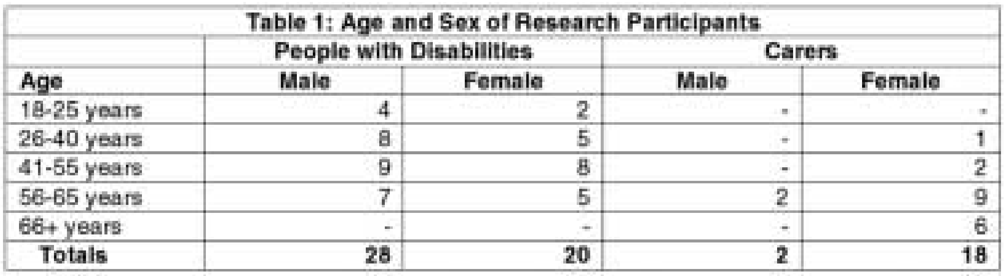

Table 1: Age and Sex of Research Participants				
	People with Disabilities		Carers	
Age	**Male**	**Female**	**Male**	**Female**
18-25 years	4	2	-	-
26-40 years	8	5	-	1
41-55 years	9	8	-	2
56-65 years	7	5	2	9
66+ years	-	-	-	6
Totals	**28**	**20**	**2**	**18**

Interviewees described a range of types of impairments and accompanying disability which resulted from them. Disabilities can be severe, mild, easily recognisable or invisible. Some are permanent and others temporary or episodic. Those with physical disabilities formed the largest group. They included four people with multiple sclerosis (MS), four people with quadriplegia, three people who had suffered strokes and five people with cerebral palsy. There were also those with sensory disabilities including blindness and deafness and with intellectual and cognitive disability. Five people had been diagnosed with severe mental health issues as secondary problems. People were also coping with conditions like diabetes, cancer, thrombosis, dislocated joints, epilepsy, asthma, depression and anxiety. Some of the impairments involved high levels of pain and mobility problems and might also affect fine motor skills. Those with brain injury or stroke described more hidden disabilities with effects on memory and on their ability to concentrate and make decisions.

Table 2 compares the range of disabilities in the research sample with the primary disability among the DSP population in Tasmania. It shows that the sample (excluding those with mental health problems) is a reasonable reflection of those receiving DSP in Tasmania.

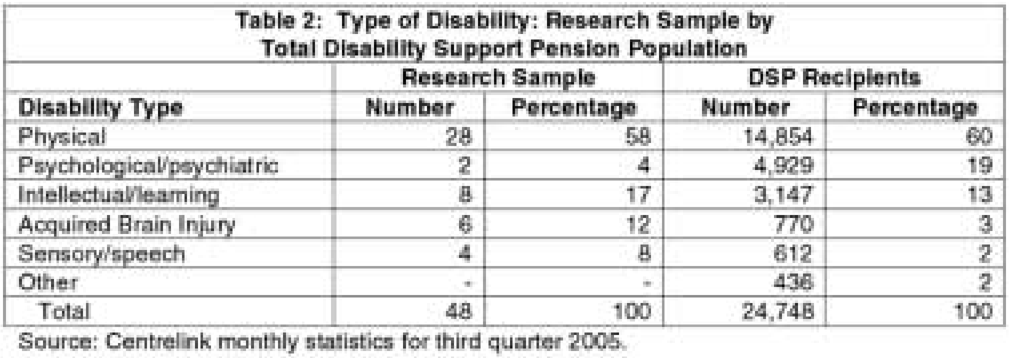

Table 2: Type of Disability: Research Sample by Total Disability Support Pension Population				
	Research Sample		DSP Recipients	
Disability Type	**Number**	**Percentage**	**Number**	**Percentage**
Physical	28	58	14,854	60
Psychological/psychiatric	2	4	4,929	19
Intellectual/learning	8	17	3,147	13
Acquired Brain Injury	6	12	770	3
Sensory/speech	4	8	612	2
Other	-	-	436	2
Total	48	100	24,748	100

Source: Centrelink monthly statistics for third quarter 2005.

The majority of people with disabilities experience the onset of their health problem or impairment in adulthood. According to a survey carried out in the UK (Burchardt, 2003), 11% of disabled adults of working age were born with a disability, 12% become disabled during childhood and the remaining three quarters became disabled during working life. This was true of the research sample where almost two thirds (62%) had acquired their disability during adult life and 18 (or 38%) had been living with their disabilities since birth or acquired them during childhood.

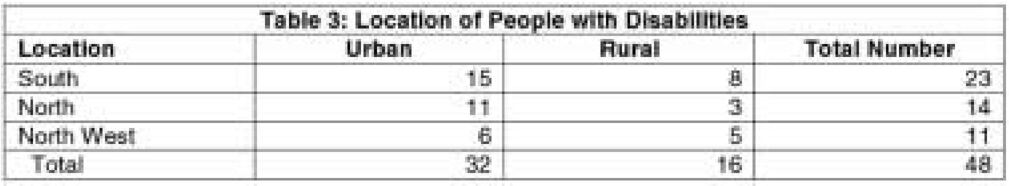

Table 3: Location of People with Disabilities

Location	Urban	Rural	Total Number
South	15	8	23
North	11	3	14
North West	6	5	11
Total	32	16	48

Interviewees were spread across the State and included people from both urban and rural areas.

Housing tenure varied. The majority of people were either home owners (20) or living in public or community housing (15). But there were also five people living in the private rental sector and a further five in supported accommodation and group homes. One person was leading a very mobile existence moving between family, friends and house-sits.

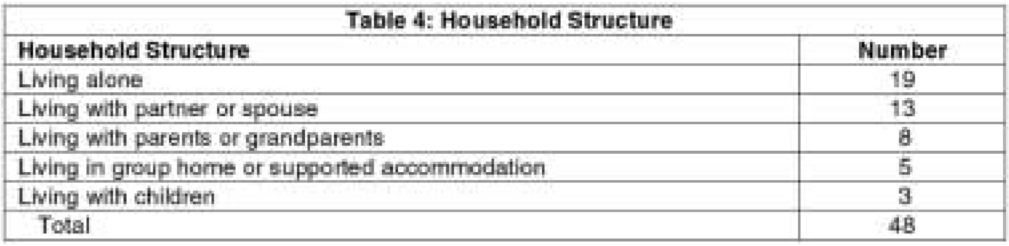

Table 4: Household Structure

Household Structure	Number
Living alone	19
Living with partner or spouse	13
Living with parents or grandparents	8
Living in group home or supported accommodation	5
Living with children	3
Total	48

Although over half were living with their partners and/or children, 40% of the sample were living alone. Whether or not they were living by themselves, most had family acting as informal carers and providing substantial amounts of care and support both financially and in kind. However there were also 18 people who said they had no regular help from their family.

Most people did not have paid work. However ten of the sample were in part time employment and two of these in supported employment.

1.6 Limitations of the Research

This study illuminates the subjective experience of disability for people in a range of different circumstances but who all share exposure to low income living and poverty. There are however some limitations to the research:

- **the size of the sample**. This was a qualitative piece of research using a small sample which cannot be described as random or representative. The concern was rather to encompass as broad a range of circumstances as possible and to elicit detailed information about income and expenditure. This means that it is not possible to undertake quantitative analysis or to draw finite conclusions about the overall population of people with disabilities in Tasmania. However it is possible to gain a strong insight into the commonalities and diversity of experiences of different groups of disabled people.

- **identifying interviewees.** The way in which potential interviewees were contacted means that they are a population who are mostly in touch with services. However the population of disabled people is not the same as those claiming disability benefits or services. Many claiming DSP do not consider themselves to be disabled and many who do consider themselves disabled do not claim any benefits or support services. It is anticipated that there are numbers of people with disabilities and carers who do not access services they might be entitled to and who are living with very little or no support. This means that the findings from this study are only the tip of the iceberg in terms of the difficulties people might face.

- **diversity**. The population of people with a disability is heterogenous and this has been reflected in the research sample. This means that to a large extent the kind of issues raised in the report are generated by the circumstances of the interviewees so that some kinds of disability and/or concerns have become more visible than others. This does not mean that their views necessarily have a greater importance or priority than others whose voices are less strident.

- **asking about income and expenditure** can be problematic and there are a number of attempts in the research literature to accurately measure the additional costs involved in living with a disability. Approaches can include asking people to estimate their additional expenditure, diary keeping and comparing the spending patterns of disabled and non-disabled people. A review of this research (Tibble, 2005) concluded that measuring extra costs is conceptually difficult. People may be unsure about the details or not willing to reveal them especially if some sources of income are semi-official. They may also fear being judged, particularly when asked about their spending priorities, and this was certainly the case among a small number of interviewees in our sample. This means that the approach adopted here was to elicit general information about income, additional costs and spending patterns rather than detailed weekly budgets.

- **ageing and disability**. Although disability affects people across the age spectrum this study is primarily about the needs of disabled people below retirement age and does not address the issues of elderly people with disabilities who have access to a different range of services and programs. However it is important to remember that the needs of ageing people with disabilities do not stop when they reach retirement age and that many of the findings will be directly applicable to people with disabilities aged 65 years or more.

It is important to emphasise that no particular effort was made during the course of the research to include extreme examples of poverty and disadvantage or of failures to access essential services. This means that what is documented in this report is the ‘ordinary’ experience of living on a Disability Support Pension for the majority of people rather than exceptional cases of hardship and difficulty.

1.7 Structure of the Report

This section has described the motivation for undertaking this study, the research aims and methods, who was involved in the research and what the limitations are. Section 2 provides a background to the qualitative research data by collating what is known about the numbers and characteristics of people with disabilities in Tasmania and the links between poverty and disability. It describes the policy and legislative framework and the service network which people have to negotiate.

Section 3 looks at the impact of disability on the lives of those who are disabled and their carers. It explores the process of becoming disabled and examines the needs of particularly disadvantaged sections of the disabled population. Sections 4 to 9 describe in detail the experiences people have had in accessing assistance across the service spectrum. This includes income support, employment, education and training, community care, assistive technologies, health, housing and transport. Section 10 looks again at these issues but from the perspective of carers. It examines the services available to assist them and the impact of the caring role on their own lives. Section 11 brings together information on the additional costs of disability and the extent to which disabled people are living in financial hardship. Finally the last section draws some conclusions and presents a range of recommendations which have arisen from the research.

2. BACKGROUND

This chapter collates what information is available about people with disabilities in Tasmania, including the links between disability and poverty, outlines the National and State policy framework and provides an overview of the service network for people with disabilities.

2.1 The Number of People with Disabilities in Tasmania

How many people are there with disabilities in Tasmania? Information comes from population surveys and service usage data. Every five years the ABS carries out an extensive survey providing detailed statistics on the prevalence of disabilities in Australia. This shows that in 2003 there were approximately 111,700 people in Tasmania, or 23.5% of the population, living with a disability which has lasted or is likely to last for at least six months and which restricts everyday activities (ABS, 2004). Approximately 37,100 Tasmanians (or 7.8 % of the total population) had a profound or severe core activity restriction. This means that they sometimes or always require assistance with daily activities in order to live a reasonable lifestyle. Of these it is estimated that there are 22,100 adults who are of working age. Not all of this group will require or receive formal services but it is this group which is the main focus for service provision and support.

This research targeted people with disabilities living on low incomes. For the purposes of the study this was defined as recipients of the Disability Support Pension. In 2005 there were 24,748 (or 5% of the population) living on the DSP with a range of disabilities. Well over half (60%) had physical disabilities (see Table 2 on page 12).

DSP recipients are more likely to be male (60%) than female and are spread across the age range but with the highest proportion (58%) aged from 40 to 59 years or middle aged. Seven hundred people (or 2.8%) identify as Indigenous or Torres Strait Islanders but this is considered to be an underestimate. Geographically the spread of DSP recipients across the state follows the population density with 48% in the South, 27% in the North and 25% in the North-West. However some local government areas have higher concentrations of people with disabilities in the working age population. These include Brighton and Glenorchy in the Hobart area, Tasman and Huon, Derwent Valley, the South Midlands, Central Highlands, Burnie, George Town and Break O'Day and are consistent with higher rates of deprivation and disadvantage generally recorded in these areas.

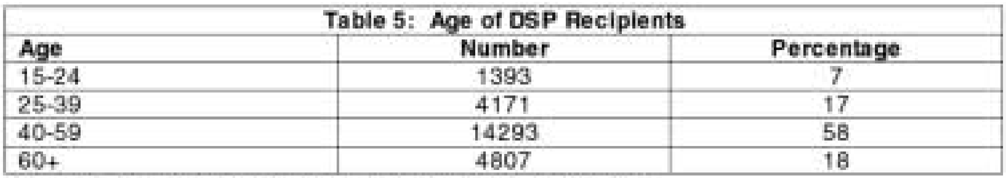

Table 5: Age of DSP Recipients

Age	Number	Percentage
15-24	1393	7
25-39	4171	17
40-59	14293	58
60+	4807	18

Source: Centrelink monthly statistics for third quarter 2005

Centrelink collate statistics on the type of accommodation people are living in. Among DSP recipients 41% are homeowners or purchasing their own home, 17% live in public housing and 19% in private rental accommodation including caravans and mobile homes. One hundred and sixty three were in government funded aged care homes and 5,620 were living in private homes with parents or in boarding houses, hostels and other forms of accommodation. Thirteen per cent (or 3,180) of DSP recipients were on reduced payments indicating that they also had an income from employment.

Data from non-government agencies in Tasmania indicates that there are approximately 700 people of working age who are blind or with vision impairment and 26 guide dog users. There are also about 300 deaf people in Tasmania most of whom would use sign language as their main form of communication. In addition, one in three of the general population will have hearing loss to some degree.

As data on disability is usually taken from population surveys and relies on self-reporting it commonly underestimates the prevalence particularly for disabilities which are undiagnosed, misdiagnosed or stigmatised; for example mental health or acquired brain injury. A new disability question in the 2006 Australian Census will allow small area data to be improved for information on sub-populations of people with disabilities.

Numbers are growing. The last decade has seen a substantial rise in the population with support needs living in the community and a growth in demand for services. This is due to advances in medical technology which mean more people survive traumatic injury or health problems. The numbers with severe disability have increased by 9.6% between 1998 and 2003. However there is no evidence that age-standardised rates of severe disability are rising and the rates of people with severe disabilities as a proportion of the population has not changed in the last 20 years (AIHW, 2005). The likelihood of disability increases with age so as the population ages and as life expectancy increases there are more people with disabilities in Tasmania at older ages. Tasmania is also projected to age more rapidly than other jurisdictions (Productivity Commission, 2005) and as there is a parallel increase in demand for services with age this will have a significant impact on the ability of public housing, transport, health and other services to meet the needs.

2.2 Special Needs Groups

There are sub-sections of the population of disabled people who may have particular needs. These can include women with disabilities and people with neurological and/or high and complex needs. The groups listed below are those which came to the fore during the research and are not necessarily those who have the greatest needs or who should take priority.

2.2.1. Aboriginal and Torres Strait Islanders

A national survey (AIHW, 2005) provides information on disability in the Indigenous population. It suggests that Indigenous people have severe disability rates which are at least 2.1 times those of other Australians and the prevalence is higher at all ages but particularly among those aged 45-64 years. This compounds the disadvantages they already experience and Indigenous Australians of working age with disabilities are less likely to be employed, have lower income levels and have completed fewer years of schooling than their counterparts in the non-indigenous disabled population.

It is difficult to estimate how far Aboriginal people use specialist disability services because although it is mandated that services should record Indigenous status and monitor take up this information is often not collected. However it is estimated that service usage is substantially lower than would be anticipated from the high rates of disability. There are currently no targeted services for Aboriginal people with a disability in Tasmania.

2.2.2 Non English Speaking Background (NESB) and Culturally and Linguistically Diverse (CALD) People

There is no Tasmania-specific information about the NESB and CALD populations with disabilities and indeed no one in the sample identified as being NESB or CALD. However data from elsewhere indicates they can experience discrimination on account of their disability, their ethnicity and the assumption that such communities 'look after their own'.

A report by an advocacy organisation (MDAA, 2005) in New South Wales identified a series of issues for NESB and CALD groups with disabilities including inequitable access to services, cultural incompetence among providers, a lack of accessible information and substantial unexpressed demand for services. There can be particular issues for carers in these communities where asking for help may be perceived as failure and this serves to heighten social isolation and lack of support.

2.2.3 People with Acquired Brain Injury (ABI)

Recent years have seen a growing recognition of the needs of people with ABI. ABI is an injury to the brain occurring after birth and resulting in a deterioration of cognitive, physical, emotional or independent functions. It can be due to trauma, infection, substance misuse, neurological disease or stroke and the impact can result in lack of insight, memory loss, poor concentration, lack of planning and problem solving ability, impulsivity and irritability. There may be physical changes like dizziness, epilepsy, fatigue, visual or hearing problems, socially inappropriate behaviour and personality changes. This means it can also be associated with family breakdown, unemployment, mental health issues, depression, isolation and loneliness. There is evidence to suggest that people with ABI are over-represented in the criminal justice system including prisons and in the homeless population. Advocates assisting those with ABI report involvement in legal aid and court work in support of their clients.

ABI is often called the invisible disability as there may be no outward signs and less is known about it than more 'traditional' forms of impairment. This can create difficulties in accessing support. It might mean being offered inappropriate forms of assistance or being misdiagnosed as mentally ill or with an intellectual disability. It has been argued that a major barrier is that there is no legislated form of assistance because 'cognitive impairment', although not excluded by the Tasmanian Disability Services Act 1992, is not specifically listed.

Approximately 5,200 Tasmanians state that they have experienced substantial disablement or interference with their activities due to brain injuries (AIHW, 2003). However relying on self-reported information can severely underestimate the actual numbers and there is now a consensus that these are much higher, particularly as many with ABI remain undiagnosed. In order to obtain more accurate data a Neuro Trauma Register is being established at the Royal Hobart Hospital to track people through the hospital system. However this will not include those who have been undiagnosed or misdiagnosed.

2.3 Poverty and Disability

Research has clearly demonstrated a strong correlation between disability and poverty across Australia (CARC, 2004). This is due to a combination of factors which include low incomes, a greater likelihood of unemployment, restricted employment opportunities and additional costs due to disability. People with disabilities are likely to experience:

- **lower workforce participation rates**. Just over half of all people with a disability participate in the labour force compared with four out of five in the general population (CARC, 2004). Participation rates for those with a profound disability are 30% compared to 80% for those with no disability (ABS Social Trends, 2005). They also face discrimination from employers in finding jobs, they work for lower wages and they have higher costs associated with being in employment or with looking for work. Joblessness in households with a disabled adult is 2.5 times higher than in households with no disability (ABS, 2005). Currently only 9% of DSP recipients have a part-time job and a further 6% participate in an employment program (ACOSS, 2005).

- **low incomes**. There is extensive evidence that people with a disability in Australia are experiencing serious financial disadvantage. Disability reduces the average gross weekly wages of women by 24% and men by 17% (HREOC, 2005). For those who are unable to work full time the main source of income is the Disability Support Pension (DSP) but there is a common perception that it is inadequate and does not cover the real costs of disability. Stringent eligibility criteria apply which mean that more than a third of applicants for the pension are rejected (ACOSS, 2005). The median gross income for 15-64 year olds with a disability is half that of those without a disability and income was substantially less for those reporting a profound core activity limitation (ABS, 2003). Indeed Australian has one of the lowest levels of personal income among people with disabilities in the OECD[4] (HREOC, 2005).

- **a higher cost of living due to disability related expenses**. The costs of disability are defined as the regular costs incurred because of the disability which are not faced by non-disabled people. They are not luxuries or lifestyle purchases but basic needs like transport, medication and medical treatment, staying clean and healthy, special aids and equipment and home modifications. They mean that 'secondary poverty' is forced upon households that would otherwise manage if they did not have the costs associated with a disability. It has been calculated that the additional costs of disability are proportionately greater for those on lower incomes (Berthoud et al, 1993) consuming a larger percentage of their disposable income.

  There is a wide variation in additional costs both within and between different impairment classes which makes the nature of the impairment a poor indicator of need. However those with a severe or profound disability have a cost of living above the rest of the community even though the DSP they receive is no more than that received by those with no additional costs. Despite Government initiatives to assist people to meet the additional costs there is evidence that disability continues to outweigh these forms of support and remains a major barrier to labour market and community participation (Gleeson, 1998). It also means that approaches which use income measurement as an indicator of standard of living are problematic in the field of disability (Lister, 2004).

Overall having a disability is very expensive and associated with a substantial increase in the incidence of financial hardship and a higher probability of experiencing severe financial stress including having to sell things or seek help from others (Saunders, 2005). In addition income poverty is recognised as having multiple dimensions making people vulnerable to broader disadvantage and social exclusion. Financial insecurity together with attitudinal barriers can combine to reduce the ability of people with disabilities to participate in employment, education, health services and social and recreational activities and heighten a sense of isolation and exclusion.

Disability can also entrench and deepen pre-existing disadvantage and the onset of disability is by no means a random occurrence (Burchardt, 2003). Those who are already disadvantaged are at a significantly greater risk of becoming disabled. There are strong associations between being poor, out of work, and with low educational qualifications and the risk of developing long term health problems or impairments. This means that the most vulnerable - the low paid, unemployed and self employed - face higher risks and are the least well protected from becoming disabled.

The link between disability, poverty and a wider social exclusion was clearly demonstrated in Anglicare's research about the experiences of Tasmanians living on low incomes with severe mental illness (Cameron & Flanagan, 2004). This outlined the cycle of poverty and ill health for those with serious mental illness and the implications for their carers. Those living with mental illness account for approximately one quarter of the total numbers of those with disabilities in the State.

A disability organisation in Victoria (Wilson et al., 2005) conducted a national poll of 180 people with disabilities to assess economic hardship and social participation. Respondents identified significant restrictions on their participation in a range of activities due to economic factors including loss of income, the cost of getting there, the cost of support and the cost of aids and equipment. Overall two thirds to three quarters were prevented to varying degrees from participating in social and recreational activities and 26% said that they were always or often prevented from participating. Those reliant on government benefits were up to five times more likely to experience these difficulties than those with a wage or private income. The poll also found that those in group homes experienced higher levels of exclusion in all domains than those in family homes or living independently.

The extent of additional costs faced by people with disabilities has led to calls for a universal disability allowance and the Senate Community Affairs References Committee Inquiry into Poverty (CARC, 2004) recommended that 'the Commonwealth introduce a disability allowance to meet the additional cost associated with disability'. Given that some disabled people have high additional costs and others have none the policy dilemma is to provide assistance to those who need it in proportion to their needs but in a way which is readily accessible, non-stigmatising and reasonably efficient to deliver.

---

[4] The OECD is a group of 30 countries whose membership is dictated by their being market-driven and democratic. OECD provides a forum for these countries to discuss and coordinate economic and social policy.

2.4 The Policy Context

Changing attitudes to disability on the part of governments and the broader community have been expressed through the implementation of a range of legislative initiatives and policies designed to better include people with disabilities in the wider society. It is a complex area of social policy because of the size and diversity of the disabled population and the range of organisations involved in service provision (Lindsey, 1996). Originally viewed as a family, a charity and then a welfare issue, disability is increasingly seen as a human rights concern and a community responsibility. The emphasis is now on protecting the rights of people with disabilities and providing opportunities for them to fully participate both through the provision of disability specific services and through modifications to mainstream services to increase their accessibility. As Lindsey has pointed out, translating these aspirations into reality remains a continuing challenge.

Awareness of the difficulties faced by people with disabilities was highlighted during the International Year for Disabled People (IYDP) in 1981. IYDP aimed to lower the barriers that prevented the achievement of equality with able bodied people. It was a major force for change heightening community awareness of disability issues and providing a vehicle for people to push for greater autonomy and a wider recognition of their rights. This fuelled a move away from institutional responses during the 1980s towards a more community orientated approach and an emphasis on community integration based on the principle of 'normalisation'. Deinstitutionalisation has indeed been very influential and meant that the last decade has witnessed a large increase in the numbers of people with support needs living in the community and a move to provide more flexible services responsive to individual needs. Equally important has been a move away from specialist to generic services to promote integration and enable people to participate in mainstream education, employment and recreation activities.

These trends are not unique to Tasmania or to Australia and have been experienced by most other OECD countries. All have embarked on programs of reform to improve the lives of people with disabilities and have found that despite some progress they are still likely to live in poverty, experience disadvantage and discrimination and have limited opportunities.

The key legislative and policy initiatives which govern the current provision of services to people with disabilities in Tasmania are:

- **Disability Services Act 1986,** providing a legislative base and a comprehensive framework for the funding and provision of disability support services funded by the Commonwealth. It was accompanied by a Statement of Principles and Objectives which recognised that people with disabilities have the same rights as other members of society.

- **Disability Reform Package 1991,** aiming to change Commonwealth income support payments to better encourage integration into the workforce and increase the capacity of rehabilitation, training and employment programs. It introduced the Disability Support Pension with eligibility dependant on a rigorous assessment of capacity to work.

- **Disability Discrimination Act (DDA) 1992**. This 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, education, banking and guidelines for providers of insurance and superannuation. It identifies the State as regulator and individuals as having a role in enforcing their rights. The Human Rights and Equal Opportunities Commission (HREOC) is the body charged with protecting these rights and advocating on behalf of disabled people. A recent review of the Act (Productivity Commission, 2004) found that the DDA had been reasonably effective in reducing discrimination but there is still some way to go particularly in improving opportunities in employment, tackling attitudinal barriers and improving the situation for those with mental health issues and intellectual disability.

- **Disability Services Act Tasmania 1992,** aiming to increase service accountability and consumer focus in state based services. It outlined 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. It has been criticised for focusing on 'the least restrictive alternatives' for disabled people rather than 'assisting people to be all they can be'.

- **Commonwealth Disability Strategy,** first introduced in 1994, is a whole of government strategy aimed at 'enabling the full participation of people with disabilities' by assisting Commonwealth organisations to meet their obligations under the Disability Discrimination Act 1992. It obliges Government agencies to remove barriers which prevent people with disabilities from having access to policies, programs and services and encourages them to provide information in accessible formats, employ people with disabilities and consult with them to find out what they need. It was originally intended that each jurisdiction would develop its own parallel document governing the services for which it was responsible.

- **Anti-Discrimination Act 1998** prohibits discrimination and provides for the investigation and conciliation of, and inquiry into, complaints of discrimination and others forms of prohibited conduct. It promotes acceptance of the fundamental principle that all persons regardless of specified attributes including race, lifestyle, disability or gender have a basic right to participate in public and social life without unfair discrimination, victimisation or harassment. It places a positive, pro-active role on all organisations to ensure that its provisions are known and adhered to by all managers, employees and others. The complaints handling and dispute resolution provisions of the Act are currently under review.

- **Commonwealth State/Territory Disability Agreement (CSTDA).** This agreement provides the national framework for the funding and provision of disability support services for those who require ongoing or long term support and clarifies federal and state/territory responsibilities. The main CSTDA services are accommodation and community support services, community access and respite services and employment services. The current or third agreement 2002-2007 has five key policy priorities - improving access to generic services, strengthening across-government linkages and families and improving demand management, accountability and quality for specialist disability services.

  As it stands at the moment some are of the view that it serves to entrench the fragmentation of service provision and that the fourth agreement should provide more resources to meet the needs, improve pathways and linkages between service systems and improve quality. There are also those who would like to see the demarcation line between Commonwealth and State responsibilities redrawn with either the Federal Government assuming full responsibility for the provision of disability services or the transfer of administrative responsibility from Commonwealth to States.

- **Disability Framework for Action 2005-2010.** This is a 30-page document issued by the Tasmanian Government which lays out a 'whole-of-government framework' for Tasmanians with disabilities. It is based on seven guiding principles as specified in the Disability Services Act 1992 - equity, access, inclusiveness, autonomy, recognising and supporting diversity, non-discrimination and prioritising resources. It is also structured around four priority outcomes - fostering human rights, providing access to high quality services, increasing safeguards and advocacy and working collaboratively. The Premier is responsible for overseeing the implementation of the Framework with assistance from a Disability Advisory Council acting as a reference group, with half the membership consisting of people with disabilities, families and carers and including the Minister for Health and Human Services. The Disability Advisory Council reports annually to the Cabinet Policy Committee on progress. A Disability Bureau will also be established within the Department of Premier and Cabinet to promote the Framework and assist with implementation. All government agencies will be required to prepare a Disability Action Plan documenting how commitments in the Framework will be met, identifying specific and measurable priorities, targets and benchmarks and action taken to promote disability awareness within agencies. The implementation of the Framework will be reviewed in 2008.

  These initiatives have been welcomed for providing an overview of key areas which need to be addressed, encouraging agencies to promote the inclusion of people with disabilities and generally raise awareness of the issues. At the same time there has been criticism of the lack of defined actors, timelines and resources identified in the document.

- **Tasmania *Together*** is a vision for the State based on an extensive community consultation. It encompasses 24 goals and 212 benchmarks reflecting the concerns of Tasmanians. Progress towards achievement of the goals and benchmarks is monitored by an independent statutory authority, the Tasmania *Together* Progress Board and results are reported through Parliament. It has been criticised for not adequately reflecting the priorities of people with disabilities. This is now being addressed by the development of specific disability-related benchmarks.

- **The Way Forward: A New Strategy for Community Care** (Department of Health and Ageing, 2004) is based on a review of community care programs which found a complex and diverse system with multiple barriers to access and inequitable service delivery. The review identified a need to bring all community care programs together under an overarching framework and address their roles and responsibilities. It proposed:
  - a single 1800 number to provide information about eligibility for government community care services
  - a consistent approach to assessing need across Australia with consistent eligibility criteria
  - a streamlined information system via a common assessment tool so that a client only has to provide personal information once

- better co-ordinated planning across Home and Community Care provision and other community care providers.

Despite extensive consultations carried out in 2003 and 2004 to prepare for the development of a strategic approach, Disability Services in Tasmania is still operating in the absence of a strategic framework. The finalisation of a draft framework prepared in 2005 was delayed by a restructure of the Department of Health and Human Services. A strategic direction will now be developed as part of a common planning and performance management framework across Divisions within the Department.

2.5 Welfare-to-Work Reforms

The upward trend in the numbers of DSP recipients in the past ten years has made reducing welfare dependency and increasing workforce participation among people with a disability a priority for the Australian government. The welfare reforms introduced in July 2006 tighten eligibility for the DSP by reducing the work capacity requirement from 30 to 15 hours a week. This means new applicants for income support who have a disability and are able to work 15 or more hours a week within a two year period at award wages in the open labour market will receive enhanced Newstart or Youth Allowance rather than the DSP and be subject to part-time mutual obligation requirements. The Government has stated that the changes will be accompanied by extra employment services to promote workforce participation including disability open employment services, vocational rehabilitation and the personal support program.

An analysis by the National Centre for Social and Economic Modelling of the impact on people with disabilities (Harding et al, 2005) has shown that under the new system financial losses for new applicants with disabilities are substantial. It means:

- a loss of income for those pushed onto the lower rates of Newstart Allowance of between $46 to $120 a week or up to a 26% cut in living standards. The gap between the DSP and Newstart will increase in future years as the DSP is indexed to average weekly earnings while Newstart is indexed to the generally lower consumer price index. It is anticipated that restricting eligibility criteria for the DSP will result in rejecting 60% of all new applicants.

- higher effective marginal tax rates (or the percentage of an increase in earnings lost to income tax). Rates will increase from 40% for those on the DSP to 60% for those on Newstart Allowance.

- a stricter income and assets test. A single homeowner with assets over $157,000 loses entitlement to any Newstart Allowance. In contrast a pensioner loses $3 per fortnight of DSP for every $1,000 above this level. This means that a person with a disability who is a homeowner and who inherits $200,000 from their parents is not entitled to Newstart Allowance but would have been entitled to the DSP under the previous system.

- loss of concessions. Those with enhanced Newstart remain eligible for the pension concession card but their eligibility is reduced as eligibility for Newstart ceases at a lower level than eligibility for the DSP.

- a more demanding set of mutual obligation requirements where those on the DSP will not be 'asked' but 'required' to look for work if they are to remain eligible. The new compliance system is based on suspension of payment for eight weeks if people do not meet activity requirements. This could have serious consequences for many households including the risk of homelessness through an inability to pay rent.

- DSP recipients can access the Pensioner Education Supplement worth $31.20 a week for full time study. Newstart recipients are placed on Austudy while studying but are ineligible for the supplement. They also lose their entitlement to rent assistance.

Overall it is anticipated that the reforms will reduce the attractiveness of paid work and discourage people from undertaking part time or casual work as additional income is eaten away by the loss of benefits, the impact of income tax and the additional costs of workforce participation with a disability. Although the reforms will not directly affect the disposable incomes or effective marginal tax rates for those already in receipt of DSP and who remain on that payment they will make people less willing to try working due to a fear that if they can only work for a few hours a week or if they subsequently lose their job they face going onto Newstart with the additional pressure of meeting mutual obligation requirements. These pressures fuel anxieties that work will jeopardise levels of benefit in the future.

There are concerns that the interaction between the changes to income support, employment assistance and industrial relations may have a negative impact on people with disability and affect disability employment and the protection given to employees with a disability in the open workplace. Certainly in the short term the reforms will reduce the incomes of many who are already reliant on a poverty level income and only add to the financial and other pressures in this vulnerable group. It has been estimated that over 2,550 people with disabilities will be worse off in Tasmania. It has also been estimated that Tasmania will have a proportionately greater number of disabled people worse off than all other States and Territories apart from South Australia (ACOSS, 2005).

2.6 Overview of the Service System

Most people with a disability of working age get support and assistance from family and friends. In addition the government - at federal, state and local levels - provides a range of services through state and federal legislation. There is a mix of mainstream and disability specific services with some generic services specifically targeting people with disabilities. This makes it difficult to get an accurate picture of the extent of funding and support going to people with disabilities. This section gives a brief summary of the service system. More detail can be found under particular service sector headings.

2.6.1. Commonwealth Services

For people with disabilities the Commonwealth provides:

- income support including the disability support pension and mobility allowance;
- planning, policy setting and management of employment services and funding to organisations to provide employment and training services;
- accommodation support, respite, independent living and recreation services;
- joint funding with states and territories for the Home and Community Care Program (HACC), aids and appliances, advocacy, information and print disability services;

- Continence Aids Assistance Scheme (CAAS);
- services for veterans; and
- provision of pharmaceutical and other medical benefits.

Complex negotiations to determine how much money is received by States and Territories to provide services result in the Commonwealth State/Territory Disability Agreement (CSTDA). This is the basis for the provision and funding of specialist disability services for those who require ongoing or long term episodic support.

2.6.2. State Services

The state government has day-to-day responsibility for programs in all of the important spheres of life for people with disabilities from education through to specialist disability services.

In Tasmania the lead agency is Disability Services. This is a business unit or program of the group Human Services which is located within the Department of Health and Human Services and also includes Children and Families, Housing and Youth Justice. Disability Services aim to provide a range of specialist services to clients and are mandated to assist access to generic services. They offer a transitional service and point people in the direction of generic services so that they are not stigmatised or stereotyped by the disability banner or the provision of separate services. Although limited by resources in theory they provide:

- a service co-ordination team assessing individual needs and assisting access to services within the community. This is the key point for linking people with disabilities into generic or specialist services;
- a resource team of allied health professionals providing specialist advice, assessment, interventions and education;
- centre-based respite services across the State;
- residential accommodation run by Disability Services and NGOs;
- vocational and community focussed day option programs;
- short term support focusing on skill development;
- an information and education unit;
- an individual funding unit; and
- a regulatory role in policy, planning, funding and purchasing and establishing and monitoring service standards.

The target group for Disability Services is defined by the Tasmanian Disability Services Act 1992 which stipulates 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.

Those aged over 65, those with psychiatric problems, substance abuse disorders, behaviour disorders (like ADHD or social and emotional problems), those in post acute care and those with chronic medical conditions are excluded unless there is a permanent disabling condition and they are unable to benefit from medical services. Disability Services are not geared to temporary conditions. These are considered to be medical issues which should be dealt with by health services. This means that episodic disabilities like rheumatoid arthritis may be ineligible for assistance. When clients have additional conditions, for example mental health problems, the extent of Disability Services involvement will be determined on a case-by-case basis.

The scope of Disability Services was widened in 2000 to incorporate those with acquired brain injury. However the bulk of the clientele are ‘traditionally’ people with intellectual disability (46%). Those with a physical disability form 16% of the clientele and only 7% have acquired brain injury and 8% neurological disabilities and progressive conditions (AIHW, 2005). At any one time Disability Services are working with approximately 3,500 people. This means that most people living with disabilities in Tasmania are unknown to Disability Services and have not had any contact with them.

2.6.3. Local Government Services

Local government in Tasmania is made up of 29 councils each responsible for a municipal area and for the health, safety and welfare of the community. Councils vary in the extent to which they provide services specifically for people with disabilities. For example Hobart City Council has:

- an Equal Access Strategy. This seeks to address both physical and attitudinal barriers to accessing Council services and works through the Access Advisory Committee to improve access to buildings, parks, streetscapes and services as well as raising awareness in the broader community. The Committee is made up of Aldermen, Council staff and representatives of key community organisations.
- a Mobility Map or guide to access and facilities for people with limited mobility including accessible toilets and disabled access parking zones.
- temporary parking permits for people with temporary disabilities.
- a free wheelchair service which can be booked for weekend use.
- a developmental role in awareness raising about disability issues in partnership with local agencies.

Smaller and more rural councils do not necessarily have the resources to be as active in this area.

2.6.4. Non-governmental Organisations

Approximately 70% of all services for people with disabilities are provided by the non-government sector. These services include supported accommodation, day programs, personal care and advocacy. They also include general information and support, case management and coordination, respite, referral and crisis intervention. They may be providing leisure and recreational opportunities, life skills development, community rehabilitation and pre-vocational or employment support. There are also a range of consumer organisations promoting the interests of people with particular kinds of disabilities, their families and carers.

The diversity reflects the range of disabled peoples’ experiences, identities and interests. At the same time it has also hindered the development of a coherent disability sector response to issues and policy developments. Competition for funding as well as groups seeking to further the interests of their own members and users has meant an emphasis on the recognition of difference between groups rather than commonalities. Many are cautious about their dealings with government and reluctant to criticise in case they jeopardise their funding. Few are involved at a policy level and there is currently a shortage of mechanisms for channelling the service wisdom they have accumulated so that it has an impact. Altogether the diversity of the sector has served to prevent the formation of an effective consumer lobby and made collective action difficult to achieve.

2.6.5. Regional Issues

Tasmania's population is small and relatively decentralised when compared to other jurisdictions and services are not evenly spread across the State. Despite expectations that rural areas should have access to city services some areas are poorly served and many anticipate 'looking after their own' rather than accessing services. Gaps in provision are prevalent across the range of services from accommodation options, respite and personal care and support through to transport and access to health services. As one interviewee said '*all the services seem to end in Burnie and it's far worse now than it was five years ago'*. A lack of services in rural areas impacts on the consumer in a number of ways. It adds to the cost of service provision, reduces choices and options and creates an additional demand for transport.

However living in a more rural area is not always a disadvantage. As some people pointed out a smaller service network means that staff are more likely to stay in their jobs, to know each other, to work together more effectively and to have opportunities to be more flexible than in larger urban areas. This was the perspective of a number of providers on the North West Coast.

2.7 Unmet Need

There is a clearly demonstrated unmet need for a range of services. A study (AIHW, 2002) of access to disability services found a system under pressure and highlighted outstanding needs for accommodation, respite, community and employment services. The levels of unmet need in Tasmania are consistent with national levels. The Coalition of Disability Advocacy Groups[5] identified a backlog of unmet need in 2005 for essential services which they described as unacceptable and due to a failure to maintain non-government sector funding at a level to be able to effectively respond to increasing client need.

State budgets have varied in the extent to which they have recognised the extent of unmet need and allocated additional sums on top of recurrent funding for disability services. In the 2005-06 State Budget $112.155 million was allocated with an additional $80 million over a four year period. However it has proved problematic to clarify both how the recurrent and the additional funds have been allocated. Indeed Tasmania has been criticised for its lack of financial transparency in disability expenditure (Access Economics, 2003). Despite the injection of funds there are still outstanding needs and in July 2006 there were over 490 people on waiting lists for a range of services including:

- 26 people requiring long term supported accommodation options
- 262 people waiting for individual support packages (ISPs)
- 92 people waiting for day services
- 111 people waiting for aids and equipment

There are also young people in nursing homes and those who cannot leave hospital because there are insufficient financial resources to support them in the community. These waiting list figures are an underestimate because it is impossible to calculate the level of unmet need in rural areas where there is no government disability support infrastructure.

---

[5] The Coalition was formed in 2005 to advocate for substantial increases in funding for Disability Services in Tasmania to address unmet need and advocate for a forward planning approach with growth funds in the Budget to avoid future crises.

2.8 Summary

Overall as the levels of unmet need demonstrate the de-institutionalisation process has not been accompanied by adequate financial resources and this has impacted negatively on the quality of life for people in the community especially those with more severe disabilities. Despite a range of legislation and policy initiatives many aspirations of the disability movement have not been achieved and there are still discriminatory attitudes and unequal access to services. This is not to suggest that no progress has been made and many enjoy a greatly improved quality of life. But there are significant equity issues where some get a lot and others get nothing.

The division of responsibilities between the Commonwealth and State/Territory governments and the contracting out of many services to a broad range of non-governmental organisations has resulted in a complex and fragmented maze where agencies have their own administrative and funding arrangements and target different groups. Small scale incremental development has fuelled low expectations and heightened a sense of frustration. It also means difficulties in collecting consistent data which hampers coherent forward planning and co-ordination, serves to further compartmentalise needs and responses and promotes a crisis management response.

The outcome is duplication, gaps and confusion and as the following report demonstrates consumers are the losers.

3. SOURCES OF INCOME

Some people with disabilities are able to maintain full or part time employment. Others are reliant on income from government benefits or compensation payments. However, whether they participate in the workforce or not, the level of support they receive is dependant on how, when and where their injury or disability was acquired rather than the nature or severity of that disability.

A two tier system of income support exists which divides people with disabilities into the compensable and the non-compensable. Those that are compensable under a range of insurance schemes can get access to significantly better levels of replacement income and on-going support and hence a better quality of life. Those who are non-compensable are reliant on income support payments through Centrelink and a broad range of services in the community, many of which are under-funded.

In addition there are also those who fund their care privately through private settlements and veterans who have been injured in the defence service or during wars. They are provided with compensation payments and care and support through the Department of Veteran Affairs.

3.1 Centrelink Services

There are two main disability related income support payments:

- **Disability Support Pension (DSP)** is a means tested payment for those aged 16-65 years (or 62 years for women) who have a severe disability that has been assessed by medical or other experts chosen by Centrelink. An exception is made for blind people who are able to receive the DSP without a means test. This is sometimes called the 'blind pension'. Assessment involves a detailed written application form, a face-to-face interview, written reports from doctors and specialists and assessment by a medical and/or work capacity assessment expert using standardised tests of impairment or work capacity.

  For those aged over 20 years the single DSP rate is $499.70 per fortnight. It allows for a private income of up to $64 per week (or $106 per couple) before any deductions are made. Above this there is a 40% reduction in the DSP for each dollar earned. The DSP provides an annual income of $12,992 boosted with concessions on utilities, pharmaceuticals and health care.

People with disabilities may also be receiving Newstart Allowance and Youth Allowance and there is an exemption from activity test requirements for those who, due to their medical condition, illness or injury, are temporarily unable to work or study.

- **Mobility Allowance** is a non means tested income supplement paid to people with a disability including those on Newstart and Youth Allowance to help with transport costs associated with employment or job search, vocational training or voluntary work and who are unable to use public transport without substantial assistance. It is $71.40 per fortnight and a lump sum advance equal to six months' allowance may be paid once a year. A new higher rate for job seekers with the capacity to work 30 or more hours is proposed.

As well as counter staff there are a number of disability officers based in Centrelink offices across the State who can offer a more comprehensive service to people with disabilities. They operate as matchmakers and link people with disabilities with services and information, disseminate information about disability in schools, conduct disability awareness training with other Centrelink staff and work with the families of people with disabilities. Their role is currently being reviewed and there are concerns that if it is broadened to include other groups the disability expertise they carry will be lost.

Recipients of the DSP are also entitled to a pension concession card. This entitles them to a range of concessions on national, state and local government services as well as some private sector concessions. The core areas agreed by all state and territory governments are energy consumption, water and sewerage, municipal rates and transport. There are other concession areas which vary between jurisdictions. In Tasmania people with disabilities can also get taxi subsidies, ambulance travel and most recently companion cards to provide support to attend particular events or venues with a carer for the price of a single ticket.

3.1.1. Experiences of Centrelink

Many people who we spoke to had good experiences of dealing with Centrelink. They had found them helpful and efficient. Those with a positive experience had often been able to find someone in the office who was able to spend more time with them to explain things and to help.

Others however had experienced problems in getting information about what they might be entitled to. Sixty percent of Centrelink work is now conducted through call centre networks and the internet which has considerably reduced the amount of personal contact with clients. This can impact on people with disabilities. Many are reliant on mobile phones and long waits to have queries answered become a major financial issue. Phone services can also disadvantage those who have difficulty following prompts or who are hearing impaired.

Those with sensory disabilities can encounter particular problems. Because AUSLAN is the first language of many deaf people they can have difficulties in understanding and interpreting written information from Centrelink because of language barriers. Although Centrelink is able to pay for any interpretation services required this does not always happen:

> *I went to Centrelink myself and I was writing notes on bits of paper but I wasn't really sure if I was understood or not. Then they sent me a letter and it was all wrong so I had to go back in again and go over my earnings. Often it is difficult simply because of a word that I might not understand. (Joy, 38, living with deafness)*

Some people reported a lack of sensitivity towards disability issues among Centrelink staff. One man commented that staff had been rude and impatient because of his speech impediment. Another that the Centrelink environment had exacerbated the problems he experienced with processing information, concentrating and anger management caused by an acquired brain injury. A third commented on the lack of allowance made for those with intellectual disabilities, for example, having to continually explain why it took twice as long to complete a TAFE course so that he or she could continue to receive the Pension Education Supplement. As one woman said, '*They don't realise how much you are dealing with and that Centrelink issues are only one small part of the whole picture.'*

Although for most people applying for the DSP had been relatively straightforward this was not so in all cases. Being made to 'jump through hoops' during the assessment process, the inability of Centrelink to do home visits and the lack of allowance made for disability in communications with Centrelink had all impacted on our respondents.

> *They stopped my payment three times on the basis that I hadn't presented my form personally. So I rang Centrelink and asked to speak to the regional manager and asked who's paying for the taxi and they said we can't do that. I said you have a file on me which is two inches thick and short of a miracle there's not going to be any change in my situation so therefore you are being discriminatory so can you restore my pension forthwith. They did and gave me an exemption from this personal presentation. (Janine, 60, living with physical disability)*

> *They refused him and sent him a letter. He was suicidal at the time and the letter said the head wounds were closed head wounds only (which was completely wrong) and so they refused him on this basis. They also told him his schizophrenia was only temporary. Sending a letter to a schizophrenic who was suicidal - well where is the sense in that? It could have been the death of him and I was absolutely disgusted and shocked. Then I got the administration order and I approached a Welfare Rights Advocate organization and we got him the DSP without him having to see anyone again. (Madeline, 53, caring for 31 year old son living with ABI and schizophrenia)*

> *I had heaps of problems getting onto DSP. It wasn't so much what the doctors said or the way that the form was set up. Because you can hold a conversation, people think what is wrong with you but they don't see you on a bad day where it is even an effort to scratch yourself. So it took five years then from coming out of hospital to get on the Pension. It was difficult because we lived in quite a remote place so funds were stretched badly. House payments wouldn't get made because of medical treatment - you did one or the other. (Diana, 54, living with ABI)*

There were general administrative failures that had created high levels of stress and anxiety for benefit recipients.

> *They mucked up my Mobility Allowance last year. They sent me a review letter which I filled in and posted back and then I got a letter from them saying that they hadn't received it so they sent me another one. I filled that one in and sent it back. Then I got another letter to say that they were going to discontinue the payment because I hadn't replied. Anyway I ended up filling in four forms and posted them all back and finally it was re-instated. I sent the last review form by registered mail and after about two dozen phone calls as well trying to find out what was going on. (Denise, 52, living with cerebral palsy)*

Those with less visible disabilities like ABI or mental health issues had particular problems. In some cases it meant playing down the positive and emphasising the negative in order to show conditions were not improving. Some people were able to effectively speak for themselves and had managed to get what they wanted. Others had relied on help from advocates to guide them through.

> *They were aware that I couldn't fill in forms myself but you actually have to be a little bit assertive and tell them what it is you can't do and what you would like them to do for you. If you don't do that you probably don't get the same service. (Anna, 56, living with blindness)*
>
> *I dealt with them through the MS Society and they've (the MS Society) been fantastic. Financially they helped, getting onto the right people because trying to get into Centrelink and talk to them is just the pits. You can't. They cut you off or put you down the line, it's been dreadful. (Linda, 55, living with MS)*

Service providers did report difficulties in trying to advocate for their clients with Centrelink. When they had spent time fostering relationships with staff it worked well but others reported incidents when they had been barred by Centrelink staff from assisting. They considered that guidelines for Centrelink staff in working with advocates were not necessarily consistent or flexible enough and even when an individual had been named as the authorised person it did not guarantee that they were included in discussions. This could create particular problems when working with non-verbal clients.

Problems in coming to terms with their disability, the lack of information about what was available and the assessment processes involved had all served to delay or even prevent people applying for the benefits they were entitled to.

> *I don't get a disability pension, I get a small superannuation and mobility allowance which gives me a health benefit card. I probably could get part disability pension but I don't want to tell Centrelink all my business. People know so much of my personal private life and I can't bear for anyone else to know any more. I don't have to tell them much for mobility allowance. (Mary, 57, living with physical disabilities)*
>
> *Sarah has actually been on a DSP since 2004 but she should have been on it before that, probably since 2000. There is no-one out there that can sit you down and say to you that you can get this or this or this assistance. You just find out little snippets. We didn't understand that she could have been on the DSP a lot sooner than she was. I think one of my daughter's friends told me. (Laurie, 54, caring for his wife with renal failure)*
>
> *When I was studying I didn't apply for the disability support pension when I should have and I kept putting that off until 1999. I just put it off because I didn't think I was that disabled. It's about acceptance. (Steve, 31, living with blindness)*

3.2 Compensation Payments

Most people receiving compensation payments have been injured in work related incidents or as a result of motor vehicle accidents but there are also payments from criminal injuries or victims compensation, personal accident and sickness insurance, sporting injury, public liability and medical negligence compensation. Those entitled to compensation can receive income replacement in the form of regular or lump sum payments for varying lengths of time. They also get help with medical expenses, rehabilitation, aids and equipment, accommodation, home and vehicle modifications and personal support costs.

For those injured in car accidents the Motor Accident Injury Board (MAIB) currently pays a maximum total sum for medical and disability benefits of $400,000 unless claimants are classed as ‘future care’ or requiring daily care for at least two hours per day for an indefinite period. In these cases there are no time or cost limits and MAIB will provide for all medical costs, personal support and equipment. In February 2006 there were 78 future care clients in Tasmania and 81% of these were of working age. According to MAIB very few clients reach the $400,000 ceiling. There are currently 3,500 claims per year but the vast majority of these involve small payments for transport or medical costs and do not involve anything which might be called ‘disability’. MAIB also fund other agencies to provide on-going support to compensable people with severe disabilities. These include the construction of group homes and independent units in the North and South for respite and short and long term care. Management of the accommodation and support is outsourced to Anglicare. As one woman said,

> *If you’re MAIB you’re different. Once you are MAIB you get the lot. Once anyone has an accident they still should be given help but when you get MAIB it’s everything, 24/7. (Faith, 61, caring for husband with quadriplegia)*

More people die or are injured through work related causes than by car accidents. Under the Tasmanian Workers Rehabilitation and Compensation Act 1988 employers are legally obliged to take out workers compensation insurance with one of a number of private insurance companies licensed by the WorkCover Tasmania Board in the state or to self-insure. If injured the insurance schemes require workers to participate in rehabilitation and injury management programs to expedite their recovery and return to work in return for weekly income replacement benefits, medical and travelling expenses. Weekly payments continue for up to nine years from the date of the injury or until the worker reaches 65 years. This means that the goal is to make people as independent as possible before the money runs out. There are also lump sum payments for permanent impairment in addition to weekly payments.

3.2.1. Experiences of Compensation Payments

The main criteria for inclusion in the research sample was being in receipt of the DSP. This means that we did not talk to people currently in receipt of compensation. However a number of interviewees had either received compensation in the past or had made decisions not to pursue compensation claims. Respondents reported difficulties with the process of claiming compensation. These problems are commonplace and a recent qualitative study (Parrish & Schofield, 2005) of thirty injured workers and their experiences of the claims process in NSW has highlighted a number of difficulties. These include delays in the claims process, irregular or non-existent payments forcing reliance on Centrelink benefits, hostile attitudes of claims officers, lack of knowledge about entitlements and low take up, especially among unskilled and mobile workers, and significant income losses moving from compensation benefits to the DSP.

Given that applications for compensation usually have to be made shortly after injury and/or may involve reliving traumatic events respondents described difficulties in coping with the claims process.

> *I need to put in an application form to victims of crime. I really need the money but I’m not well enough to go and chase it. If somebody said to me you’re entitled and we’ll apply for it and help you get it, fine I’d sign for it. My victims of crime money will help me pay for an ergonomic chair that lays back so I can sleep because I can’t sleep because of the pain. But I can’t do the claim until I feel*

> *better. They said if you want anything you have to fight us for it. I don't have the energy or the inclination to fight victims of crime. The maximum I can get is $20,000. (Sarah, 53, living with ABI)*

> *We can go for compensation if we want to but we don't want to do it now because of the stress. I am trying to keep us as stress free as possible. (Cindy, 58, caring for husband with physical disabilities)*

> *I was a little slow in filling out the paperwork. The hardest part after the accident was having to relive it and we both had post trauma. In the first couple of weeks you have to write it up for the insurance company and I found that writing it down on paper was so real and also very stressful while we were both dealing with our injuries. (Ellen, 52, caring for husband with ABI)*

The payment of lump sums could also cause problems.

> *The MAIB either wanted to give me a payout or continue on paying x amount of my wages and some for grief or hardship down the track. I took a lump sum. I ended up with enough compensation to set myself up in my own home and get my wheelchair and what I needed and I thought I would have enough for ever and a day. I was unaware of what medical materials you need as time goes on and expenses. If I had my time over again there is no way I would have gone that way. I would let the MAIB pay either 60% or 80% of my wages and foot all my medical bills and buy the things I need. You have no way of forecasting what a wheelchair is going to cost you in two years time, ten years time or twenty years time if you are still here. If I had my time over again I would never have taken that compensation because the compensation runs out. (Ron, 44, living with quadriplegia)*

Service providers were also concerned about those who are awarded lump sum compensation payments by the courts but who do not have the ability or skills to manage them adequately. This makes them extremely vulnerable to exploitation and there have been incidences where despite losing all the money the fact that a compensation payment has been made has excluded them from receiving Centrelink benefits.

A lack of information can complicate the transition from compensation to Centrelink payments. It can also mean losing the ability to fund additional benefits - for instance passive or alternative therapies - which can be very valuable in effectively managing a disability.

> *About eighteen months ago we lost the wage replacement from MAIB and we could have gone to Centrelink. Having not had anything to do with them I was told no that I was on too high a wage and that he would not be eligible and then somebody told me yes you are. I should fill out some papers and take them down to Centrelink but nobody actually tells you. I would just like to have a phone number that I could ring just to find out first if I am eligible or not and then fill out the paperwork if need be. (Ellen, 52, caring for husband with ABI)*

Service providers reported difficulties for those awaiting the payment of financial compensation. Insurance companies do contact Centrelink to notify of compensation before any money is actually paid out but some have Centrelink payments cancelled before they have started to receive compensation leaving them with no income at all. The promise of compensation can also operate as a barrier to Disability Services for support and information. And if an individual does receive care at minimal cost, once compensation payments are made any government support they might have received has to be paid back.

3.3 Employment

Employment can be the main factor protecting people with disabilities against the risk of poverty and disadvantage.. How far were respondents in our research able to access and sustain employment? Altogether we spoke to ten people in part-time work; two of these were in supported employment. In addition many people in the sample were able to talk about their experiences of trying to gain employment or of moving into study and training to improve their employment prospects.

3.3.1. Employment Programs

The Commonwealth Government is responsible for employment programs. It provides:

- **Centrelink services**. These include an assessment of the type and level of support required in employment, referral to mainstream or specialist disability employment services and an employment entry payment of $312 available to those on the DSP to meet the additional costs of entering the workforce. There is also the Personal Support Program which provides six months support to assist those with multiple non-vocational barriers to access employment and become job ready. Exemptions from activity test requirements are available to those receiving enhanced Newstart Allowance.
- **Job Network,** which offers individualised support to move people into employment. Specialist Job Network providers address the specific needs of job seekers with low to moderate disabilities and provide career guidance, work preparation, on the job training and ongoing support and liaison between employee and employer. They also offer advice on workplace modifications, wage subsidies and supported wage assessments.
- **Disability Employment Network,** which assists those with moderate to severe disabilities to gain employment and provides on-going support to retain employment.
- **Commonwealth Rehabilitation Scheme.** This provides vocational rehabilitation programs tailored to suit individual circumstances including return to work programs, assessments, work conditioning, job training and placement, workplace modification, pain management and counselling.
- **Employer Incentive Strategy** encourages employers to provide opportunities for people with disabilities and it can subsidise employees' wages for up to 13 weeks. The Workplace Modifications Scheme funds the leasing, hiring or buying of modifications or adaptive equipment. Although there is no funding cap, it is subject to availability of funds and is only accessible by workers whose jobs are in jeopardy rather than job seekers for equipment to assist them to seek a job or participate in work experience or voluntary work. It does not allow workers to upgrade adaptive equipment.

In addition there are a number of supported employment enterprises across the State which provide direct employment for people with a disability who require ongoing support to work.

3.3.2. Experiences of Employment

Those that did have some paid work found it had a big impact on their self esteem and identity. The work provided a routine and rhythm in their lives which they valued and which met some of their social needs. On the other hand those who had an employment history but had found themselves excluded from the workplace due to acquiring a disability mid-career found the experience distressing.

> *I have been in systems analysis and design. I used to work for little businesses that were setting up and set up their payroll, their computer systems so everything would function and run. Now I go to my refrigerator and I can't find the cheese. I was just getting sacked all over the place. That was breaking my heart. It would get to the stage where they would just say we can't have her no more. (Sarah, 53, living with ABI)*

Acquiring a disability early in life can lead to cumulative disadvantage whereby individuals receive below standard education, poor development of life skills and interpersonal communication. They also lack experience of part-time work. This can have a big impact on self identity and reduce their chances of employment in the longer term.

> *I did one year of teacher training but they didn't want blind teachers in their system. The main option for blind people if you weren't in sheltered employment was to be a telephonist. The one thing I didn't want to be was a blind telephonist but that's what I ended up being. No one saw an opportunity in giving me a traineeship or any administrative responsibility. I was just on a switchboard. There are a lot of people reaching their 50s and 60s now who may for a lot of their life have been unemployed or working but not to their full potential or full earning power. (Anna, 54, living with blindness)*

Disability can hit when individuals are at their greatest earning capacity and at the beginning of their careers. This was true for a number of people in our sample. It can result in losing superannuation and being pushed into lower skilled and lower paid work. People with disabilities fare particularly badly in superannuation coverage. Anglicare's Tasmanian Community Survey (Madden, 2006) found that 62% of those living on the DSP had no superannuation. This compares with 45% among other benefit recipients and 11% among the general population. Relapse can also create difficult employment situations with hospitalisation and long periods of sick leave making it increasingly problematic to retain paid employment. Although injured workers are taken back into employment because of a statutory obligation those who acquire health problems which impact on their working lives have no such claim. Some people had good reports of employers who had been flexible in allowing them to remain as long as possible in work.

> *I worked in a technical trade. When I got diagnosed with MS I found that problem solving was a problem and I got very tired very quickly. They looked after me, they really did. I finally got terminated at Christmas. It became an effort to try to work and I was pushing it. (Daryl, 52, living with MS)*

Experiences of using disability employment services varied:

> *It's hard to find anything. Disability employment works with you and sees your needs and you feel like you're in control of what you want to do. Other employment services want outcomes in 15 weeks so they don't have a lot of contact with you. (Jim, 30, living with cerebral palsy)*

> *I have gone through the Commonwealth Rehabilitation Service and they have no idea about how to get a quadriplegic some work. (Tim, 22, living with quadriplegia)*

> *I am going through CRS and I have been striving for the best part of four months now working out what is available with my needs as well as looking at what adaptive equipment I might need in the workforce versus the qualifications I have already got through studying. I am like a dog with a bone with this. I will keep going with it until I find something. I am optimistic. I am looking for customer service or public relations. One of my strongest points is my ability to communicate. (Mat, 22, living with cerebral palsy)*

Three major obstacles to accessing and retaining work for people with disabilities are discrimination, the additional costs involved for both the employee and the employer and the complexities of managing part time work whilst retaining access to the DSP.

3.3.3. Discrimination

A review of the Disability Discrimination Act (Productivity Commission, 2004) found that discrimination in employment remains a major issue and that even in the public sector employment rates for people with disabilities are falling[6]. A number of people in our research sample had experienced discrimination in finding a job and/or obtaining promotional opportunities or were working for lower wages. There are also discriminatory practices including being required to hold a driving license or to undergo a medical assessment before employment is confirmed. As one woman said, '*People won't give you a chance and it's only when you get into one job that you can get another.*' Some had resorted to self employment or had used informal networks to gain work.

> *I have a Bachelor of Applied Science. My MS has been really severe; not at all subtle. I took on a part time job at the time but was sacked, effectively because they didn't want to modify the building because I was using crutches. I got very angry and I was going to take it up and I really wanted to but I also really wanted to keep working in the industry and I knew that would really burn a bridge. It was a double edged sword really and then funnily out of that I got a lot of contracts. So all the money I had saved I used to put a concrete slab down in my parent's backyard and we built a lab. I ran my own lab for seven years before my MS started to affect my hands and then I had to close that. Now I have a job doing office work three days a week for twelve hours a week. I have a great boss who is actually a friend and he helps me. He put a ramp up for my wheelchair and I use the toilet in his house. (Stephanie, 32, living with MS)*

Others preferred to work in more sheltered environments:

> *In a deaf environment it is much easier to find work and feel comfortable. In a hearing environment it is a hassle with communication and it can be depressing. A lot of people won't talk to me so I am left out of the loop and am often the last to know things. (Joy, 38, living with deafness)*

It was commonly believed that many employers assumed it would be too expensive to employ a person with a disability. A concentration of employment growth in the small business sector which was less likely to be able to afford any modifications required was accentuating these difficulties. Employers were also known to cite occupational health and safety legislation to rationalise their decision not to hire someone or not to undertake workplace modifications. This is despite research which shows that people with disabilities are more reliable, have good productivity rates and superior attendance records (CIPD, 2001).

> *Once I became unemployed a major barrier to my re-entering the workforce was that I constantly had to face negative beliefs about blindness from employers particularly at a level that is commensurate with my experience and skills. I was applying for a lot of jobs but I would take a magnifying glass along to my interviews. They were really fine until that got pulled out of my pocket and they had paperwork for you to fill out. There was a drop in the enthusiasm in their voice and their tone would become quite unsure, awkward. They would start talking faster and say we will fill that paperwork out for you and we will call you. I would never hear from them. That was when I decided I needed something behind me and that is when I decided to attempt getting myself a qualification. (Steve, 31, living with blindness)*

> *People are discriminated against because it's going to cost their employer to modify the workplace. It's alright for the government to say we've got a bucket of money and an employer can apply for funding. But the maximum amount they might receive is $2,000 which would go nowhere. It might help widen a few doors but it won't modify the bathroom or the workplace so the person with a disability can be gainfully employed. (Jack, 47, living with cerebral palsy)*

Despite avenues for redress through disability discrimination legislation there are problems for people with disabilities in using these routes (Newell, 1995). Discrimination can be very hard to identify and measure and there is a significant burden on the shoulders of someone who chooses to lodge a complaint. It takes a lot of courage and stamina to pursue it when they feel discriminated against and expecting individuals to take on the system can be unrealistic. Many are not willing to pursue a complaint because of the lengthy process and the emotional and financial costs involved. There are channels for individual complaints but not to address systemic discrimination or laws, attitudes and practices which are viewed as neutral but which entrench inequality and disadvantage.

> *I went to the ADC (Anti-Discrimination Commission) and said could you send me a form and they said we will post it to you in hard copy. I said no, that is not suitable for me and they said oh well you will just have to get someone to fill it out. The first time I put a complaint in, my dad had just died and I didn't want to have to hassle mum, she had enough on her plate. So I left it for about 14 months and then I just had to put one in. I sat down with a friend and re-formatted the forms and made them more accessible. It eventually got addressed when I took it to the Federal body against the State body. When you take out a complaint about employment barriers it is not going to get you the job because it can take a year to resolve and by that time the position you originally applied for was only 12 months. Sometimes it seems I would be better off just remaining on my DSP because I have gotten so sick of having to struggle for a fair go. This further disadvantages me because it decreases my independence and affects my financial stability and reward for hard work. When you are struggling to keep pace in the workplace you just don't have the physical or*

---

[6] The number of disabled employees in the Commonwealth public service has fallen from 5.4% in 1996 to 3.8% in 2005. This falls short of the 11.3% of the general workforce classified as disabled. More than one third of those employed were in the Centrelink service (Enablenet 2005)

> *emotional energy when you arrive home to begin self-advocating. (Steve, 31, living with blindness)*

Awareness of the levels of discrimination meant that many people with disabilities had difficult decisions to make about whether or not to disclose their disability when applying for jobs.

3.3.4. Additional Costs

The additional costs involved for a person with disabilities to take up employment can be substantial. They include participation costs like maintaining and servicing a wheelchair, time restrictions (it might take two hours to be work ready in the mornings and be dependant on the prompt arrival of a home support worker), the availability of flexible hours (to cope with fluctuating health and medical appointments) and an accessible workplace and toilets. There are also the costs in terms of energy: the ability to work and to prepare a meal and do the housework.

Transport is a major issue. If individuals are unable to use public transport and are reliant on taxis the cost is exorbitant and rising with the increase in fuel prices. The Mobility Allowance is inadequate in offsetting this level of expense and it has been estimated that the mobility costs of people with severe physical disability and vision impairment are four times the value of the mobility allowance (Graham & Stapleton, 1990). This impacts on people's ability to seek and remain in employment. Combined with on-going personal care needs it can create insurmountable obstacles.

> *I am in a hard situation for work - as much as I would like to be able to do something, I would have to be able to do it from home because otherwise I would need someone to help me get to and fro and deal with any mishaps that might occur during the day. I would really like to go back to work but I need a job where I can come and go but there are no jobs like that. (Ron, 44, living with quadriplegia).*
>
> *There are expenses which my sighted colleagues do not have. These range from daily costs such as taxis to the high cost of adaptive equipment such as screen readers or Braille note takers. Other disability related costs include services such as personal readers and administrative assistance. For example, I have on occasions had to pay more than $100 to have a work presentation professionally laid out. Whilst federal government assistance is available to meet some of the additional costs of employment like Mobility Allowance the most significant form of assistance provided, the Workplace Modifications Scheme, has important limitations. It does not cover the regular cost of upgrading or repairing adaptive equipment which can range from $100-1500 per item. (Steve, 31, living with blindness).*

As people commented, the disability related costs of employment often end up being met by the employee and while individually they might appear minor their cumulative impact could be substantial enough to make employment unfeasible. A significant factor in meeting these extra costs was the non means tested DSP (blind).

> *It allows me to offset the additional costs of working and ensures that non-discretionary disability related costs are not an impediment to entering and remaining in the workforce. The DSP (Blind) is arguably the primary contributor to the high labour force participation rate of blind people relative to people with other disabilities. (Steve, 31, living with blindness)*

Interviewees considered that they could not be expected to participate in the labour market without reasonable levels of assistance to offset the costs involved.

3.3.5. Welfare-to-Work

Undertaking part-time, casual or sporadic work whilst on the DSP can complicate communications with Centrelink. Some interviewees described the complexities operating as a potential barrier to seeking employment particularly given the implications of the welfare-to-work reforms. A man living with blindness described how the difficulties he faced in keeping Centrelink informed about his earnings had acted as a catalyst to a downward spiral of debt:

> *Trying to keep track of finances and how much money there is coming in and out when you are blind is enough of a chore. I was always on the back foot either overstating hours and therefore having to pay back and having concerns about breaching. So first I have to organise someone to read the letter from Centrelink and then get back to them by the date otherwise your payment is frozen. I have to organise someone extremely trustworthy to go through bank statements to determine overpayment or attend the bank and pay extra fees for a print out of the current statement which includes overpayment. I call Centrelink and make an appointment to discuss the changed circumstances (after being in a queue for 45 minutes), find an assistant to help organise any additional paperwork needed for the meeting, fit in with my employer, go to the meeting and discover the Centrelink payment will be reduced until the overpayment is paid back. The power is cut and the fridge with bulk items of food to save money is unusable. I organise the mail to be read and discover the power was cut because there was not enough money in the bank account for the direct debit with Hydro as Centrelink has reduced the fortnightly payments. Its $50 to get the power back and I am then penalised by the bank with an overdrawing fee. (Steve, 31, living with blindness)*

> *One thing I find really hard is whenever I try to better myself or my situation, it is like I get slammed into the ground. I cannot work for anyone else because I am not fit enough and I won't be covered with any insurance. I have to be self employed. If they would allow someone like me to work at my own pace and in my own way instead of criticising me. They should be praising me for having a go instead of being judgmental and then maybe we might have a chance of getting off the DSP but they don't. There is no middle ground. You either end up staying here forever and a day on a low income, be treated like dirt by Centrelink or go to work full time and then collapse. They are the choices. They should have a program where you can go from the lower level and gradually be able to get up to the higher level with confidence and feel that your effort is rewarded. (Madeline, 53, living with vision impairment and osteoarthritis and caring for her son with ABI)*

A number of people expressed concerns about what the reforms would mean. They considered that it would fuel a reluctance to seek or try paid employment because of the fear of losing DSP and having to return to the lower rate of Newstart Allowance if the job did not work out. Work for people with disabilities was not necessarily there and even if it was they faced high levels of discrimination in accessing it. Even though at the time of the research the reforms had not been implemented, they were already affecting the employment decisions people were making.

> *I did a disability awareness afternoon and they paid me for that. I notified Centrelink and I then had to notify them every two weeks of my income even though it was just one job until I got a separation certificate. It made it very difficult so I have become very wary of all that - getting paid and losing income - because as of July if you can demonstrate you can work 15 hours or more then you will lose your disability pension and it will be harder to get back on. I am very concerned about it. It's a concern for everyone who has a disability. (Jim, 30, living with cerebral palsy)*

> *I had to change my working hours because of the new Government law where I couldn't work more than 15 hours a week because then I would be deemed unemployed and therefore not receive my DSP. So I spoke to my boss about this and we agreed to change it to 12 hours a week so I could still get my DSP. I saw it coming and so I planned ahead and made sure I don't get caught. I think it is unfair, I really do. (Stephanie, 32, living with MS)*

A number of respondents wanted to see more responsibility being passed to employers so that they are prepared to take on people with disabilities.

> *Employers need to be educated. It's no good having a lot of people on Newstart who have varying forms of disability and finding that the employers are going to actively bar them from work. There is a debate which goes on. Do I, when I'm applying for a job, front up when I first apply and say I've got vision impairment or not? Some say they should, some say they should do it when they get into the interview. Once they walk in the door with a cane and hand over a decent CV at least they've got a chance but if they say it on the telephone they haven't got a chance. They have to spend money on educating the other side because the employers in the end make the decisions about whether they employ someone. This is where they've got it all wrong in taking a person from DSP to Newstart. (Anna, 56, living with blindness)*

3.4 Education and Training

One way for people with disabilities to improve their employment prospects is to engage in education and training and indeed many of those in our research sample had done just this. However low levels of education are prevalent among people with disabilities. Only 21% of those with severe or profound disabilities has completed year 12 compared to 49% of those with no disability. Sixty nine percent of disabled people have no non-school qualifications (ABS, 2004). Educational achievements also vary significantly between disability groups. Those with sensory disability have the highest success rates while those with intellectual disability have the lowest (Cavallaro et al, 2005).

3.4.1. Assistance with Accessing Services

Some assistance is available to people with disabilities so that they can better access educational opportunities:

- **Centrelink** has an Education Entry Payment of $208 available to those undertaking an approved course of study and who have been receiving a Centrelink payment for at least 12 months. It helps with the up front costs of taking up study including buying books and paying student union and course fees. Special consideration is also given to those receiving Youth Allowance, Austudy and Abstudy in allowing extra time to complete a course and/or reducing workloads. The Pensioner Education Supplement is currently $62.40 per fortnight and available to DSP recipients if the workload doesn't fall below 25% of a normal full time study workload.

- **Supporting Individual Pathways Program (SIPP)** is administered by Disability Services to assist a successful transition into post school life and to maximise an individual's potential for further education, training and pre-vocational options. It provides assistance to meet disability related support costs including specialist equipment if it is not available elsewhere and personal care. Although SIPP can assist people to acquire the skills to use public transport there is no financial support available to meet additional transport costs. The target group is those with high support needs up to the age of 25 but there is some flexibility depending on the individual's circumstances.

- **assistive technology funds** are available through educational institutions like the University and TAFE to provide learning support for students, for example, computer software and interpreter services to be used on campus. However there is no financial support to acquire computer technology and other study aids for use at home. This makes external study problematic.

- **Disability Liaison Officers** are the main contact points for TAFE and University students with disabilities providing advice about educational pathways and dissemination of information about educational assistance to other services.

- a range of **scholarships and awards** are also available for students with particular kinds of disabilities, for example, hearing impairment.

Although educational institutions take responsibility for providing education related support, no agency takes full responsibility for the provision of personal support hours to allow students to access post-secondary education. Some assistance is available through SIPP but whether students are able to access it or not depends on the age of the student and what other demands are being made on a limited funding pool.

Because students do not necessarily disclose their disability it can be difficult to quantify the number of disabled students and their educational and employment outcomes. This makes it problematic to plan and allocate appropriate levels of funding.

3.4.2. Experiences of Education and Training

Among our research sample there was a low level of awareness of the kinds of assistance available to students with disabilities. Although some people had received considerable support, others had not and also expressed concerns about the level of additional costs involved in pursuing their studies.

> *I went through my education but I didn't really learn anything. I slipped through the net in high school and college and it wasn't until I went to TAFE that I really got to do something. I did the Certificate 3 in Community Work. I really loved it. I got a lot of support. Getting there was a cost with the transport because not all the time could my parents pick me up. (Jim, 30, living with cerebral palsy)*

> *To find out what aids were available to help me even turn pages of a book, I discovered the cost was astronomical. This particular aid was about $6000. At TAFE just getting books onto CD, you are expected to buy the text book first and then you could get it on to CD. (Tim, 22, living with quadriplegia)*

> *The challenges of overcoming barriers and getting information accessibly when you are at University - being able to get through all the reading material in order to do assignments. I had to defer or repeat subjects through no fault of my own. Also the ability to sit down with your peers and get ideas off them, that was another barrier, not being able to go through with the same people. I had no way of taking notes. What they do have is student note-takers and they basically do their own notes and type them up and they are paid by student services I think, $30 a month for their week's notes. They would get their notes in but not on time and it would depend on the quality of notes as well. I just think it would have been easier to have the lecture notes as a word document. That was the biggest battle. (Steve, 31, living with blindness)*
>
> *Getting the support mechanisms in place is always a challenge, just basic things like toileting and a scribe to take things down off the board or to dictate what I say for an assignment. I get help from the Individual Pathways program through Disability Services. You put down the hours that you would prefer in accordance with how many hours you are studying and from there it is assessed with what money is available. If you are lucky enough you get the hours that you request. I use voice recognition software and I have got funding for that. I found TAFE to be really good once I got into the classroom in terms of delivering the academic side but actually the organisation and negotiation to get all my support mechanisms in place and time schedules I thought was a bit lackadaisical. The problem with Disability Liaison Officers is that they are not experiencing what you are directly. They didn't appreciate properly just how hard it was to do something without their full support and cooperation. (Mat, 22, living with cerebral palsy)*

How far do qualifications allow people with disabilities to access employment? National statistics of those reporting a disability and attending higher education have been collected since 1996 and the numbers have increased both in higher education and in vocational education and training (VET). However, despite a big increase in students with disabilities the same increase has not been noted in the workforce.

3.5 Volunteering

If people are unable to engage in structured work or education and training opportunities volunteering can allow them to acquire skills and interests as well as participate in the community. Volunteering Tasmania provides opportunities for people with disabilities to volunteer and currently has a partnership with the Department of Premier and Cabinet to explore the barriers to volunteering for people with disabilities and develop guidelines for government agencies. Barriers can include the cost of transport, a lack of adequate personal care and support and the values and attitudes of those using volunteer assistance.

A number of people in the research had been involved in voluntary work and greatly valued the connection it gave to the community as well as the opportunities for social interaction and for acquiring skills to make them more employable. Voluntary work could include working for charitable organisations, doing Spine Safe teaching in schools or political activities. What they particularly appreciated was the opportunity to give rather than continuously receive.

4. LIVING IN THE COMMUNITY

Care and support in the community is based on the philosophy that most people value being able to live in their own home but can find this difficult without assistance. Personal care and support delivered to people's homes allows those with care needs to remain in their home and offers them opportunities to choose their own lifestyle. It entails providing assistance with the basic and essential tasks of daily life. These include getting up and going to bed, washing, toileting and bowel care, preparing food and eating. It can also include shopping, home maintenance and cleaning, washing clothes, banking, transport and social support. Effective personal care and support is vital in order to provide any genuine alternative to institutional care.

Community care services in Tasmania are currently delivered in a complex environment through separately funded Commonwealth and State programs and through a range of providers often with different accountability requirements, funding, eligibility criteria and assessment procedures. Multiple entry points, diversity and fragmentation can make finding out what's on offer and who does what, for whom and where an almost impossible task particularly when decisions often have to be made at a time of fundamental change in a person's life.

Half (25) of our research participants were accessing varying levels of personal care and support. This chapter describes the process of becoming disabled and what needs that generates, examines what personal care and support services are available and documents the experiences of people with disabilities in accessing and using them.

4.1 Becoming Disabled

What does it mean to live with a disability or to acquire one in adult life? Among our research participants disability had impacted on people in different ways depending on its severity and nature. Some people were unable to dress, shower or feed themselves and required help with all their daily activities. Others were able to live independently with and without the help of aids and equipment or with some domestic or social support. One third were dependant on wheelchairs or used them for substantial periods of time. For some people their disability was stable, for others it was deteriorating.

However for the majority of interviewees acquiring a disability whether it was early or later in life was a major life event for themselves and their families. The changes it imposed on paid employment and income, daily activities, social and emotional lives and the risk of poverty illustrate the relationship between becoming disabled and being socially excluded. It could mean a dramatic reduction in living standards or a compounding of existing disadvantage and coming to terms with the situation, negotiating access to new services and benefits, re-assessing employment options and coping with the emotional burdens all took their toll.

The process of becoming disabled was described by those who had acquired their disability as adults through traumatic injury, through disease or through acute health problems. They described the impact on themselves, their family and children as well as their employment and income levels.

> *I was 42 when I had a stroke. I had to stop parenting my boys who were 12 and 16. The boys were so traumatised. I went out of the door and I came home eleven months later to find I was redundant. I had a partial paralysis of the vocal cords and have no movement on one side. I'm a hemiplegic. I have no sense of time and my ability to take in information is damaged. I have only the one hand on a good day. In a sense my disability is a hidden disability. I can't work. (Janine, 60, living with physical disabilities)*
>
> *It affects every aspect of your whole life especially your psyche. When I first got home I think I drove the kids and my wife away. I am separated now. You deal with it every day physically but mentally it's the hardest. The only memory I have is waking up in Melbourne and them telling me I was a quadriplegic, paralysed from the nipple line down. I was going through a change mentally and physically. The kids wouldn't come down because every time they did I would ask them to do something. I was putting more and more pressure on my wife and she was looking after me consistently all day. What really annoys me now is that I can't do anything and have to watch people do it. It drives you nuts in your head. It's so frustrating. (Rod, 38, living with quadriplegia)*
>
> *I have been living with it for about twelve and a half years now. It has changed my personality for a start and my marriage has failed because of it. I have severe memory problems and visual problems as a result of the surgery. It is very up and down. You never know how you are going to be from one day to the next and since the surgery I don't know who that person on the other side of the mirror is. It has been a major upheaval. I knew that I had changed but I couldn't put it into words and it took me five years before I got onto the Brain Injury Association. When I eventually met the Manager and he gave me some literature to read I just burst into tears because it was all there in black and white; all these changes that I had noticed but wasn't able to communicate about them. I had trouble trying to find any sort of assistance. (Diana, 54, living with ABI)*
>
> *I was diagnosed with MS in 1996 but I knew I had it about a year before that but I didn't want to face it. I was 22 years old and I was at University so I had to try to deal with a diagnosis with that kind of magnitude and finish a Uni degree and then start a career. So that was a bit tough but I did it. There is not one thing that it leaves alone although probably my sight is not affected. Obviously I am in a wheel chair so I can't walk so there are limits there. I still drive a car which has hand controls so that is good. (Stephanie, 32, living with MS)*

People described difficulties both in getting a diagnosis and then in coming to terms with it, with continuing their parenting roles and maintaining relationships with others. The adjustments required to everyday life could be considerable including new needs for financial and practical support, adjusting to a life without work and to much lower levels of income. Some found becoming dependant, having to ask for help and knowing the impact it was having on their family very hard. One interviewee living alone with a severe physical disability requiring high levels of personal care described a typical day:

> *You wake up when someone knocks on the door. They've got a key and they come in and turn on the radio, turn the jug on. They strip the bed back, cover me with a towel, put the rung out and the sling on. I'm usually as stiff as a board at that time. I've been lying on my back all night in the same position and can't move or roll over. I get out of bed onto a shower chair with a bowl underneath and*

> *I go to the toilet. Then I have a shave and clean my teeth and then I have a full shower, wash my hair. Then I'm dried, put on the smelly stuff and then put a shirt on in the bathroom, go back into the bedroom, hoisted out of the chair and back onto the bed with this lifting machine. I am dressed, put back in the chair and I stay there for the rest of the day. I am belted in, shoes are on and shoe laces checked. My leg bag is here and I can empty that myself. So I am independent when it comes to urination and I can empty it into a urinal. But defecation is different altogether because I'm not strong enough to transfer like a paraplegic is. I have to be lifted. So once I go out it's just Russian Roulette, you just hope for the best. Food preparation, the carers do that. I usually select what I want and Woolworths is just round the corner here. The carer comes again half past four to half past six and they help cook my tea. They come back half past nine to put me to bed. That takes about an hour and a half by the time you're lifted up and you might want to use the toilet. (Rod, 38, living with quadriplegia)*

Ageing has a major impact on the lives of people with disabilities and, as an issue, is relatively new as increasing numbers of people with disabilities survive into old age. Not only can the ageing process compound the impact of disability but people with disability can also suffer from premature ageing. Those who have lived with disabilities since birth or for long periods of time described how the process of ageing was faster for people with a disability. For example the over use of the shoulders to manipulate a wheelchair could mean arthritis and loss of muscle strength.

> *The way I walk the more quickly I age. It's the stuff now I can't do. I can't dress myself, wipe my bum, there's no dignity to any of it. I used to be able to do things like my grocery shopping. It might have exhausted me but I could do it. It's the limitations to life style which is such a pain. (Mary, 57, living with physical disabilities)*
>
> *Brain damage isn't progressive but it's the effects of the brain damage on the body and it's got worse over the years. I've now got sclerosis as well and a fractured vertebrae and the arthritis in my hips is starting to bite. My walking is getting more difficult so a wheelchair in the next six years is in the offing. (Denise, 54, living with cerebral palsy)*

Overall exploring the process of becoming disabled highlights the importance of recognising the difficulties associated with the transition from non-disabled to disabled or from non-carer to carer and the need to provide help and often specialist assistance at this time.

4.2 Personal Care and Support Services

For people with disabilities who are not covered by compensation payments there are three main sources of personal care and support in Tasmania. These are:

- **Informal assistance** with daily activities from family, friends and other informal carers. The majority of personal care and support is provided in this way.

- **Home and Community Care Program (HACC).** This is a joint Commonwealth/ State initiative which provides funding for personal care and support services to frail older people and people with disabilities and their carers to sustain them in the community, enhance their independence and avoid premature admission to long term residential care. Seventy-five percent of clients are aged 65 years or more but Tasmania has approximately 5,380 people of working age receiving HACC funding (HACC, 2004). It includes personal care, home help, community nursing services, respite and day centres, minor home maintenance and home modifications and case management services. It also includes advocacy and can cover transport for non medical needs.

- Anyone having difficulty in performing everyday tasks and who may, without assistance, require admission to residential care is eligible but personal care is capped at 15 hours per week which means HACC cannot meet the needs of those requiring more than two hours care per day. For those in receipt of the DSP 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.

- HACC services are delivered through a multitude of non-government organisations across the State who have different levels of funding and may or may not specialise in different aspects of care. Some are funded to provide personal but not domestic assistance or social support. Others provide the whole range or are specialist case management agencies who oversee the coordination of care for those with high and complex needs. What this means is that one individual can be receiving personal care in their home from a number of different agencies.

- **Disability Services** provide a gateway into personal care services through the Intake Officer and all assistance they offer is free. Those clients who require lower levels of care and can ‘self-manage’ are referred to services in the community by the service co-ordination team. Those with more complex needs are visited at home and their needs assessed over a six week period. If they do not have the capacity to access community services themselves they can be assisted in doing so by the service co-ordinators. Those with personal care and support needs above the levels which can be provided by HACC services can gain assistance through:

    - **short term support**. This is intended to meet short term personal care needs with a focus on skill development programs and achieving identified goals. It is anticipated that any longer term or recurrent needs are met through HACC funding or by accessing an individual support package.

    - **individual support packages (ISPs).** These provide recurrent individualised packages of personal support and/or respite for periods of more than 6 months and for up to 34 hours of support per week. To be eligible for an ISP applicants must be aged under 65 on entry, require support to perform non-specialised personal care and related tasks, have a disability as defined by the Disability Act, not be in receipt of compensation for continuing care and be able to personally direct workers or to use an advocate to do so. In addition the applicant must not be living in supported accommodation.

> Applications are considered by a Referral Committee every month for recurrent funding and every three months for one-off support and a waiting list is maintained and prioritised according to urgency of need. Once allocated a contract about the type of support required will be negotiated with service providers and approved and monitored by Disability Services. The contract is reviewed annually. Clients can also set up their own private company to manage and administer the package without using a service provider. Few have taken up this option because of the complexities involved.
>
> 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 can be used to purchase essential aids and equipment which are unavailable from other funding sources. Services can also be 'blended' so that a person with a disability could have twenty five hours ISP, three hours HACC funded domestic assistance and short term funding from the Carer Respite program. This gives the individual more choice about how a package is delivered and by whom.

Individualised funding packages given directly to people with disabilities to purchase the services they require has been the key goal of the disability movement for the last two decades. They are heralded as a means to achieving independence and control and improving the quality of services by giving people the freedom to determine the type of assistance they receive and how it is delivered. In a 'direct payment' system individuals are given cash to purchase what they need. In Tasmania ISP recipients are allocated a number of hours which they can use as they wish. The recipient is involved as far as possible in the design of the package, the recruitment, selection and direction of support workers and negotiating the contract of service with providers. As employers rather than passive recipients of services people with disabilities can, in theory, change providers and workers as they please and take a more holistic approach to their needs.

However the potential of ISPs has only been partly realised. Anyone can apply but a shortage of funding means that in July 2006 there were more than 260 people who had been assessed as requiring a package on the waiting list.

4.3 Pathways into Care

Pathways into living in the community can be different for each person but when the need arises it is often a time of anxiety and traumatic change due to a catastrophic event or a deterioration of functional capacity. This means that the need for accessible information about what may or may not be available in terms of support is paramount. This was a key issue for the majority of our research participants.

Commonwealth Carelink Centres aim to provide one entry point to community aged care, disability, residential and other support services which allow people to live independently in their own homes. They offer information about the range of services available, how to contact them, eligibility criteria and associated costs. Centres are accessed by a free national telephone number which connects to the nearest call centre or shop front locally. However only two people in our research had accessed the service and they had not found it particularly helpful. One person said they had just been given the number for Disability Services. Others found the name confusing and associated it with aged care or mixed it up with Centrelink. This made them reluctant to use it given previous experiences they might have had with Centrelink.

Disability Services are another potential gateway to community care but people's experiences of using them as a source of information were mixed. A number of people had been pleased with the assistance they had received from service coordinators. However more commonly there was a widespread misunderstanding about their role. Some were reluctant to approach them; although they might have personal support needs they did not consider themselves to be 'disabled' or they perceived the service as only for people with intellectual disability. Others thought that anyone in receipt of the DSP was entitled to a hands-on service from Disability Services and were confused when they were referred elsewhere. For people living with disabilities and seeking information about their entitlements the name 'Disability Services' was a misnomer and did not provide them with what they needed.

This left the majority of our research sample to find their own way through what was variously described as 'the maze', 'the mess' or the 'spider's web' of services.

> *Unless you actually enquire about what services are available then people are not normally keen to tell you. So you have actually got to do a lot of prying and literally ask specific questions about what is available and what is not. There is never one person. It is always several people and you will find a lot of people will do a lot of buck passing and say "we don't handle that" and they will say you need to speak to this person or that and before you know it you have spoken to fourteen different people and you still don't have the answers you need. (Mat, 22, living cerebral palsy)*

> *It has been tough. Whether you are at Centrelink or somewhere else you would learn different snippets of information from different people. There is still a lot of stuff that we don't know about. No-one can actually sit you down and say you are entitled to this or to that - just nobody seems to know. (Cindy, 59, caring for her husband with multiple disabilities)*

Discharge from hospital is a key point when information about supports available in the community could most usefully be disseminated. However this was often not the case and in the absence of specific discharge protocols whether someone received information or not was a question of luck or encountering the right member of staff. Peak bodies representing the interests of people with particular kinds of disabilities were keen to disseminate information about their services before people were discharged from hospital. However this had proved difficult to establish and was not occurring on a consistent basis. They described the continual turnover among hospital social work staff as a major obstacle to getting information out to those who needed it.

> *When I was admitted to the hospital, the social worker came around and introduced herself and said I will be back to have a chat with you later on and I never saw her again, not at all. So it's been extremely difficult. I have always said that the day you leave hospital, somebody from Centrelink should be there to say you are going to have this or that problem for a while so we will organise your payments or whatever. (Diana, 54, living with ABI)*

> *You look to the health professionals for guidance. You have never been in this situation before and you naturally think they will be able to help you. But it's really strange. You've spent 40 years being who you are and then your life turns around in ten minutes and you have no yardstick. You think the system is going to say well look this is what you do now but the system doesn't. It says that's it,*

> *we've done our bit. There is help out there but it's knowing how to access it. There is no one stop shop, just this wall of paper. You don't know what you're doing so you don't do anything whether it's part of denial or the anger and acceptance. (Janine, 60, living with physical disabilities)*

> *When we came back from Melbourne it was like he was the first case and it was who do we go to and who do we see and how are we going to organise the support and care that we needed to provide for him. It was difficult. In the middle of it I divorced from his Dad which didn't help in trying to sort things through and there was no support through this. They looked after him but not the whole family unit. (Trish, 52, caring for son living with quadriplegia)*

Some people had found a path through the maze. They were they lucky ones who early on had developed links with a support agency or with one individual who was able to smooth their path and help them to access the information and support they needed. This could be their GP, a particular health worker or disability organisation or a carers support group. But whether this actually happened was ad hoc and people were just as likely to get information through chance conversations with friends or informal support networks, or the internet.

> *It's very difficult. You go round in circles. You've got to actually know somebody who's had some help with a service and they will say to you if you go to there you can do the same thing. If you get someone at the other end of the phone who doesn't know what you're talking about, they won't refer it on to someone because they are not prepared to say no. There's a lot of red tape and you find a lot of brick walls. (Rose, 62, living with physical disability)*

Those with sensory and communication disabilities could be particularly disadvantaged in accessing information.

> *The internet is great but only if the service that provides assistance for people with disabilities makes their website accessible. I am further disadvantaged in a world that prioritises the provision of information in visual form. Ironically improvements in technology have in many cases entrenched this disadvantage through the adoption of inaccessible methods of communication and interface with users such as push pads, visual displays and pdf formatting which cannot be read by screen reading technology. (Steve, 31, living with blindness)*

However it is not just a case of having access to information but also the support necessary to allow people to act on the information they do have. It was apparent that for some people there was a need for personal contact rather than just a voice at the end of a telephone and as one woman said, '*I needed prompting from other people to say you should go and do this and this. I knew it all in the back of my mind but it never clicked at the time.'* Being able to accept help was not necessarily straightforward and could require support.

> *He resists because it's an acknowledgement of his capabilities. You're dealing with someone who doesn't want to acknowledge that they're losing a little bit more of their independence. (Lily, 61, caring for her husband living with physical disabilities)*

This lack of information had a number of consequences. It meant that some people had missed out on services, in some cases for years, which had had a significant impact on their ability to manage, particularly financially. They had been functioning without accessing transport subsidies, Centrelink benefits, help with aids and equipment or domestic assistance. It also meant engaging in a continual fight for information and to get basic needs met which left people exhausted, frustrated and angry.

> *The services that are available are with different organisations and instead of collating them all together and giving you something to say you are entitled to this and entitled to that it just doesn't happen. You have to find out these things by word of mouth. The services are not working together to show what is available. I thought our local district nurse of all people would be able to tell us but she didn't know anything about it. So no one works together. They say to me you've fallen through the cracks, well they are very big cracks. We have been paying hundreds of dollars for shoes and if we had gone there (community equipment scheme) in the first place we would have paid $50 and that was it. You would think after fourteen years that someone would have told us before this year. So for years and years we paid all this money out. (Sharon and Mike, 50s, caring for their grandson living with multiple disabilities)*
>
> *There has been a lot of things we haven't been told. We learnt a lot of things from other people. No one has ever told us what we are entitled to and you really have to fight to get something. If you stood back then you wouldn't get anything. Once we did start working with one agency it was such a relief to know that there was an organisation out there that backed us up. Before that I just felt so full of emotion it was overwhelming me. Centrelink should be making sure that other than receiving the pension people are getting all the other services that are available to them. We had to be very proactive, nothing just comes to you. (Deb, 72, caring for her daughter living with multiple disabilities)*
>
> *One of the things that struck me very early on in the piece was that I'd see people receiving services and they would be angry and I'd think how rude, I couldn't be like that. Now I understand where they are coming from because it's all the frustration. Everything becomes such a drama to do. You spend all your time surviving. (Janine, 60, living with physical disability)*

Most considered that one point of information would be very valuable and two people emphasised the need for a national data base of services to also assist those planning to move inter-state:

> *In Tasmania there should be a service where you can go and they would tell you about services or programs or packages available to you, a one stop shop. They say those are the Commonwealth Carelink Centres but it needs to be personalised. You should be able to walk off the street and be greeted by someone and able to liaise with that person for the next week or two weeks until you find out what services are there and how the services can assist your needs and put you in touch with the relevant people and go from there. (Jim, 30, living with cerebral palsy)*

These concerns were echoed by service providers who themselves found it difficult both to field enquiries about services and refer people on to the most appropriate agencies. Some had responded by providing and reviewing their own information provision. So for example one provider of personal support distributed a fridge magnet with some key telephone numbers at the point of assessment. But as one agency said, '*It's about knowing the system and even we learn something new everyday, even though we've been in the system for years.'* Interestingly a number of service providers were unable to explain to the researcher how the service system worked.

4.4 Experiences of Receiving Personal Care and Support

In our research sample eight people had individual support packages and a further 17 had varying amounts of personal, domestic and social support hours through HACC funding. As well as assisting with basic care needs like washing, dressing and undressing and going to the toilet, support workers were involved in helping with managing finances, shopping, accessing health and leisure services. For example one couple with intellectual disabilities were living successfully in the community with 12 hours support a week to help with shopping, cleaning, financial management and accessing other services.

Although individuals greatly valued the ability these services had given them to live independently and their basic care needs were predominantly met they also reported a number of difficulties in dealing with provider organisations, accessing the level of support they needed and relationships with support workers.

Firstly there are those who have problems getting access to any support in the home at all. This can be especially difficult for those with less visible disabilities like cognitive impairment where there may not be any physical manifestations. Many people voiced the view that those who make the most noise and who understand how to work the system were more likely to get help.

> *We first applied to Disability Services for help about six years ago. We were told they might accept her but she doesn't quite fit the criteria. We were told at one point to refer her to mental health because she had got no problems. I have had to fight and become a squeaky door for the six hours funding we have now. It has taken a lot of work and effort to get those six hours. They know I'm a dual carer and that I am overstretched (Pamela, 61, caring for husband with Parkinsons and daughter living with cognitive disability)*

Secondly if they can get help not everyone is able to get the number of support hours they feel they need and they may be reliant on informal carers to make up the shortfall. Perhaps they only get three hours a day which is just enough to get up and go back to bed again. They might like a daily shower but have only enough hours for three showers a week. It is difficult to get care at the weekends and to get social support hours which has a big impact on peoples' ability to participate more generally in the community. This can be in stark contrast to those receiving care through compensation payments, particularly MAIB, who get as much personal support as they need and social support to access the community and participate.

> *I am grateful for the care I do get but it would be nice to have more. If I had had a car accident I could be getting up to 24 hours a day without having to rely on my family as I do now. I need someone with me overnight as I can't do anything by myself. If I didn't have my family I would probably be stuck in a group home which I wouldn't be too happy about. (Tim, 22, living with quadriplegia)*

Surviving on the minimum meant that any cuts in hours could have severe consequences. It also meant that some people were over-serviced and hung onto hours they did not necessarily need in case they were required in the future.

> *I get two hours care per week. I was originally on four hours. She helps me shop and her main job is helping me get the food and the normal stuff like housework and helping me fill out forms. She helps me do a lot of normal things that everyone has to do. But they changed that six months ago and it's had a disastrous impact. How would you feel if you lost two hours of life support per week? (Kevin, 50, living with vision impairment)*

> *I get an hour one week and half an hour the next of home support. They tidy the room up and clean. The personal carer will also vacuum the room. Some days he comes in and I just have half an hour and he goes off again. Because I don't make use of the full hour with things to do I was thinking about reducing the time from five days to three days a week. But he said don't because you might not get the hours back. Sometimes you need services when you don't need them so they are there when you do. (Daryl, 52, living with MS)*

Unlike those with ISPs who can bank unused care hours or use them to pay for essential items of equipment, those reliant on HACC funding cannot. This means that unused hours - possibly because a carer was sick or unavailable - are lost:

> *With the allocation of hours it got to the stage where so many hours had built up because they couldn't find a carer for him down here and prior to that we had been without one for over twelve months. The hours had built up and it was over fifty hours and it was their fault because they didn't advertise. We asked them if they could possibly put some of those hours towards a wheelchair van but they will only do it towards equipment and not a van. I would have thought a wheelchair accessible van should be classed as equipment. (Sharon and Mike, 60s, caring for their grandson living with multiple disabilities)*

Thirdly those who did not have an individual support package described difficulties with the scheduling of support hours and in dealing with providing agencies. Although agencies will try to meet individual demands as far as possible fitting in with agency schedules did mean being at the mercy of the staffing roster. This could dictate when you got up in the morning and when you went to bed with very little room for flexibility. People using the services were not necessarily informed of changes to staffing or schedules and there was a perception that the growth of larger agencies in this sector had occurred at the expense of being able to provide a more personalised and intimate service tailored to individual needs. As one carer said, '*Services have changed but not in the right way. They are not the friendly "can-do" staff, they are clinical now.'*

> *I don't get any individual funding, I take what I'm given and be bloody grateful for it or else. My usual person that comes to me tomorrow can't come because she has to go and do another person as a special thing and I still don't know who's going to come tomorrow morning in her place or what time they are likely to come. Mondays and Wednesdays to fit in with the carer's arrangements taking children to school I go to bed at quarter to seven and then Tuesday, Thursday and Friday I go to bed at 7.30. Weekends it has to be eight o'clock in the morning which is my big lie in but they will often make it quarter to eight and they don't ask me. The theory is you can go as late as you like but the practice is most*

> *nights I'm ready for bed at eight o'clock. It depends on who your personal coordinator is, whether the person is okay or not okay and how much they involve you in the process. (Mary, 57, living with physical disabilities)*
>
> *They come in between nine and ten every day. It's supposed to get me dressed but I'm not a performing seal. Some days you might want to sleep in but you can't sleep beyond nine o'clock. They regiment you. You like to do things when you feel like it. I find it very hard. (Daryl, 52, living with MS)*

Fourth, crucial to the provision of personal care and support in the home is the quality of the relationship between support workers and those they care for. Many of the people we spoke to were very happy with their carers. They had developed good relationships with them over a number of years and valued the care they offered and their skill levels. Others however commented on the lack of choice, training issues and attitudes and problems in recruiting and getting rid of carers they were not satisfied with.

> *One girl who's been with us for 15 years is leaving and he will really feel that terribly. So will I. She's great. They are all good. They don't interfere with you, they leave you to it which is great and suits me fine because I've got control. Sometimes we have to interview and that's a drama in itself. Changing and getting new ones is awful and they have to get to know you and you help them for weeks, for ages. They all have families and another life and I can't get the right person to do it. There is too much training now, far too much training. (Faith, 61, caring for her husband living with quadripleia)*
>
> *You don't really have a lot of choice around the carers you have. In theory you do but in practice you don't. I have one at the moment who originally was only going to come on a temporary basis. I find it really difficult. She has the coldest hands you can imagine. I asked her to warm them up before she touches me but she thinks it's a joke. But her actual level of care is good and the only way you can get rid of them is by saying there is something really wrong and that's offensive. I also have home help. I used to have two hours a week but it's been cut back just recently to an hour and a half. It covers fairly basic cleaning like the bathroom, the kitchen and the floors. You have to get used to some of those things, that nothing is done quite as you like it. I daren't go and look because I know if I do my blood pressure will just rise. (Mary, 57, living with a physical disability)*

Unlike the child and aged care sectors there is no national benchmark for workers in disability support which can mean low levels of pay and training. It is becoming increasingly difficult for agencies to attract trained workers and services commented that the quality of disability support workers was often low and training not appropriate for the job. There is also little access to professional development. One result is that the field is recruiting people who are not necessarily suitable for the task. Responsibility for training can also pass to people with disabilities themselves and many in our sample spoke about the time involved in having to train their carers. Several people were also concerned that far too much training was required of support workers. These requirements could serve to put off those who potentially were very good carers especially as the most important criteria was having the 'right attitude' and personal skills rather than any particular knowledge base.

> *It's your home and their work place and you have to engineer something both can live with. Some people are better at that than others. There is always the view from the providing body that there is a conflict of interest between what is good for our employees and what is good for our client. Often it's lip service to client focus and the ways in which it can be undermined are very subtle. It can take the form of a sort of abuse and people don't realise it. It can manifest itself in the subtlest way. You will find that when the person serving the meal likes something the plate looks like it's about to erupt with it. I don't like brussel sprouts and even seven is too much for me. Not everyone has the right attitude. There are those that want to fix your life. There are those who mother you. (Janine, 60, living with physical disability)*

> *Having been cared for has made me realise how much it comes down to people. You can have all sorts of carers but it comes down to just how they go about doing things for you and their innate sense of knowing what to do. (Tim, 22, living with quadriplegia)*

When things did go wrong people found it very hard to complain.

> *When you are on the receiving end of a service you are in a fairly vulnerable position and you don't want to upset people and communication becomes fairly complicated. When people are coming in day after day on that personal level - there are bound to be personality conflicts and issues and things like that and it can all get quite complicated. Sometimes some of the carers haven't worked but it's very difficult to criticise or comment. (Tim, 22, living with quadriplegia)*

> *In the past I had to speak up and say I'm not happy with the support workers and this is the reason why. I have learnt that if I don't speak up about it it continues and my emotional health goes down if I get a bad support worker. (Jim, 30, living with cerebral palsy)*

Lastly how far had cost been a barrier for people in accessing the levels of support they required? For most of those paying for HACC funded services this was not an issue and HACC fees can be waived at the manager's discretion especially when medication and continence costs are high. However for some the $10 maximum fee per week was a large sum out of a small budget and the assumption that there was sufficient discretionary income to cover it was challenged. There was also the view that personal care is a different kind of commodity to transport or food which everybody has to pay for. This meant that for some research participants there was a strong objection to paying for personal care particularly as people pointed out they had not chosen to have a disability.

The costs of employing people in your own home also have to be met. When a number of workers and/or hours are involved these costs can be considerable.

> *If you have care people coming in you have to provide amenities. It might be coffee, toilet roll, heating. Because overhead lights affect my balance I don't use them but they have to have them to work. It's part of having a social response to what should be a professional situation and everybody has a different understanding of professional depending on their background. (Janine, 60, living with physical disability)*

The situation of people with an ISP compared favourably to those who were dependant on HACC funding for their personal support and care. Although support schedules can still be dictated by the availability and flexibility of staff in any one organisation, recipients particularly valued the ability to bank care hours and the possibility of translating those banked hours into items of equipment. For instance one woman had purchased a two-way radio to keep in touch with her son.

> *I am fortunate in that I have my own individual support package. There are very very few and very few people have got them. I had to wait for six years before I was able to get one. Prior to that I was getting the same amount of hours but they were coming direct from my service provider and I was very limited with what I was able to do with any accumulating hours. With the ISP now I can accumulate up to 50 hours each year and it's up to me what I do with those 50 hours. I get 34 hours per week and that accumulates to four and a half hours a day. An hour and a half to get out of bed, have my shower, get dressed, get all my paperwork done, have breakfast and then an hour for lunch, an hour for the evening meal and an hour to go to bed. I get Kim for two hours a week for ironing and doing my housework and two hours a week for someone to do the washing for me. But I need at least another three hours a week for someone to come and help me with the shopping and do some cooking for me. My parents still provide 20 hours a week. Under the guidelines for my package shopping isn't classed as personal care so my parents still have to do the shopping for me. They come in for at least four hours a week to help me do my paperwork and filing and Mum still does the cooking for me of all my meals. She will bring them down and put them in the freezer for me. So when my support worker comes for lunch I already have the meal cooked so it can be eaten and washed up and if I need to go to the bathroom. It would be impossible for them to cook a meal. (Jack, 47, living with cerebral palsy)*

Having an ISP requires an understanding of the framework and having the skills to operate it. There were those who had been waiting for years for an ISP but there were also people who did not want the burden of having to do it all themselves.

Both those with ISPs and those without commented on a lack of support to assist with shopping. ISP hours cannot be used to buy shopping support and although HACC funding can the support is not necessarily available or appropriate. Many had to rely on friends or family or shop staff to assist them. One woman had assistance from St John Ambulance. Another did her shopping on the internet.

> *I got three hours a fortnight mostly just to help me do my shopping because I get stuck on buying products and meals. She didn't really help all that much. She would just wander off and say you try and do this yourself but if you have troubles come and find me. I would be walking around the supermarket almost to the point of being in tears because I would be looking for something and couldn't find it. Then I would get agitated and once I get agitated I get disorientated. (Diana, 54, living with ABI)*
>
> *One of my main problems is shopping. If I want to go shopping and save money I have to go to a large supermarket and to do that I either have to have someone of my own choosing spending time walking round the supermarket with me or I have to arrange for one of the staff to go around with me. Some people are happy to rely on the staff getting them what they actually want. With a friend it's*

> *much easier because they think along the same lines as you do. If you shop with a person from a supermarket, it's a bit like shopping on line. I choose to shop in a smaller supermarket where things cost more but you get that extra service. (Anna, 56, living with blindness)*

There are also concerns about a lack of domestic assistance. This covers domestic chores like cleaning and clothes washing as well as shopping and banking. In the longer term it can have a vital impact on health and hence on the risks of institutionalisation. The shortage of social support hours to go to the pub or attend a meeting also impacted on people's ability to participate in the community but it was difficult for agencies to prioritise social support hours when it might be at the expense of others with a basic need for personal care in order to survive in the community. These problems in prioritising scarce resources were acknowledged by both providers and service users.

Ageing has implications for people's access to services and for the boundaries between disability and aged care services.

> *Once a person with a disability reaches the age of 65 they are classed as an older person and they are no longer regarded as a person with a disability so when they apply for funding in certain areas the government says sorry you're not eligible. You have to move to the old age pension and you can't receive benefits under the DSP. All the networks I've established will probably go. (Jack, 47, living with cerebral palsy)*

4.5 Coordinating Care

Once hours have been allocated through HACC or through Disability Services recipients and/or their informal carers are usually left to coordinate their care. Although organisations try to minimise multiple service providers this is not always possible and to get the hours a person requires may involve 'blending' services from a range of different organisations. It means that one person can have a number of service providers and several different support workers coming into their home. There might be a nurse visiting regularly for clinical needs, two organisations providing a number of hours of personal care and a third providing bowel care. A fourth might be providing two hours of domestic assistance a week and some social support. The diversity of providers can be seen as positive in being able to provide choice. However each provider will also receive a referral, do their own assessment, prioritise and allocate hours and undertake an annual review. This means that their clients are required to justify their need for support several times over. To complicate matters organisations are not necessarily aware of the involvement of other organisations. This is dependant on the client divulging the information and could therefore lead to duplication of services and over-servicing. Different agencies have workers employed under different awards and with different qualifications. Low pay in the sector encourages support workers to make up a reasonable income by working for more than one organisation. The implications of this are that a support worker can go into a person's home on a Monday as the employee of one organisation and return on a Wednesday as the employee of another organisation.

> *To live in a situation like mine and for people like me it takes on the logistical proportions of the Napoleonic wars. You have got to be really organised. You have to be able to organise those people that help you. And not only do you have to be able to coordinate the many aspects of staying in your home you also have to be the quality control person as well. I am the one who knows what's*

> *happening and they should ask me but they don't always do that. (Janine, 60, living with physical disability)*

> *I get 34 hours a week with one service and about seven hours a fortnight with another who only look after my bowel care. Today they came in at about 8.00am until 9.30am. The community health attendant came in at about 8.30 am to help me get on to the commode. Then another carer comes at about 9.00 am to do things and a second comes at 9.30 and stays until 10.30-11.00. The first carer will have left by then. Then someone will come back at lunchtime and stay until 1.30-2.00pm. Then the last person will come back at 9.00pm to put me back to bed. My mum comes between 2.00 and 6.00 pm four afternoons a week. (Tim, 22, living with quadriplegia)*

Having several support workers coming in and out of the house could be exhausting and confusing for people with disabilities and as one man said, '*It drives me nuts.'* It also has a big impact on privacy. When multiple service providers are involved it can mean difficulties in effectively co-ordinating care. One person may require two support workers to be able to have a shower. Those two workers may come from different organisations but it is vital that they arrive at the same time. Few HACC organisations are funded to provide case management services and in their absence the burden of coordination can fall on the person with a disability or informal carers. This can be a demanding and onerous responsibility and some service providers described its absence as 'the missing link'. It could also mean that people felt very alone with their situation and some of those who had been 'in the system' for a number of years felt that the quality of service had deteriorated.

> *They don't give you a phone call and say how are you these days. My husband could be in hospital or dead and buried and they wouldn't know. I am grateful for them but I have been hurt when no time sheets have gone up so he's obviously been in hospital ill but nobody calls. It's all about money now. The personal touch has gone. The care is there but.... (Faith, 61, caring for her husband living with quadriplegia)*

> *For years we never saw anyone, they never follow up. I rang Disability Services and said why haven't you been down for four years to see her. They said because we haven't heard from you and they put her into self management. I asked them what they meant by self management because she can't look after herself. They rang back and apologised and one of them came down but they still don't follow anyone up. (Deb, 74, caring for her daughter living with multiple disabilities)*

> *Disability Services were very good but once they set you up they're gone, they've finished with you. You are so grateful and in a world of your own so you can't think, but then it's 'see you later'. There are others to go onto, I realise that, but you never hear from them again. (Faith, 61, caring for her husband with quadriplegia)*

> *We weren't even on Disability Services' list until this year. They didn't even know Simon existed. Even when they put us on that list we've never had any help from them. They never come. (Sharon and Mike, 60s, caring for their grandson living with multiple disabilities)*

Disability Services provides a ‘service co-ordination’ role not ‘case management’ and the absence of someone whose focus is keeping in touch and monitoring how people are going is not part of the service system unless there are high and complex needs. For services this might be seen as mainstreaming or empowering people to control their own lives. For consumers however it was a manifestation of neglect and made them feel isolated and alone.

4.6 Summary

As many research participants commented, accessing personal care and support is a battle. There are those who have problems navigating the support system and struggle to manage without any support services. For those who find a way in, it’s about going through a provider assessment and receiving a basic minimum, the minimum amount of service you can cope with. For many people it has little to do with having access to a quality of life and anything above survival levels is considered a luxury. This can include adequate amounts of domestic assistance and social support. Those without high support needs fight to get any care at all even though a small number of social support hours could revolutionise their lives.

The shortage of funding generates waiting lists and cuts in service levels and because there is no guarantee that once support is in place it will be ongoing it can precipitate crises of care. Providers try to meet priority needs and it means that available resources are targeted at those individuals and families in very difficult circumstances rather than being able to intervene in situations to prevent a crisis occurring. The fragility of the system means that people are not prepared to speak up because of fears of losing services altogether. The end result is a service network which allows many to lead severely impoverished lives while at the same time pushing the few into situations of acute need.

5. ASSISTIVE TECHNOLOGY

Aids and equipment or 'assistive technology' can be a key aspect of life for a person with a disability and significantly affect their functioning, increase their participation and generally improve the quality of their life. Assistive technology ranges from wheelchairs and other mobility equipment, hoists for lifting and showering, bathing, toileting and continence aids to sophisticated electronics and computers for communication. Aids are sometimes categorised in terms of technological sophistication - low (toilet supports or hand held showers), medium (wheelchairs and mechanical lifters) and high (electronic communication boards and voice amplifiers).

Approaching half (48%) of all people with a disability use assistive technology (AIHW, 2003) to enhance their independence. Some of the people we spoke to required no equipment at all. Others were using a range of aids and we also interviewed 19 wheelchair users.

5.1 Assistive Technology Services

To assist people in accessing appropriate assistive technologies there are a range of Commonwealth, state and territory-based and non-government schemes which provide free or low cost aids. Each have their own eligibility criteria.

5.1.1. Commonwealth Services

Eligibility criteria for these schemes depends on employment or veteran status, type of impairment and how it was acquired. They include:

- Rehabilitation Appliances Program and Home Modifications. These programs are only available to Veterans and include continence equipment.
- Australian Hearing Services for concession card holders with an annual service charge of $25 for maintenance of hearing aids and batteries.
- Commonwealth Rehabilitation Services, providing equipment to people entering the workforce.
- Continence Aids Assistance Scheme (CAAS) providing supplies to those in employment who are eligible for the DSP or mobility allowance.
- Workplace Modifications Scheme, which contributes towards the cost of aids and workplace modifications for those in or entering the workforce.
- Commonwealth Carer Respite Centres, which can provide one-off funding for small items of equipment which offer carers a break.
- The Commonwealth Government offers tax offsets for some of the higher cost items. In 2004-05 they subsidised 20% of net medical expenses over $1,500.

5.1.2. State Services

Each jurisdiction manages a single equipment scheme and in Tasmania this is called the **Community Equipment Scheme (CES).** It operates under state-wide guidelines through three regional outlets and aims to facilitate the discharge of people from hospitals, enable integration into the community and prevent premature admission to institutional care. Each region operates like a lending library with its own pool of equipment. As well as standard equipment - like mobility and self care aids, communication devices, surgical footwear and some home modifications – it can also provide non standardised and customised equipment usually for items costing over $500. The eligibility criteria are being in receipt of a concession card or Centrelink payment, not receiving any compensation settlement and being ineligible for other schemes. To access assistance an assessment is required from a health professional, usually an occupational therapist. Assessments are 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 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 provision panel for those who reach the cap, require expensive equipment or who cannot afford the charges. Compensable clients whose claims have not yet been settled can access the scheme but are required to sign an undertaking to fully reimburse CES for all items and repairs.

CES also operate a **Continence Service** which offers free assessment, treatment and management of continence through a continence nurse and outreach clinics. Excluded from the scheme are those eligible for CAAS, residents of nursing homes and those with short term needs of up to three months.

The **Spinal Account** provides equipment for mobility, self care, home modifications and continence for non-compensable traumatic spinal cord injury. The Account does not cover assistive technology. It works in line with the CES but provides more generous assistance - up to $8,000 - for wheelchairs and will also cover the maintenance costs including tyres and batteries. The majority of clients are young male quadriplegics and paraplegics.

Disability Services operates an ad hoc one-off funding pool resourced by slippage monies and a bonus. This can cover mobility and transfer equipment, respite and one off personal support, home and vehicle modification and alarm systems. 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 particular aids 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 every three months. 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. A one-off application to Disability Services for maintenance or servicing may be considered when all other funding sources have been exhausted.

The Artificial Limb Scheme is administered by the Department of Health and Human Services and provides and maintains prosthetics with the client paying 15% of the scheduled cost.

Non-government organisations may distribute equipment on a long term or temporary loan basis at competitive rates. Some also manufacture their own equipment. Fees for 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 Royal Guide Dogs have adaptive technology services for those who are blind or with vision impairment which includes assessment, installation, training and follow up support.

The **Independent Living Centre** in Launceston aims to match individual requirements, including finances, with the most appropriate assistive technology. It offers displays, consultancy services, mobile outreach services and occupational therapy support. They also maintain a register of second hand equipment.

In addition there are a number of **commercial business operations** which import products which customers purchase outright. Some will offer payment and hire schemes and cover repairs and servicing. Prices are now considerably cheaper than they were five years ago.

Finally under the higher forms of **insurance cover** most health funds provide some form of benefits for aids including hearing, medical and mobility aids and prostheses. The maximum benefit and time period allowed between claims varies between schemes.

5.2 Access

The variety of sources of assistance and the differences in funding streams, eligibility criteria, administrative processes and availability create a fragmented system where no one is responsible for monitoring or coordinating schemes to provide a comprehensive service. This can be both inequitable and confusing for those trying to gain access to assistive technology.

This is at a time when demand for assistive technology is increasing as people live longer, acquire age related problems and survive traumatic injury. Additional pressures come from the incidence of relationship breakdown and split families so that equipment for children with disabilities is then required in each household. There are also growing numbers of ageing carers requiring lighter weight equipment and an increase in average body weight requiring an increased weight capacity of equipment (especially for those over 110 kilos).

The overall budget of the Community Equipment Scheme has not increased for six years beyond occasional top ups. This has limited its ability to meet demand, to increase the range and quantity of equipment on offer and to cover the cost of maintenance, repair and replacement of loan equipment. This causes delays in supplying standard equipment, unpredictable waiting times and a necessity to prioritise clinical need at the expense of aids to promote community integration and participation. For example, a wheelchair to be used for shopping can take a low priority. The scheme also excludes many people with disabilities. These include:

- those who do not have a concession card. They have to buy or hire equipment and costs can often be substantial. This can apply to those with temporary or episodic disability; for example MS. They may have to hire a wheelchair at extra cost and are unable to access help with continence aids. The MS Society can meet some costs in crisis situations although it is not part of their regular funding arrangements.
- residents of nursing homes. This is a big issue for young people, often with degenerative conditions, who are living in nursing homes and who lose access to the CES on entry. Exceptions are made for any customised equipment obtained through the CES that they might need to take with them.
- employed people. They only have access to aids and equipment through the Commonwealth Rehabilitation Scheme.

Although respondents in our sample had good experiences of using the CES scheme and felt it was efficient and affordable, they also reported being excluded from accessing the equipment they needed by a lack of information about where to go, eligibility criteria, the application processes and costs. This can result in a reduction in their ability to live independent lives and a greater reliance on personal assistance from a support worker.

5.3 Mobility and Other Equipment

Being mobile is a basic need but research participants were keen to point out that, although the general public might assume that if you need a wheelchair you are assisted to get one, this is not necessarily the case. Anglicare spoke to 19 wheelchair users and a number had experienced difficulties in meeting the costs.

> *This wheelchair cost $18,000 and the most the State Government will give under their funding scheme is $6,000. There is a huge gap and if people don't know where to go and who to talk to how are they expected to find that $12,000 gap? Fortunately I know the right people to talk to, the right forms to fill in, the right phrases to use. It's working through the system. For some people, because of the disability, they might need very specialised equipment which means that they can't afford other things, like groceries. It is 15 years ago when I bought the bed and I can raise or lower the head or foot. That cost $10,000 so imagine what the cost would be now. It is $400-600 to get a specialist cushion so it minimises the possibility of pressure points. You can get a special mattresses for your bed but to get one of those is $2,000. It's those things that add up. (Jack, 47, living with cerebral palsy)*

The $6,000 cap in the CES on individual items of equipment is often too low to buy powered mobility especially if some customisation is required. A powered, customised wheelchair with head controls, computer devices for communication and pressure care can cost $12,000-24,000. Lifting equipment like hoists and tracking systems can be in the $5,000-6,000 range. There are other areas where the scheme falls short: for instance, CES will pay up to $400 for customised shoes recommended by a podiatrist but some cost as much as $750. Some people had been forced to fundraise to meet the gap between what the state provided and their actual mobility and other needs which they found demeaning. For those in more rural areas who were disadvantaged by a lack of local equipment outlets and having to travel to apply for and obtain the items they required even fundraising was not a possibility. As one family said, '*There's no fundraising down here. There's not even a football club, so you're flogging a dead horse.*'

> *It is demeaning to be asked to fundraise. I have met the cost partly through the Community Equipment Scheme and I have also approached individual organisations such as Rotary which has been quite helpful. Even though I can be quite an outspoken person I do feel a bit funny about asking people to help me with money. It is a pride thing I guess as opposed to the department who are given money to provide services to you. (Mat, 22, living with cerebral palsy)*

Many considered that it was pure chance whether they had or had not obtained the equipment they needed. It was a question of applying at the right time or getting a good occupational therapist who was able to push their case.

> *This thing is only on hire and it's not really suitable. Mine is coming but because Disability Services is broke there's a funding shortfall at the moment so I'm probably going to have to self finance. Everything is up in the air so I'm just*

> *waiting. The new wheelchair will be paid for by one department, the MS Society are putting in some and we are waiting for Disability Services. I qualify for it but they're broke. That poor woman in the paper before Christmas who couldn't go home - well I'm affected the same as she is. (Daryl, 52, living with MS)*
>
> *I've got an electric wheelchair now which I've had for the last five years. The Government subsidised it. The reason was that I applied at the end of the year and they had a lot of money left over and they looked at the list of people who needed equipment and spent the money by the end of the financial year. I was a lucky one. (Jim, 30, living with cerebral palsy)*

There were also reports of long waiting times for standard pieces of equipment which had caused problems.

> *I have a shower chair. I got a form sent to me and I signed it. I had to wait and I couldn't shower myself, it was months. (Sally, 32, living with intellectual disability)*

The market place for aids and equipment is dominated by specialist manufacturers. This makes it small and therefore expensive and the ability to shop around can have a big impact on the price. Some people had found the application process so onerous that they preferred to meet the costs themselves.

> *We bought the walking frame ourselves. We know about the CES and we actually have a seat in the bath that comes from them. But we didn't try. We just went and bought one because she needed it. We didn't want to waste the time and effort and arguing and the doctor's report. (Laurie, 55, caring for his wife with renal failure)*

A major gap is the lack of assistance available to acquire wheelchair accessible vehicles and/or modifications to vehicles like racks or carriers to accommodate wheelchairs. These costs are not usually covered by any of the schemes. The exception is the ad hoc funding pool held by Disability Services which will consider vehicle modifications for wheelchair users.

> *If I want to take the chair I really have to get a taxi because I can't fit it into my car and I haven't got my car done. Ideally I would like a lovely expensive car where I could just clamp the chair down and drive along but ideal is not going to happen. People make assumptions that these services just happen and wheelchairs are just provided but it's not the case. (Mary, 57, living with physical disability)*
>
> *I got the wheelchair rack from Calvary Hospital. I had to wait 12 months for that because they only have one and I was second on the list. I can't use it because I can't lift the wheelchair on and off. It does drop down to the ground so you can roll the chair on but I can't handle that very well. The idea is that my husband does it. If it gets to me having to do it I'll get a hoist put on the top of the car so that you can hook it from the ground when you're sitting in your car. (Denise, 52, living with cerebral palsy)*

Once equipment has been obtained recipients become responsible for the ongoing costs involved in maintenance and for upgrading as people age or as their needs change. For instance it may have taken years to acquire funding for a ramp but it then becomes impossible to maintain it safely due to the costs involved. This can mean using unsafe aids and having to make equipment last beyond its use-by date. The CES offers an annual service for wheelchairs but the routine maintenance costs like batteries, tubes, and tyres are the responsibility of the user. Those eligible for the Spinal Account have these costs covered. The implications are that maintenance costs can cause financial hardship and the higher the use of the wheelchair and the more significant the disability the higher the cost.

> *There is $400 per annum to spend on batteries and I have to meet the cost of that myself. They only last a year. And then there's the cost of tyres - another $200 a year and sometimes more. This year I've gone through two punctures. Fortunately my father and my brother were able to repair them. But for a lot of people with disabilities they don't have the family support and networks to do that and they have to pay. (Jack, 47, living with cerebral palsy*)

Some people reported difficulties in paying $50 per year to CES but they also considered that CES was flexible about repayment arrangements, gave time to pay and made efforts to make contact to see what can be negotiated. Eventually however debts are passed to a debt collection agency.

There is also a reluctance to ask for additional items of equipment and people tried to limit the requests they made. They felt guilty about using public money and were also aware that as time passed they would require more funding for up-gradings and other items of equipment.

> *We have paid half our chairs each time and I think I paid for the last hoist. It was broken, we paid for that, you feel that you should. And the last shower chair, we paid for that. I'm still paying for the last chair. I know there are other people out there. I'm paying $5,000 towards this chair now over a long period of time. (Faith, 61, caring for her husband with quadriplegia)*

Guide Dogs and Companion Dogs can be important aid to mobility, practical support and social interaction but they can be expensive. There is some assistance with costs. Unlike other states, Royal Guide Dogs in Tasmania cover all vet bills, food dishes and initial food. However other expenses can be substantial including regular grooming which can cost up to $30 every few weeks.

> *A person with a guide dog has to think about whether they can afford to have enough yard for their dog and if they haven't whether there is space for the dog to have a run. There are lots of other costs too. They have to maintain the dog, feed the dog. It could be quite a few thousand dollars a year for them to be mobile. These are all the things that if a person is on a DSP can eat into their pension or if they're working it eats into their salary which means there's less of it to do the things everybody else does. (Anna, 56, living with blindness)*
>
> *At least you can have a companion. You can sit here of a night time and talk to the dog. You can tell it anything and the dog will not tell any secrets. You can have some confidence in it and it can be your best mate. If I drop something on the floor I have to wait till a carer comes to pick it up for me whereas a dog will do that for you. They will open doors for you and be able to let me out because it will be a pull down handle. They load washing machines for you if you want them to. They press lift buttons, get your wallet out of your bag, amazing. (Rod, 38, living with quadriplegia)*

5.4 Continence Aids

Managing continence is a major issue for many people with disabilities and inadequate management can become a real barrier to participating in the wider community. The cost of incontinence products varies greatly depending on the degree of the problem and the type of product being used but most people find it very expensive. Varying levels of assistance with meeting the costs are available from:

- **CES Continence Service,** providing up to $1,000 in supplies per year with the client contributing half of the cost. Once the $1,000 limit has been exceeded customers can still access equipment but at full cost. They can also apply for hardship provision and occasionally assistance may be given to fill the gap through Disability Services. The scheme provides a free assessment by a continence nurse to ensure the right product choice.
- **Spinal Account,** meeting all continence expenses.
- **CAAS,** providing up to $471 per year in continence aids to those of working age. The provision of supplies is not linked to assessment or treatment. When the CAAS subsidy is exhausted customers 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.

Access to continence programs ceases once the customer reaches 65 years unless they continue to be wage earners.

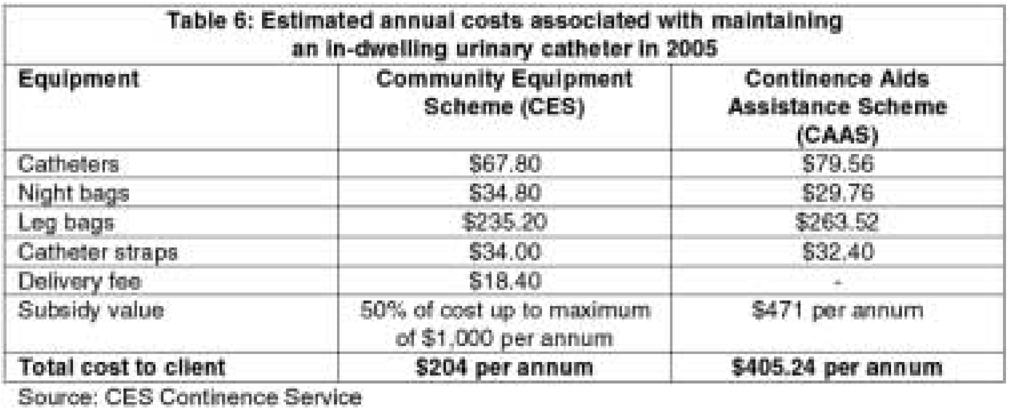

Table 6: Estimated annual costs associated with maintaining an in-dwelling urinary catheter in 2005

Equipment	Community Equipment Scheme (CES)	Continence Aids Assistance Scheme (CAAS)
Catheters	$67.80	$79.56
Night bags	$34.80	$29.76
Leg bags	$235.20	$263.52
Catheter straps	$34.00	$32.40
Delivery fee	$18.40	-
Subsidy value	50% of cost up to maximum of $1,000 per annum	$471 per annum
Total cost to client	**$204 per annum**	**$405.24 per annum**

Source: CES Continence Service

Table 6 estimates a twelve-month supply of bladder drainage equipment based on routine four-weekly catheter changes, weekly leg bag changes and monthly overnight bag replacement. Costs increase significantly if the individual develops a urinary tract infection or their catheter becomes blocked and these can be regular occurrences for some people. When this does occur the catheter and bag need to be discarded and replaced with a new sterile catheter and bag. Any contaminated equipment also needs to be thrown away. It is difficult to budget for these increased costs. Some people might have to change equipment every week for a period of months or several times in a few weeks if there is infection. In addition urinary leakage around the catheter means the associated costs of containment such as pads, bed protection and additional laundering. There may also be the cost of optional equipment like drainage bag stands which cost from $9 to $20 and sturdy leg bag straps which cost $15.60 a pair. There is also the cost of detergent and bleach to clean the overnight bag daily.

A registered nurse is required to change the catheter and a home visit costs $5 (capped at $10 per week) for those who hold concession cards. At a minimum that adds an additional $60 per annum to the overall costs.

Although users of the Spinal Account were happy with the continence subsidy, users of other schemes reported difficulties in meeting the cost of their continence needs and were finding that the subsidies, particularly through the CAAS, barely met the expense.

> *The Government only allocates $471 a year and if I do a standard order that is about $100 a pop and I would go through a batch probably every couple of months. My next funding doesn't come through until July and so far already I have had to put about $300-$400 in out of my pocket. That $470 barely meets the requirement and I don't use them every day so I feel a lot of empathy for someone who uses them every day. There is no other source of funding for that currently. Also the Government was looking at reducing the funding last year and enough people kicked up a stink and thankfully they backed away from that idea. (Tim, 22, living with quadriplegia)*

> *The maximum amount of money the Commonwealth government will provide is $470. With me that's gone in two months or three months. The sheaths that go onto me they are $2.50 each and I go through seven of those a week. So the $470 is gone in six months just on that. So for the rest of the year I have to get organisations like ParaQuad to help out. I reckon my continence equipment costs me easily a $1,000 per year. That's on top of the $470 the government provides. (Jack, 47, living with cerebral palsy)*

As one person said, '*CAAS only provides for a quarter of the needs of the fully incontinent*.' A survey (Australian Quadriplegic Association, 2000) found that 68% of respondents allocated continence equipment did not have enough to last the year. Some had tried to meet the additional costs by applying to Disability Services for one-off funding but had not necessarily been successful.

> *I have used all my funding and reapplied for a one-off grant but was advised yesterday that there is no money. We'll apply again in February. So it's sit and wait. The continence sister came out to me and has put in some recommendations. Unfortunately it's very expensive. (Janine, 60, living with physical disability)*

The impact of having inadequate continence support is significant in all aspects of daily life and particularly on community and social participation. It can mean that people economise on changing themselves and do it less than they should. One man calculated it cost him $1.60 each time he went to the toilet. Some people will not eat or drink when they are out because there is no carer there to help with the toilet or with pads. Indeed many respondents said that it meant it was easier not to go out at all.

> *You would be sitting in a pub or someone's place and suddenly have a bowel action and think 'oh no'. I was so devastated. I've got to go now, why, no I've just got to go. Your life revolves around your bowels to a certain extent as a quadriplegic. If they're not working properly you have a shit of a day. If you can get a good bowel routine going, which I am just on the verge of - and it's taken nearly 3 years to do that - things are better. (Rod, 38, living with quadriplegia)*

In addition to equipment there are also the costs of purchasing continence medications which are not scripted. These include cranberries and other pills to keep the bowel working properly.

Managing continence is considered to be a specialist area. Other health professionals may be unfamiliar with it and not necessarily see it as a treatable condition which can be managed to greatly improve the quality of people's lives. The CES continence service did report some difficulties in working with disability support workers around these issues. Assessing and treating residents in group homes was dependant on support from residential workers to bridge the communication gaps and ensure a continence regime is both established and maintained. However continence nurses had found a lack of consistency and commitment among group home staff which effectively denied residents a service and forced them into using pads as the only option.

5.5 Communication Technology

Communication technology can be vital to allow people with disabilities to manage their everyday lives and their finances, access services and obtain information. It has a multitude of uses. It can be used for environmental controls like opening doors and turning on lights, heaters or videos. It can involve voice commands for computers or microwave ovens or special adaptations to mobile phones and other pieces of basic equipment so that people with a disability can use them. It can greatly reduce the need for personal assistance from a carer and allow people to better control their own lives.

> *I have voice recognition software and the program for the computer uses voice commands to control the lights, heater and stereo etc. There is an intercom and a remote opening door. There is a microphone stand to buzz to get Dad. There is a special disabled access phone. (Tim, 22, living with quadriplegia)*
>
> *Some people would prefer to have their microwave oven talk to them and you can get a box besides it which talks but that costs about three times more than the actual oven does. So you have to think of other ways of getting round things. I have stuck Braille labels on the appropriate parts where I push. That was very cost effective. You are aware that you buy the same equipment as other people but you don't get the money's worth out of it because you can't use all the functions. If I bought a DVD player there are certain functions I wouldn't be able to use. My mobile phone cost me $200 and the only thing I can ever do with it is make calls and receive calls. I can't run my telephone book because I can't access it. (Anna, 56, living with blindness)*

Yet funding for electronic aids is patchy and can depend on knowing where to go and then putting in a successful application. The CES will pay up to $2,000 for a piece of communication equipment. However, although such equipment requires regular updating, no funds are available to cover these costs. There is also an unwillingness to fund basic equipment like lap tops as they are not seen as disability specific. No other government subsidies are available for the purchase of equipment or technology outside the workplace with the exception of students up to the age of 25 who can access funding to purchase software for use at home.

The Telstra Disability Equipment Program does provide specialised equipment but it is hired at the same rate as a standard telephone. This can include teletypewriters, computer modems, hands free phones, volume controls and visual alerts.

People with sensory disabilities are particular dependant on communication technology. Deaf people may require flashing lights on door bells, telephones and on baby alarms and vibrating devices in the bed to act as smoke alarms. A portable system including all these aids costs $900 but there are questions about who pays. Public housing is responsible for installing basic equipment but in the private rental market there is no onus on the landlord to provide these aids which means that private tenants and home owners have to meet these costs themselves. In addition an AUSLAN interpreter costs $120 for two hours or $800 for a day and this is often seen as an individual responsibility.

Blind people can be badly hit by the lack of subsidy. In order to access basic information they may require Braille note takers at a cost of $8,000, a computer with the capacity to run blind software costing $2,000 and screen reading software costed at $2,000 with upgrades at $1,500. In addition they might require a talking scanner for $5,000:

> *If I buy new computer equipment I have to think carefully about what I spend my money on and get my priorities exactly right. Originally when I bought my first computer I bought a lap top and then I had to pay $1,200-1,300 to actually get the software to allow me to use it. I upgraded that which cost me $700. But if I had to buy the software program which I use to read the screen and talk to me that would have cost me $1,700. So that's an extra cost just for me to turn on my computer and know what to do with it. I have to have the ability to read print and I use an optical character scanner. It reads it out loud in a synthetic voice. It doesn't read handwriting. You can buy an ordinary scanner and then you buy software which you load onto your computer which would cost you about $3,000. I decided not to do that because it's important I can read things straight away if possible. So I decided to buy a stand alone one which cost me about $4,500 so I can still read. To get a PDA with a Braille display so you can do all the things you expect with email that's $8,000. So that's just to get me to the electronic equivalent of pen and paper. (Anna, 56, living with blindness)*

There is now TADAustConnect, a new nationally available low cost internet service for people with disabilities and older people dependant on government benefits. This means that it is possible to go online for $5.50 per month including unlimited downloads. There is also a one off connection fee of $12.

5.6 Summary

As technology improves it is increasingly able to revolutionise people's lives and improve both emotional and physical independence. However the costs are also increasing and can be a huge expense in limited budgets. Assistance available to meet some of these costs is fragmented and inequitable and provided by a mosaic of services where eligibility differs according to the type of impairment, how it was acquired, age of the applicant, where they live and in what sort of accommodation.

So although people living on the DSP have access to financial subsidies this does not necessarily allow them to meet all their basic needs particularly with mobility, continence and communication. It means that income poverty is compounded by an inability to make full use of assistive technologies to participate and improve the quality of their lives.

6. HOUSING

The difficulties low income households face in accessing affordable housing in Tasmania are well documented (Cameron, 2002 & Gabriel, 2004). For people with disabilities there are additional barriers. 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. Building regulations do not ensure accommodation stocks are adaptable or accessible and there is no national framework for implementing adaptable housing standards for new building construction. This means that the design and construction of private dwellings has consistently failed to adequately consider the needs of adults with disabilities.

The quality of housing is a major concern for enabling the delivery of home based care. Given that the key objective of community reform in Australia is to promote community based rather than residential care packages the lack of financial resources and policies which link housing with care and support has been described as 'unfortunate' (Bridge et al, 2002). The separate development of disability, ageing, housing and care programs has led to substantial unmet need, major barriers to providing appropriate care for people with disabilities and an increase in dependency and social exclusion.

Inappropriate accommodation and limited community support can result in a loss of contact with services, itinerancy and homelessness and this can be a particular problem for those with acquired brain injury and mental health problems. Both groups have a higher risk of experiencing factors associated with homelessness including family breakdown, loss of social support networks, lack of affordable housing, unemployment, illness, drug and alcohol use and criminal behaviour (Cameron & Flanagan, 2004). However it is difficult to quantify the extent to which people with disabilities appear in the homeless population and the Supported Accommodation Assistance Program (SAAP) which provides assistance to those who are homeless or at risk of homelessness has no single data item in the data collection which can easily identify clients with a disability.

Research participants were mainly contacted through support services and were home owners or living in public housing, private rental accommodation and supported accommodation in the community. This meant we were able to pick up on experiences of accessing appropriate accommodation across the housing sectors. However it was problematic to contact homeless, mobile or transient populations of people with disabilities so their experiences have not been collated.

6.1 Home Ownership

Owning your own 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 dwelling or downgrade by selling their house and buying somewhere smaller. This is a common response for those who acquire a disability as adults and releases the financial resources to purchase the modifications, equipment and care that they need.

> *We sold for $370,000 which we split up and that's how I bought this. This is going to be a disabled unit by the time I finish with it. That ramp at the front door,*

> *I got a mate to put in. I've got a wider door coming. I've got an electronic system going on so when you come in it's just like a bank card and you swipe it through the sensor. Each carer will have one. At the moment I ring my mother up and say can you let me out and she comes across. I've got a brand new kitchen going in which will have a gas cooker and I've had that designed so I can get underneath and cook. I will be able to cook myself, which will add that little bit more of independence. It's all funded from the money I got from the house. (Rod, 38, living with quadriplegia)*

Some people who return to their own homes may need modifications to ensure accessibility and improve their physical independence and ability to perform self care activities. These might be minor modifications like hand rails or major renovations involving structural changes like new bathrooms or ramps. But it does mean that they incur costs over and above those faced by non-disabled people. For those who own their own home getting these modifications can be a lengthy process and may keep people in the hospital system despite no longer needing medical attention. They are hard to fund for home owners who are dependant on the DSP and do not receive any compensation payment. Indeed there are long delays in getting modifications across Australia (Phibbs, 1999) and tight eligibility criteria for different schemes. The options for home owners in Tasmania are:

- **HACC funded home modification and maintenance service** where users pay a $10 maximum service charge and pay for the cost of materials.
- **Community Equipment Scheme (CES),** which can undertake minor modifications like grab rails and ramps. Again installation is free but the user pays for materials.
- the **Spinal Account** will fund minor modifications for those with traumatic spinal injuries.
- **Disability Services** can fund minor modifications if funds permit.
- **Commonwealth Rehabilitation Services.**

These schemes fund minor rather than major modifications and these limitations had forced a number of our research participants to fundraise or to consider selling and moving somewhere smaller or more appropriate.

> *This unit was built onto the existing house and was funded by us. The Spinal Fund paid $2,000 for home modifications. Any further additions will be paid for by Dad or myself. My ex-girlfriend's mother was very involved and she got lots of businesses involved and there were many fundraising dinners. The Aero Club donated $12,000 from the first air show. The Rugby Club I used to play for raised $7,000 and the RAF raised $15,000 or more and there were lots of individual donations. The local community also did lots of fundraising which covered environmental control gadgets and air conditioning, the TV and stereo, the bed and the van which cost about $9,000. (Tim, 22, living with quadriplegia)*
>
> *We had to fund the rails inside ourselves. At the moment we would very much like to modify the bathroom and if Jim goes into a wheelchair fully then we won't be able to lift him and put him into the bath. The lifting is going to become a big problem. Also the layout of the house is not all that good. We are looking at major renovations really or we may have to look at selling the house and buying another home. (Pamela, 61, caring for her husband with Parkinsons and her daughter living with cognitive difficulties)*

Although blind people may not require major home modifications there are issues about making the home safe, for example, having maximum light available, clear pathways and aids for cooking. However again there is little assistance in purchasing these aids and making a home safe can require a lot of planning.

> *When I was working I did things that cost money to make the home as low maintenance as possible, making it liveable for the greatest amount of time. This meant getting rid of the garden so you don't have to worry about someone doing it. I had it all paved. I know that I can live in this house now for almost as long as I need to. If I need to change steps into ramps I can probably do that. (Anna, 56, living with blindness)*

6.2 Public Housing

Disability related costs account for income which could have been invested in security of tenure. This usually means that reliance on income support precludes house purchase and makes people with disabilities more reliant on social housing.

Across the State Housing Tasmania provides 465 properties for disabled tenants. This includes 16 disabled persons units, 335 multi-purpose units and 114 adaptable housing units. Four hundred and twenty six are available to rent from Housing Tasmania and 39 are managed by community based organisations. Some adaptable housing units are GETSmart homes[7]. Housing Tasmania also provide disability group homes which are managed by other agencies.

There is a modifications service to make existing properties more accessible. This is free and no costs are involved for tenants although the budget is limited. Applicants attend an assessment with an occupational therapist before they are housed to identify whether modifications are required. Any needs are either addressed by modifying the property or by the allocation of a property where modifications already exist. Existing tenants can also request modifications and there are options for transfers to alternative properties if the changes required to the current property are cost prohibitive or inappropriate. Waiting times depend on the extent of the work required. During 2005-06 Housing Tasmania spent $300,000 on modifications[8] but as it can cost up to $50,000 to fully modify a kitchen or bathroom a few major modifications can decimate the budget and modifying older properties is avoided. Smoke detectors are fitted in all properties. Housing Tasmania will also pay for interpreting services for deaf people accessing their services.

Most participants in our research valued the service they had received and as one woman said, '*I am really pleased because they have got onto the modifications straight away.'* However others had difficulties and had to battle to get the modifications they required.

> *This unit wasn't purpose built so when I moved in it was what you call a multi purpose unit. I had a huge battle with the Housing to modify it. I had to battle with them to have the heater on the wall put in. I had to battle with them because I don't use a bath so a bath was no use to me. I had to battle with them to get the bath taken out. (Jack, 47, living with cerebral palsy)*

---

[7] GETSmart Homes are based on the principles of adaptability and sustainability and provide easy access to community services, circulation space, level entrances and wider doorways.

[8] Source: Housing Tasmania, March 2006.

There are long waiting times for public housing and currently there are 902 applicant households for public and Aboriginal housing with at least one household member with a disability[9]. This represents approximately 29% of the total waiting list. On average these applicant households have been waiting a year (51 weeks) from the day they were assessed and categorised onto the waiting list. Given the shortage of resources the focus is on highest needs tenants and those who are at greatest risk of being unable to maintain appropriate accommodation in the private market. Housing Tasmania also recognises that the private rental market has a limited capacity to meet the specialised requirements of a person with a disability. This means that under the applicant assessment procedure, as well as allocating points according to the adequacy, affordability and appropriateness of their current accommodation, points are also allocated to tenants who require a modified environment. The requirement for a modified environment alone may not be grounds for receiving immediate public housing assistance but those who also meet a number of criteria including insecurity of tenure or a poor rent to income ratio are likely to be classified as high needs and attract a higher priority than others.

There are no formal allocation policies for tenants with disabilities. For example, in relation to being located in an area with access to essential services they would have the same rights as any other tenant to turn down a property. Tenants must ask permission to keep animals but it is always given for guide dogs and they will be allocated a property with a yard. Although Housing Tasmania will attempt to match properties to applicants' requirements this is not always possible, for instance if an applicant requires a quiet environment to maximise their quality of life. Indeed the shortage of properties can mean that people with disabilities are placed with the most socially disadvantaged. It also means that waits of two to three years for a transfer are common. Location of properties and delays in transfers can have a profound impact on health and on the additional costs involved in living with a disability.

> *If I had known what it was like I wouldn't have moved into the suburb in the first place. Teenagers just run rampant all hours of the night. In one eighteen month period I had called the police more than thirty times. I sent in to Housing police reports and medical reports. You name it, I sent it in and it still took two and a half years to get out of the place and we have just been so stressed it is not funny. In the last eighteen months I have had to have bowel surgery, brought on by stress and that is just another problem that I have to learn to live with. (Diana, 54, living with ABI)*

> *I got it on an emergency medical background but I believe now there's a five year waiting list and if you're not in category A which is the priority waiting list you have to wait even longer. You have no control over where they send you. I know people with disabilities having to live out at Bridgewater, Gagebrook so the cost of transport for them is astronomical. (Jack, 47, living with cerebral palsy)*

Although disability is factored into the allocation of public housing it is not factored into rental rates for those with high care needs who need to purchase equipment or services.

Overall it is difficult to know how far the needs of public housing tenants with disabilities are being met and no specific work has been done in Tasmania to quantify this. The National Social Housing Survey (AIHW, 2005) found that 46% of households identified a modified environment as being important. Of these 76% indicated that their needs were met in regards to the modification of properties for special needs. How far this is consistent with the situation in Tasmania is unknown.

6.3 Private Rental Accommodation

Like others living on low incomes many people with disabilities find it difficult to afford private rental accommodation particularly in areas where they have reasonable access to the services they require.

> *If you are a blind person looking for rental accommodation you have to consider things like proximity to public transport, reasonable distance from the areas you are likely to want to access so you don't have to use cabs. You wouldn't want to be somewhere where everything you did required a cab. It might be the best house in the world but it would be a waste of money, spending so much time paying for access. In most cities these days the areas you are thinking of are inner suburbs where prices for rent and buying are higher. So a blind person even on a wage and with the help of the DSP finds their income is very very stretched. People pay to be in areas that have those facilities, closeness to shops so you can walk or a short cab ride. (Anna, 56, living with blindness)*

> *Because I need to live close to transport and amenities I was paying 15-20% extra per fortnight to do so. I have looked into purchasing my own home and gleaned that I will be paying between 12-25% extra. During those periods when I was unable to afford the additional cost of living close to services I ended up paying a high opportunity cost in terms of social exclusion and lost opportunities for participation. My transport was 20% higher than it would otherwise have been. Unfortunately there are no subsidies available to people who are blind to offset the additional cost of purchasing or renting an accessible home. (Steve, 31, living with blindness)*

Service providers also reported discrimination against recipients of the DSP by private landlords and real estate agents, even though they have stable incomes. Landlords have expressed concerns that people with disabilities will be unable to pay the rent and/or maintain the property or manage independently and some demanded clauses in the contract that the tenancy is subject to adequate support from Disability Services or other support agencies. It can be difficult to identify direct discrimination because of a disability but certainly some interviewees considered they had been discriminated against in private rental accommodation.

> *I rent my place privately because its central and I wanted to make sure I can get to most places by walking. It didn't need any modifications only something on the steps so I know they are coming. The landlord did this at their own cost. I did rent a flat previously and needed some railings on the steps. But I was evicted at the same time as the request went in. They must be related. (Pam, 47, living with blindness)*

As much of the private rental stock is unsuitable for people with mobility or other impairments and can make impairments worse, disabled tenants require alterations. This incurs costs over and above those facing non-disabled tenants. Although some private landlords are happy to install modifications there is a reluctance by others to allow or provide necessary fixtures and fittings like grab rails and ramps to their properties. Most people get no assistance at all to help with the cost of required modifications in the private rental sector and the services which do exist have long waiting lists and are insufficiently funded.

> *We are renting at the moment. Our landlord has been good and put a heat pump in last year. There should be ramps put in especially at the front door. The bathroom also needs upgrading but I think he really wants to sell this place. If we are considering moving then I wouldn't bother asking him to do any of that. (Laurie, 54, caring for his wife with renal failure)*

6.4 Supported Accommodation

People with disabilities may also be living in small group homes and supported accommodation options in the community. Ninety three percent of group homes are managed by the community sector through a range of different agencies and many residents are people with an intellectual disability. A recent audit of government provided accommodation support in Tasmania (KPMG, 2005) identified a number of gaps in the standards of care being offered in group homes and an urgent need for reform. Five research participants were resident in supported accommodation and group homes and although the research was not able to explore this kind of provision in depth it was able to identify some of the issues for residents.

Residents pay rents set at rates which vary but which are mostly comparable with public housing and pay into a kitty for bills and food. They cover their own costs for medication, transport, day placements and personal effects and tap into personal care and support services if they are required. Personal finances can be managed by the resident, by staff, by the resident's family or the Public Trustee depending on their circumstances and skill levels. Costs for those in supported accommodation are generally rising which can mean cutting back on social and recreational activity. The costs of heating can be particularly high as many group homes have been established in older properties and require large spaces in which to manoeuvre wheelchairs but which are difficult to heat.

> *It is basically a shared residential setting with four people who all have disabilities and it is staffed on a 24 hour basis. It costs around about $280,000 a year they tell me. I believe my slice basically covers personal support and a roof over my head. The bills and heating, we pay for those out of our house kitty. That covers food. What we do is we normally do a weekly planned menu and we choose a night each to cook but often it is a joint decision. We also can have a take away too which is good. We put $280 in a fortnight and sometimes we might have to top it up a bit but generally speaking that covers it except for the heating. We get an incredibly high heating bill because of the way this house is rigged up but we have recently had a heat pump put in. (Mat, 22, living with cerebral palsy)*

> *I came straight from hospital to here. It's beautiful here. It's a bed-sit with ensuite. You have a housekeeper, you get two hot meals a day. You fend for yourself for brekkie and at weekends for brekkie and tea time. They take seventy percent of your pension plus the living from home allowance you get. You can be independent here and you are free to come and go. Mainly I look after myself. I am the youngest. It takes 55 upwards. It would be nice to have someone your own age here but you just accept it. The cost covers everything - the hydro, the bills, rates. You're still responsible for your phone. All the food is covered and anything in the fridge you can go and help yourself. (Daryl, 52, living with MS)*

---

9 Source: Housing Tasmania, March 2006.

The key concerns for research participants were the lack of choice in accommodation options, the mix of residents in group living situations and the inadequacy of information being communicated to families about residents' needs. Those with physical disabilities can find it difficult being accommodated with people with intellectual disability or acquired brain injuries.

> *It is just basically the compatibility of the people that you are sharing with because we don't have a great deal in common. The guys have behavioural and intellectual disabilities respectively, so that can be challenging to deal with on a daily basis. I don't have any of those kind of needs and I manage everything myself except for the physical aspect of my life. We quite often say none of us would choose to live together if we had an option. It is just that you have to take what services are available. (Mat, 22, living with cerebral palsy)*

It is important to include families in the care provided to residents in shared living situations but they can commonly feel excluded. This can be particularly difficult for those who have cared for their son and daughter for years before the move into a group home.

> *There are six people at the group home where Adrian is. We don't have any meetings there unless I ask for one. I feel I must be the only parent who cares what is going on. The Privacy Act drives me mad. Unless I ask I get nothing and I have said I shouldn't need to ask, I should be informed. They don't have baths, they only have showers and it is a pity because he likes a bath. His food problem is a real issue. He is given sticky things which I don't like and he can't eat chocolate at all. His weight is a problem as well. (Alison, 74, caring for her son with intellectual disability)*

What a number of people wanted to see available was more hostel or cluster accommodation with some kind of supervision on site:

> *He needs to be near family. If Housing could develop accommodation with some sort of manager who keeps an eye on people who have disabilities; for example a group or cluster of units where people can live independently but where they have somebody who is like a case worker or manager to give assistance and see that things are going well. It would take a big load off the mind of people who are carers and there are lots of people in the community who would benefit from this. (Tammy, 55, caring for her son with multiple disabilities)*

6.5 Residential Care

People with disabilities consistently report that residential care accommodation is a last resort and they would prefer their own house. However when there are 24-hour care needs or care needs exceed the maximum that personal care providers can offer under current funding there is little alternative to being placed in a nursing home.

Nursing homes are designed for the needs of the frail elderly at the end of the life cycle and they do not fit with the aspirations and life style of younger people. However there are currently 154 people aged under 64 years living in nursing homes in Tasmania, an option which was intended as a last resort, and their numbers are rising. This is an issue across Australia. Overall there are 16 people under 50 years and 138 aged 50-64 years in aged care facilities in the State[10]. Costs are higher than in other forms of accommodation and take up ninety percent of the pension leaving very little disposable income. Income is further eroded because, as nursing homes are Commonwealth funded, residents do not have access to state based disability funds that would otherwise provide for their rehabilitation and equipment needs.

Although in rural areas nursing homes may offer the chance for younger people with disabilities to remain close to their family and friends and maintain social networks they also disadvantage them in not being able to provide an age-appropriate environment and in excluding them from the services they might need.

6.6 Summary

The lack of a range of accommodation options and insufficient assistance with home modifications has a profound impact on the quality of life of people with disabilities and their ability to manage their lives with as much independence as possible. It means that people are forced into making do or having to meet substantial additional costs associated with modifying their home or living in an area which has access to the services they need. It may also mean leaving their local community and their support networks and/or running the risk of homelessness.

There is no shortage of potential models. These can include cluster and care taker developments where support is provided on site or developing innovative relationships between State and Commonwealth which allow younger people to be accommodated in their local community through an appropriate use of nursing home facilities. Individual Support Packages can allow people to choose the accommodation they want.

> *It took a lot of plugging away. I am taking up a spot for someone that desperately needs this type of accommodation and I don't. Therefore if you give me a few more hours then I can live as independently as I want and help somebody else out that really needs this service. I have just got funding approved with my ISP to look for a more suitable house and actually have people come in and support me in my own environment. This will give me a lot more say and direction in my own life. The funding has been available since January this year and we are trying to get the department to agree that while I am not using that funding and it is accumulating I can use it for any house renovations I might need to do. The availability of places is very small compared to the list of people waiting. In accordance with the ISP guidelines you can only bank 50 hours which is just a week's worth but I am challenging them in the sense that I am looking at going into a rental place but I would need some modifications done to it first so I am asking them to look at my request because my hours are outside the normal 34 hours. (Mat, 22, living with cerebral palsy)*

There may also be the potential for public housing providers to financially assist families to build adaptable units and then retain equity in the properties. This approach however is not currently available.

---

[10] Figures quoted by Disability Services. April 2006.

7. ACCESS TO HEALTH

How far are people with disabilities in Tasmania able to gain access to the health care that they need?

Recent research demonstrates that the general health of disabled people is likely to be worse than the general population and their life expectancy lower. People with severe intellectual disability have a life expectancy approximately twenty years lower than the general population, obesity is three times higher and dental disease up to seven times more frequent (Lennox et al, 2004). Among disabled people generally there are the often overlooked problems of hearing, sight, failure to immunise and weight problems. Despite worse health they encounter physical, financial and communication barriers in accessing health services when they need them.

Most people living on the DSP are reliant on the public health system. Although some in our sample had lived with disability since birth and had been able to access and maintain private health insurance this had been a struggle and they were often dependant on support from their families:

> *My sister pays mine quarterly and we pay my husband's monthly through direct debit. I have top hospital but not top ancillary which is optical, dental. I was put into medical benefits at birth when the disability was not known about and then they can't toss you as it wasn't a pre-existing condition. So my parents encouraged me never to drop out because I wouldn't get back in again. That costs us $81.15 a month. It comes out on a set date and you have to make sure the money is there and if it doesn't tie in with your wages it can be tough. (Denise, 52, living with cerebral palsy)*
>
> *Basically I am on private health and I can access pretty much generically. It is good to have that cover but again it is all cost but I wouldn't be without it. As long as I am a student or looking for work I am covered under my parents health care cover until I am 25. But if either of those things stopped that would mean that I would have to pay all of that out of my own pocket. (Mat, 22, living with cerebral palsy)*

Many people with disabilities and most of those living on the DSP have had to abandon private health insurance because they are unable to pay the premium. Indeed the Tasmanian Community Survey (Madden, unpublished) found that 70% of Tasmanians living on the DSP did not have private health insurance.

7.1 Acute Health Services

A number of participants had been very pleased with their experiences of acute hospital services. Although they might have to wait to be seen by a specialist they were satisfied with the outcome. Users of the Spinal Account and attached occupational therapist and spinal nurse for those with traumatic spinal injury were particularly satisfied with their experiences and the speed of response. Those who had formed good relationships with specialists over a period of time appreciated the understanding they had of their condition and their ability to be flexible with the timing of appointments and in responding to their particular needs.

> *The doctors here come and go like the weather so they don't get to know Simon so it's easier for us to go to one who knows what's going on. We have never had a problem medically where it's been a problem getting him seen quickly. Even when we go to the Royal if they know it's Simon, they won't keep him waiting and they put him in over the top of others. They have been very good and we get private rooms. We've been very lucky really. (Sharon and Mike, 60s, caring for their grandson living with multiple disabilities)*

However others reported difficulties. There were long waits to see specialists. For example at the time of this research there was only one neurologist in the state seeing people with MS. This meant a twelve-month waiting list and often long distance travel to access specialist care. Paying for transport was certainly a major issue when people had to travel from rural areas to major population centres to receive medical services. The Patient Transport Access Scheme (see page 93) provides some financial assistance for those accessing specialist treatment but does not adequately cover the costs involved. Some families had decided to relocate because of high travel costs:

> *We have had to relocate to Burnie to be near dialysis and have also had a few trips to Hobart. It has probably been fairly hard with extra costs. We have had accommodation paid for but of course there are meals out to pay for. Then there are fuel costs as well even though we are paid 10 cents a kilometre but it all adds up. (Laurie, 54, caring for his wife with renal failure)*
>
> *We had five trips to Melbourne this year and it's the worst year he's had. They pay for the trips but it still costs us money. They pay for our air fares and accommodation and we pay for the meals and each time you go you're out of pocket. We really felt it this year. It's also the petrol money to go to town for physio. (Sharon and Mike 60s, caring for their grandson living with multiple disabilities)*

Physical access to acute services can cause problems particularly for those with mobility issues or in a wheelchair. And people who may require support in order to access the service at all may have difficulties in finding someone to accompany them:

> *I have to have some x-rays done but I'm not well enough. If someone would come and pick me up and take me to an appointment for the x-rays I would have it done. When you need to go to these appointments I need someone. They are urgent but I just can't think through it. (Sarah, 53, living with ABI)*

Indeed some interviewees spoke about 'being lucky to survive' in the acute sector. It has been pointed out (Goggin & Newell, 2005) how many people with disabilities have care regimes, both for physical care and medication schedules, that are totally disrupted when they are hospitalised and when they are required to fit into an acute illness model based on non-disabled norms. Hospital stays could become traumatic experiences and families found themselves involved in providing basic nursing care because they were the only ones who fully understood the daily needs.

> *Whenever I have to go to hospital I am lucky to survive the experience. With spinal injuries it seems no-one has a clue, not even the doctors. With my injury I cannot feel anything at all from the shoulders down so anything that causes pain or irritation when I can't feel it, my body goes crazy and then my blood pressure can rise until I have a stroke. It can be a real worry. (Tim, 22, living with quadriplegia)*

> *Going to the hospital is a very scary experience. They have no idea that his arms and legs are out of control. They put him onto narrow trolleys and they leave him on a hard surface oblivious to sores on his legs or feet. This can all lead to months spent flat on his back thereafter. We never leave him at the hospital because of this. The problem with spinal injuries is they don't see enough of it. (Trish, 52, caring for her son living with quadriplegia)*

> *Many times at the hospital we would go in and they'd forgotten to give her her medication, she was chucked in a corner. No one wants to take the time to understand her. We've been through the ombudsman. When she had her teeth out she should never have been discharged from hospital and then when she went back in they let her dehydrate. The hospital are discriminating because they don't understand her, she's not able to speak and no one wants to understand the complexity of her needs. (Deb, 74, caring for her daughter with multiple disabilities)*

The nature of the disability could also complicate routine procedures and extend hospital stays. These difficulties were accentuated by the lack of back-up personal care and support in the community.

> *When I had my hand operated on I stayed in hospital for three weeks not because I needed to but because I couldn't get the personal care and I couldn't go to the toilet because I couldn't use my hand. (Mary, 57, living with physical disabilities)*

The failure to diagnose people with an acquired brain injury was a particular concern and they can find themselves inappropriately embroiled in the mental health system.

> *It is very difficult with head injuries. There is a lack of understanding because there is confusion with mental health. Initially when he was electrocuted he was suicidal and displayed issues that would relate to mental health. Nobody checked to see why so they had him having counselling and on anti-depressants and did all the mental health stuff but nobody actually asked what is causing this? I kept telling the staff at the hospital that he had been hit in the head and to check him out because his behaviour was quite off the show but nobody ever did. I ended up contacting Headway and they put me onto a clinical neuro-psychologist in Hobart. I contacted her and got an appointment and after two days of testing they discovered the first head injury and then the second one. (Ellen, 52, caring for her husband living with ABI)*

Lastly interviewees commented on the attitudes of health professionals and how they could have a significant impact on adjusting to living with a disability.

> *Growing up with a rare genetic disorder I was subjected to the continuous clinical*

> *gaze of medial practitioners talking about 'genetically damaged existence' and the suggestion that people should terminate affected pregnancies. I try to avoid medical practitioners since most cannot see past the ideology of medical tragedy central to traditional views of the lives of people with disabilities. They are unable to imagine life as a disabled person could be anything other than awful and tragic. These assumptions are so basic and unchallenged that they refuse to believe they are cultural prejudices rather than objective facts about the impact of impairment. (Steve, 31, living with blindness)*

Planned hospital discharge is key in ensuring people have access to the information and support they need in the community. Its absence was routinely noted by interviewees who had left hospital with little information about what might be available to them. Non-governmental organisations representing the interests of people with particular kinds of disability continually expressed concerns about not being notified about individuals being discharged from hospital. This effectively excluded numbers of people from services which could have provided support.

7.2 Rehabilitation

Rehabilitation aims to assist people to achieve the maximum degree of return to their previous level of functioning by learning new ways to compensate for abilities which are permanently changed or lost. The earlier people have access to rehabilitation services the better the outcomes can be and the lower the support needs. Early effective rehabilitation with intensive support can be the key to reducing costs in the longer term. For those with ABI these costs can include homelessness or contact with the criminal justice system.

The Commonwealth Rehabilitation Service (CRS) provides vocational rehabilitation services to people with a disability in order to gain or maintain employment. It also offers independent living and counselling services and all services are free to people on the DSP. For those not in the labour market there is only one community rehabilitation unit in Tasmania located in the South of the state. It provides a free multidisciplinary service and includes 22 transitional beds where patients can work on rehabilitation goals.

However there are significant differences between the rehabilitation opportunities for people who receive compensation and for those who rely either on private income or on the public healthcare system. Many of the non-compensable were dissatisfied with the quality and quantity of resources for rehabilitation. Whilst some interviewees had good experiences others considered that more intensive support at the right time could have made a big difference to their functional capabilities.

7.3 Primary Health Care and Preventative Health

Interviewees who had been able to develop a relationship with their GP over a period of time were happy with the service they received. They had found their GP caring, willing to spend the time required and do home visits, and understanding about the disability. They also bulk billed. Appointments were easy and quick to get and they smoothed the path to the specialists. People particularly appreciated being treated as a family and as one woman said, '*They are not treating one they are treating two, someone with a disability and a carer.*' And they were prepared to meet additional transport costs in order to stick with a GP they liked.

> *The GPs here are very very good, we are more than happy with them. Our current GP, he said it's taken him three years to get used to Simon, so it's been quite complicated so if you just threw him on somebody.... (Sharon and Mike, 60s, caring for their grandson living with multiple disabilities)*

Others had found it hard to get a good GP, someone who understood about the disability and who was accessible. They described long waiting times to get appointments and difficulties in meeting the costs if the surgery did not bulk bill. This was particularly true in rural areas.

> *It's very hard to get a good GP. I used to go to a GP and he didn't take consideration of me because I had a disability. For example two years ago I had a bad cough. I went to the doctor and he said the cough was nothing to worry about, it was only the after effect of a cold. I knew I didn't have a cold and mum and me knew there was something. We never went back to him again. It's not until you get a bad GP you realise how good the medical service you can get is. (Jim, 30, living with cerebral palsy)*

They also reported difficulties in accessing preventative health programs. One barrier can be the inability of some GPs to meet the needs of a mobility impaired person requiring medical examination in a dignified manner. A recent survey (King, 2004) measured the access that patients have to adjustable height examination beds in doctor's surgeries nationally. The survey found that many areas in Tasmania did not have access to these beds and out of 181 surgeries contacted only 33 had adjustable height examination beds. This means that some patients may have to travel long distances to access one. People with disabilities reported not having a pap smear for ten years because doctors were unable to transfer them onto fixed height beds. They also reported being examined on the floor or having to go into hospital to get routine screening done. A legacy of bad experiences in the past can operate to effectively prevent people accessing the health services they need and as one woman said, '*Some of us have had so many unfortunate experiences I haven't gone back.'*

> *I had a pap smear and breast check last year. I had an interesting experience with a male carer who wasn't trained up. He took me into Calvary and because he was in uniform they assumed he was a nurse and stripped me to the waist in his presence which was fun. I was so embarrassed. (Janine, 60, living with physical disability)*

Obesity can be a real problem for people with disabilities. Medications, lack of mobility and diet restrictions all mean a high risk of gaining weight. Yet there are very few weight loss programs which include people with disabilities.

> *To try and lose weight when you can only change eating habits and not do the exercise is the pits. (Mary, 57, living with physical disabilities)*

The costs involved in gaining treatments to maintain mobility levels or control pain effectively barred people from sustaining a more reasonable quality of life. Their inability to access massage, physiotherapy, podiatry, hydrotherapy or acupuncture could compound the impact of the disability and potentially increase the need for personal support and assistive technology.

> *I need hydrotherapy. It's like this pressure bit which gets worse and worse whereas if I could get that hydrotherapy early enough I could probably get myself much more stabilised and actually do more. I would pay for going but the personal care is the problem. If I had a package I would work it around that. (Mary, 57, living with physical disabilities)*

> *If Medibank believe that having massages and all these things for well people makes them weller why aren't they offered to people with disabilities? If you're not mobile and you can't move around and do things you can't get the optionals for yourself. (Sarah, 53, living with ABI)*

> *If he does anything physical he has trouble walking for about a week and this is due to the back and neck injuries. This was where the acupuncture was working but they have stopped it now and I really cannot afford it and it is a real loss. (Ellen, 52, caring for her husband living with ABI)*

7.4 Dental Health

There are well-publicised difficulties in accessing the public dental health system in Tasmania (Cameron, 2002) and these are accentuated for people living with a disability. Firstly the disability itself or the medication required might have an impact on dental health which increases the likelihood of requiring dental treatment.

> *Jack had ground his teeth down and we had about $1,000 worth of work done to them which he then ground out again, so it is the ongoing dental costs. The medications that he is on have created problems for his teeth as well and lots of discolouring so there have been a lot of dental costs. (Ellen, 52, caring for her husband living with ABI)*

> *I really need to go to the dentist. I had chemotherapy a few years ago to try and stop the progress of the MS. One of the side effects was some of my teeth fell out. (Stephanie, 32, living with MS)*

Secondly there are administrative procedures which can make it very difficult for people with disabilities to access treatment. These include the requirement for emergency dental appointments in the public system to be made by 8.30 am. This can be very difficult for those with strict care regimes.

Thirdly the nature of some disabilities means that individuals may be particularly difficult to treat or require tailored treatment regimes including general anaesthetic. For instance some people had good experiences of being treated in their own wheelchair. Others, despite forewarning health staff about the nature of their disability, had been refused treatment including x-rays because they were unable to leave the chair.

> *It's hard to stay still, not only at the dentist but to get my hair cut. I have sudden jerks and it takes longer for people to cut my hair or look at my teeth. For dentists or hairdressers who don't know me they get a bit phased by that. (Jim, 30, living with cerebral palsy)*

> *At the moment his teeth are a worry because he needs some anaesthetic to do some work but he is at risk with having anaesthetic so it is a worry. He wouldn't be able to sit still, he wouldn't be able to sit through the drilling. (Caroline, 50, caring for son with intellectual disability)*

Fourthly the $25 co-payment fee payable for each public dental treatment was a real barrier for many people.

> *You go round to the dental health clinic and you pay $25 each time. I thought it was supposed to be $25 for the year but it ends up for each treatment. When you say anything it's nothing like the cost of the treatment but if you take $75 out of somebody's monthly income just for dental stuff.... (Mary, 57, living with physical disabilities)*

> *I go to the state dentist. I broke this tooth in half shutting the door with my teeth. I went to the local dentist and he referred me to the state dentist and said that's where people like you should go. When I got there they said it's cosmetic. I said no I'm diabetic, it's a health issue. They said that's a $1,000. I said I'm happy to make a co-payment as long as it's reasonable. I've noticed my teeth are very loose at the moment, but this wouldn't be considered an emergency. I will have to wait until they fall out. (Janine, 60, living with physical disability)*

Because of these barriers many people had not been near a dentist for several years and had chosen not to go at all. Others had decided to go private which put enormous strain on their budget and could mean remortgaging the house or other extreme measures in order to afford treatment. The Tasmanian Community Survey (Madden, unpublished) shows that or 48% of those living on DSP had not been to the dentist in the last five years. This is a much higher non take up rate than other benefit recipients (32%) and certainly than the general population (22%).

7.5 Medication

People with disabilities may be dependant on a range of prescribed and what are described as 'optional' medications to maintain their health. This was true of participants in the research, many of whom were reliant on multiple prescriptions.

The Commonwealth Pharmaceutical Benefits Scheme (PBS) subsidises the cost of commonly used medications. It means that general patients pay $29.50 per prescription up to a safety net threshold of $960.10 in a calendar year. Beyond this amount they then pay $4.70 for each prescription. Holders of concession cards pay $4.70 for each prescription up to a threshold of $253.00 beyond which any scripts are free till the end of the calendar year. Changes announced to the PBS in December 2005 mean that patients with life limiting illness now have access to a broader range of essential medications. These include medications for pain, insomnia and anxiety.

Some people were living with stable conditions and did not require any particular medications. However others required several prescriptions a month which added up to a considerable cost - ranging from $30 to over $100 a month (or three to ten per cent of the total DSP for a single person). In addition some people were paying the pharmacist $4.50 to sort out their tablets and fill a weekly dosset box:

> *It's hard to say how much we would spend on medications - maybe $30 per month on me so at least $50 a month and maybe more at times. If it goes up I don't know what we'll do. (Sharon and Mike, 60s, caring for their grandson with multiple disabilities)*

Although people appreciated the PBS scheme, including the PBS safety net, affording the ‘optional extras’ from the pharmacy could be a real problem. These might include evening primrose oil, painkillers, vitamins, calcium and continence aids like laxatives. As people commented they were not optional but rather essential in remaining mobile or reasonably comfortable and indeed had been ordered by specialists. Nevertheless there was no assistance with the cost:

> *You now pay $4.70 for a script. That’s all right if you only get one script but if you get ten in a month that’s a lot of money. There’s also the paw paw cream or tiger balm. So by the time you get all your medications it’s pretty expensive. I am on so much stuff, I can’t believe it. I have 14 scripts a month and you usually just pay it because you have to. (Mary, 57, living with physical disabilities)*

> *The monthly average is $100 but that’s not just prescriptions, that’s other things as well. I have to take evening primrose oil because I suffer from abscesses. I also take a natural derivative for arthritis. It doesn’t help a lot but it’s just enough to take the edge off along with the other medications. I take sinus vitamins because I’m a chronic sinus sufferer and that helps too. So out of the $100 - I take five or six prescriptions a month that I have to take, that I must take and the rest is the others. Then there’s my husband because he’s a type 2 diabetic. He’s on fluid tablets as well. We are now on the free list, we’ve been on for three months. That helps a lot. The chemist bill is high and it saves about $40 a month when I’m on the free list. (Denise, 52, living with cerebral palsy)*

Additional medications required to cope effectively with continence could be a particular financial burden:

> *I have to order wipes instead of using toilet paper to eliminate infection and that is about $50 a month I have to cover. I have to have things in place in readiness for an infection which I have to have in my house. (Stephanie, 32, living with MS)*

> *For bowel care they live on Senokot granules. You have to buy Movicol, you can’t get that. I buy that by the box. Veteran Affairs can, they get Movicol and Senokot. He lives on them. It has to be hundreds of dollars. I’m always at the chemist for something. So that’s about $40 a month. They think cranberry tablets are good for the bladder, so you have to buy them and if you take one a day they are $35 a bottle with 150 in a bottle. Then cranberry juice is dear and prune juice. (Faith, 61, caring for her husband with quadriplegia)*

Costs can also soar when medications are removed from the PBS scheme and generally costs meant that people delayed filling prescriptions or did not fill them in at all. Indeed well over one third (41%) of those in our sample said that in the past twelve months they had not filled a prescription ordered by the doctor because they were unable to afford it.

> *I went round to the chemist and I couldn’t afford to get it because I’d spent all the money on other bits that were necessary. Perhaps I’m not handling the money very well. (Rose, 62, living with physical disability)*

> *He has to do without specific medication for his reflux because we can’t afford to get that particular medication until Thursday at least. (Janine and Adrian, 50s, living with physical disabilities)*

> *I gave up taking medication for my condition due to prescription coverage*

> *worsening over the past few years. Some of my medication wasn't on the PBS and I couldn't justify the costs. Some persons depend on multiple medications and most are new without generic brands. I began exhausting my coverage usually by June or July and paid out of pocket for the rest of the year. Consequently I was either forced between paying out of pocket, exhausting my prescription coverage or forgoing the best possible medication. I unfortunately have chosen the latter and it's taking its toll. I will now have to go on a new lot of medication because I have been off it for so long. (Steve, 31, living with blindness)*

Federal government supported health care does not cover prescribed medical items apart from false teeth, eye glasses and hearing aids. This means that people without private health insurance, compensation payments or private funds often cannot afford to purchase these items, for example compression stockings, neck or back braces or regular bandage changes beyond those initially provided by the hospital.

> *I had a varicose ulcer which has caused problems. I had to get it dressed every second day and I had to go to the Royal to get compression stockings. I was told they were free but they're not. They cost $48.60. You can get them round here at the discount pharmacy for nearly $30. Maybe they're not the same, but they are the travel socks. So I was told I could pay for them now or we will send a bill. I asked for a bill so I could pay it off because I just do not have it. It's nearly $50. They didn't charge at one stage but now they do. I wasn't expecting this vein to ulcerate. (Rose, 62, living with physical disabilities)*

8. PARTICIPATION AND EXCLUSION

Social interaction is a basic human need yet social isolation can be a major issue for people living with a disability and for their carers. The practicalities of rearranging support routines, communication problems, difficulties with physical access and cost implications, particularly those associated with transport, can all become enormous obstacles to having a satisfying social life and being able to participate in the community.

8.1 Meeting Social Needs

People meet their social needs in a number of ways, through work, through friends and family, through support workers, day services and accessing mainstream leisure and recreational facilities. Family, friends and the local community can be very important in providing regular contact and helping out financially with the costs of participation.

> *I have a big social network and am well known in the town. The local RSL club have taken me on board. I did drink there before my accident as a pub not a club. I have a drink there and I'm very well accepted. They put stainless steel on their toilet doors and a door bell at the door for me because I had to rely on people seeing me through the doors. They've looked after me and raised a lot of money for me when I got hurt. (Rod, 38, living with quadriplegia)*

Some people had successfully extended their social networks by becoming disability activists, associating with people engaged in the disability field and becoming involved in committee meetings and sitting on Boards. Others found that, in the absence of other contacts, the companionship of support workers had become very important to them.

> *I have made friends with my support workers and they have introduced me to their friends. Because they have worked in the disability industry it's a lot easier because they have a better understanding and are more patient. They see me instead of the disability. (Jim, 30, living with cerebral palsy)*

However service providers considered this inappropriate and felt that it led to potential over-servicing where relationships with paid carers had replaced 'normal' social interaction.

Day services can be vital in providing daytime occupation for those unable to participate in the labour market as well as offering some respite for carers. They give a rhythm to daily life and regular social interaction through a range of activities, events and outings.

> *Jack gets 16 hours a week at the day centre.. They do day-to-day living skills so that involves cooking. They paint and he has done some woodwork and made some things. His painting is very good. They also go out for a picnic lunch and Jack pays for that. He has to have $10 a day and its $280 for the term. (Caroline, 50, caring for her son living with intellectual disability)*

> *He goes to his day centre four days a week and that makes a heck of a difference. It's wonderful. They pick him up at 9.30 and bring him back at 4.30.*

> *That gives us a bit of break to do things or do nothing. It used to be $10 a day, the transport and lunch. Now it's gone up to $12. It gets him out. (Cindy, 60, caring for her husband living with physical disability)*

However attending day support involves a fee which can operate as a barrier particularly when the costs of transport are added on. In addition, although there may be day options for people with an intellectual disability and for older people, younger people especially in the 40-55 age range have little choice and few social groups available to them. Some had accessed organisations especially for people with their disability which gave them contact with their peers. But for others it meant not having anywhere to go and remaining in their home.

> *All the day services are inappropriate for his level and I don't mean to be a snob - there are just major gaps where they don't fit into any program. It is a matter of pride because he doesn't have an intellectual disability and so that makes it hard. So therefore it becomes that monotony. (Ellen, 52, caring for her husband living with ABI)*

Of course people with disabilities can also access mainstream recreational and leisure facilities and they do but there are a number of barriers which can make this problematic. Firstly there are the physical obstacles to access including structural and architectural barriers like steps, steep gradients, narrow doorways, lack of circulation space or parking space. A national survey of 1307 people (Access for All, 2006) about the barriers confronted by tourists with disabilities has highlighted problems in making travel arrangements, finding accommodation and visiting tourist venues. The survey found that many people with disabilities are discriminated against because of a lack of accessibility to venues and staff lacking disability awareness training. The Department of Tourism, Heritage and the Arts is currently developing a disability action plan which includes a database of tourism operators who have disabled access. Hobart City Council have also produced an access map of the city although people have commented that it is difficult to get hold of. An ability to access public toilets can be a key factor.

> *One thing you find is difficult is toileting. I think there needs to be a change to the building code. You often find toilet doors which have in-swinging doors into the cubicles and I can quite often be spreadeagled operating the door. Because Hobart is an historical place there are architectural barriers everywhere but even with more modern buildings. You cannot rely on ringing the place that you're going to say what's the access like because to a man they will say it's wonderful and that they've had people in a chair there before. You get there and you find that the doors aren't wide enough for the chair. (Janine, 60, living with physical disability)*

Some people had low expectations about having their access needs met.

> *I don't speak out enough in regards to places having sufficient disabled access, like shops and sporting facilities because I know it costs many thousands to add ramps and the like. I don't feel entitled to be able to demand these things and I have guilt in draining the community for this. (Tim, 22, living with quadriplegia)*

Secondly there are attitudinal difficulties which mean that mainstream recreational facilities consider that it is someone else's problem to get people with disabilities involved. For example only 2% of people with disabilities participate in organised sport compared to 56% of the general population (TASRAD). TASRAD[11], as the peak body promoting access to sport and recreation for people with disabilities, delivers a Disability Education Program to raise awareness of disability issues among coaches, teachers and sport/recreation providers and to better include people with disabilities in mainstream sports clubs and activities and in disability specific sports activities, for example the Special Olympics.

Thirdly some people require assistance to get to social events and recreational activities and difficulties in accessing social support hours to allow them to do this was a very real and very common obstacle to participation.

> *He's withdrawing more and more. He hasn't got people to take him out like he'd like. He only wants to go and see art exhibitions. We asked one organisation and she said they had a gentleman who would like to come once a fortnight. But we got knocked back because we have enough hours through another organisation for care so we couldn't have that. I'd even pay someone but you can't get the people. He does not get out like he should and there's not one carer that can drive the van, they are not confident enough. (Faith, 61, caring for her husband with quadriplegia)*

> *I would like just sometimes to be able to do something really nice with the carers instead of literally doing all the shit jobs - meal preparation, bathing, toileting. Just once or twice a year to be able to go out and not have them work and go for a meal together or a cup of coffee. It doesn't have to be a big expensive thing but just to do something which wasn't about getting through. (Mary, 57, living with physical disabilities)*

> *I would really like a carer to come in for a couple of hours a week to take him out fishing and to get him out of the house. That's the kind of thing we want. He can't walk very far anymore, so to give him some fellowship time doing what he loves to do. Just having someone there that isn't me. I would like to sit down and flop in an arm chair, close my eyes and not worry about anything for two hours and know that the carer is with him and knows what to do if anything goes wrong. That's all we want, is that so much to ask? (Lily, 61, caring for her husband living with physical disabilities)*

A lack of support available with continence needs can also be a very real issue and prevent people from participating as much as they would like.

> *I did used to have more of a social life but having problems with continence meant it was too embarrassing. The bags kept leaking and breaking and I just gave up. It's just too much trouble. (Trevor, 64, living with physical disability)*

Lastly cost was a major factor in excluding people from a satisfactory social life particularly for those solely dependant on DSP. The combination of trying to overcome mobility and transport issues, tackling physical accessibility and the change to support regimes as well as cost severely limited the ability to have any social activity and meant that many became housebound because it was easier to stay at home.

> *I guess people don't understand how limited your life is. I never go out at night. I can only do it on a Monday night because I go to a women's club and they will undo my bra at the back so when I come home I can undress. I never go for*

> *drinks or to the theatre. I used to go out for meals a lot and I never do that. Mostly it's financial reasons. If I was to go to the theatre or this dinner meeting once a month I have to pay for the dinner and on top of that the taxi to and fro. That adds another $10-20 on top of what you're currently spending. I don't have a lot of money to do the fun things. I do a lot of the voluntary work and lots of meetings but I don't have much social life really. My big social event of the week is going to friends on a Sunday afternoon to play scrabble. That doesn't really cost me anything. It helps keep the brain going. But I'm not always as sociable as I'd like to be. I would like to go to the pictures more and the theatre once in a blue moon. (Mary, 57, living with physical disabilities)*

The introduction of a companion card allowing carers and/or those supporting people with disabilities to access many community events and entertainment venues for free was certainly welcomed as a good way to reduce costs.

> *That is going to be wonderful. If I needed someone to go with me but if they don't want to go it was hard to ask them to pay for something they didn't want to see like a big show or concert so they could help me with personal support. Then I would feel I should pay for them which was a huge cost to me. (Mat, 22, living with cerebral palsy)*

Overall not being able to be spontaneous or enjoy the fun things in life was bad for the spirit. As one woman said, '*It's very wearing to have all your being concentrating on just surviving.*'

8.2 The Experience of Social Isolation

Nineteen people in our sample were living by themselves. This was due to many factors but for a significant number of people it was the result of family and relationship breakdown after acquiring an injury. Family and friends could find it very difficult to cope with changed circumstances and this was especially true for those with profound disabilities and those who had experienced the behavioural and personality changes which can often accompany brain injuries.

> *You can't participate. I've lost a few friends that can't handle being with me like I am, one really close friend who was like a brother to me. He helped me build my house and now he doesn't have anything to do with me because he can't handle seeing me like I am. Living alone unfortunately, that kills your head especially when you have two children living just up the road and you ring up and can hear them all talking and laughing and you're sitting here on your own all week. At night it's lonely. From six thirty to nine at night I hate it. You sit in a chair, you can't even get up to answer the door. (Rod, 38, living with quadriplegia)*

> *I have no social life, I have nobody. My family they do not understand. They have no idea. It upsets them to see where I came from to this. There is nothing, an empty, dark hole. (Sarah, 53, living with an ABI)*

---

[11] Tasmanian Sport and Recreation Association for People with a Disability

> *In the beginning the world and his brother comes through the door. But over time, apart from my boys, there is no one in my life who was there ten years ago because they've all moved on. The only social contact is with the support workers and they are itinerant. (Janine, 60, living with physical disability)*

Communication problems also limited opportunities to socialise and meant that people lost confidence in being able to interact with others.

> *It's very hard to socialise. I don't really socialise a lot with people and a lot of people don't really understand me and they think I've got a mental disability. My verbal communication with some people can create a social barrier all the time and a lot of time I don't want to socialise in an environment where people don't understand. I lack self confidence. (Jim, 30, living with cerebral palsy)*
>
> *I haven't been to a picture show or the cinema since I have had the brain injury because the noise and volume upsets me. When I get out of my own environment I'm not comfortable. I can get talked into going somewhere but when I get to wherever it is, I just am not comfortable especially if it is in a small area and there are lots of people then it is even worse because the volume of voices picks up and then I can't have a conversation and I can't concentrate. (Diana, 54, living with ABI)*
>
> *With family I feel left out of conversations at the dinner table and they keep saying to me I will tell you later but they don't because it's a hassle for them to sign. It would be good if they could all sign. I don't participate in any hearing type of organisations, only the deaf club. (Joy, 38, living with deafness)*

Lack of social interaction could produce a profound sense of isolation and result in withdrawal from the world.

All interviewees were asked to rate their level of satisfaction with various aspects of their lives on a scale of 1 to 10 with ten being completely satisfied and one being not satisfied at all. As Table 7 demonstrates people with disabilities had lower levels of satisfaction with most aspects of their life compared to the general population in Tasmania but particularly with feeling part of the community and with their future security.

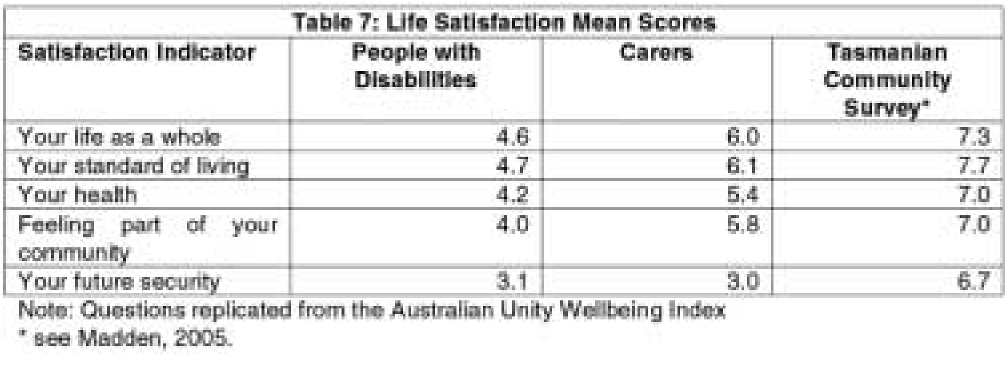

Table 7: Life Satisfaction Mean Scores

Satisfaction Indicator	People with Disabilities	Carers	Tasmanian Community Survey*
Your life as a whole	4.6	6.0	7.3
Your standard of living	4.7	6.1	7.7
Your health	4.2	5.4	7.0
Feeling part of your community	4.0	5.8	7.0
Your future security	3.1	3.0	6.7

Note: Questions replicated from the Australian Unity Wellbeing Index
* see Madden, 2005.

Carers were particularly unhappy about their future security and their current health status.

8.3 Transport

Historically, ensuring people can get to key services like health care, shops or leisure activities and employment is not anyone's responsibility and the social costs of poor transport are given little weight. For people with disabilities who are often prevented from driving this can have profound implications and lack of access to affordable transport becomes a key component of wider social exclusion and prevents them from participating in the community.

Some assistance is provided to people with disabilities through financial subsidies for the cost of transport and through improving the accessibility of services. Financial subsidies 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 is determined by completing an application form and getting a statement from a qualified medical practitioner who may charge a fee.
- **Mobility Allowance,** which pays $35.70 per week towards the cost of transport for those who are in training, employment, voluntary work or seeking employment.
- 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 pension concession card. It is issued for a five year period.
- the **Patient Transport Access Scheme,** which provides assistance with costs to all Tasmanian patients who have to travel intra or interstate to access specialist medical services. Levels of assistance are determined by distance, type of travel and accommodation required. Pension concession card holders are required to contribute $15 to the cost of each return journey. 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** will cover some transport costs in limited circumstances, for example attending designated activities or courses, or funding the purchase of a vehicle if there is more than one person with a disability in the household. There is no assistance with transport to ad hoc recreational activities.

There is also a push to make mainstream transport services more accessible for people with disabilities:

- **Metro** are progressively making their entire fleet fully accessible by 2020 in accordance with the Disability Discrimination Act 1992. Accessible vehicles have a no step entry, extendable ramps for wheelchair access, allocated spaces to accommodate wheelchairs and other mobility aids. As at July 2006 there were 38 fully accessible buses running on routes at scheduled times throughout the day.

- **Wheelchair Accessible Taxis (WATs)** are now available in the main urban centres but not in regional areas. The Human Rights and Equal Opportunity Commission (HREOC 2002) estimated that about half of one per cent of the population are reliant on WATs but these numbers will increase with an ageing population. A review of WATs in Tasmania was carried out in 2005 to gain customer feedback about the service. The findings show that needs are reasonably well catered for and the past 12 months has seen a big improvement in availability but that there are some gaps in rural areas (Myriad Consultancy, 2005).
- The **Red Cross** provide transport to and from medical appointments for people with disabilities and the elderly for a small fee of $5. However routes are limited and the service does not cover all areas. Neither do they have any wheelchair accessible vehicles.
- **Community Transport Services** were established in 1990 with Home and Community Care (HACC) funding to promote social integration and access to community services like shopping or day centres for those living at home. The service aims to provide a flexible, comprehensive and integrated transport service for people with disabilities, the frail aged and their carers who, without transport support, are at risk of premature or inappropriate admission to long term residential care. The service operates state wide with 72 vehicles, 20 of which are wheelchair accessible and 440 volunteers. The minimum fee is $4 for a door-to-door return journey; Smithton to Hobart costs approximately $65. The service is very dependant on driver and vehicle availability and there is no evening or weekend provision. Increasingly, in the absence of other medical transport, the service is being used to access non-emergency medical services rather than community facilities. Those eligible for HACC services are also eligible for Community Transport.
- some **non-government organisations** have also received HACC or charitable funding to purchase vehicles for transporting service users. These services however are ad hoc and not coordinated with community transport. Indeed some organisations find that although they have acquired a vehicle they are unable to afford the running costs.

In addition there is the **Disabled Parking Authority Card**. This is available from the state government to access designated parking spaces. It 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.

Shortcomings in transport infrastructure have not gone unrecognised. The Department of Infrastructure, Environment and Resources (DIER) has undertaken a major review of regular core passenger services in Tasmania to improve their delivery. The Terms of Reference for the review include assessing each service and/or route against the application of the Disability Discrimination Act 1992 standards. In addition the Rural Transport Solutions Project has been initiated to improve the mobility of those in rural areas including people with disabilities.

8.4 Experiences of Accessing Transport

Some people we spoke to were fortunate to be located near to most of the services they required and were able to use public transport when they needed to go further afield. Others were not so lucky and faced a range of obstacles in being able to go where they wanted.

8.4.1. Private Transport

Interviewees described their experiences of trying to become mobile or of trying to sustain their mobility using private transport. Modifications may be required so that they can continue to drive themselves or they may require a modified or new vehicle which is able to accommodate a wheelchair. Both options are expensive but there is very little assistance to cover the costs. Certainly most people who require a wheelchair accessible vehicle have to fund it privately or are forced into resorting to fundraising.

> *The car has had new wheels to allow for the wheelchair and I have added hand controls to allow for braking and accelerating and also added cruise control. I got no financial help and there wasn't even a qualified hand control instructor available in Launceston (although there is now) so I had to go up and do it in Burnie. (Stephanie, 32, living with MS)*

> *We have been trying to buy a wheelchair accessible van. We borrowed some money from the bank thinking we would have enough to buy a reasonable wheelchair van but it turned out the money we had just wasn't sufficient. I approached Lions, and I didn't really want to, to see if they might help us out. They said yes but six months has gone and we haven't heard a word from them. To get something reasonable it would be about $15,000 and that's just to put the wheelchair in and for him to then sit inside. Soon he won't be able to walk at all and that's on the cards which means we have to lift ten and a half, eleven stone in and out of the car. We can find them but they're too old and too much mileage and we need a reliable one. I just don't like asking anyone and now I am really sorry I opened my mouth. Rotary are good and they've donated $1,000 to help us out. (Sharon and Mike, 60s, caring for their grandson living with multiple disabilities)*

Ensuring that there is enough money to run any vehicle and cover maintenance costs becomes a very high priority and the rising cost of petrol had hit many people very hard. Over a third of participants (36%) commented that they had been unable to pay the car registration or insurance on time due to a lack of funds:

> *Without that car we would not have a life. It's required hand control. We manage but not very well. If I know there's a car service coming up. I book it well ahead and if I can't pay it in time I ask for an extension. I've changed my mechanic for someone cheaper. I put it in last year and was told it would be $250 and I allowed for that. It's due for new tyres but I can't buy four at a time. It's our biggest expense. (Denise, 52, living with cerebral palsy)*

> *When the petrol went up we went from $50 a fortnight to $50 a week. It doubled and then we had the tyres because we were coming up three times a week. That was $200 for two new tyres. (Cindy, 60, caring for her husband living with physical disabilities)*

Interviewees also commented on the parking problems they experienced particularly difficulties in parking wheelchair accessible vans where there has to be enough room to allow entry and exit from the van with a wheelchair:

> *We have three disabled parking spaces here. They are not marked on the ground, the sign is just this big and ninety nine percent of the time you have someone else parked in it. It's the lack of signage. I've put in a submission to*

> *move it round the corner where the street is wider, the volume of traffic is less and if you are transferred from a wheelchair into a car its more accessible (Rod, 38, living with quadriplegia)*

8.4.2. Public Transport

There are a range of barriers for people with disabilities in using public transport including accessibility, availability and concerns about safety. These issues are shared by others in the population including parents with prams, people with heavy shopping and those with temporary disabilities. There can also be difficulties in finding out about public transport and interpreting timetables due to the size of the print or the amount and type of information given. In addition to the paucity of public transport generally, especially in more rural areas the minimal availability of accessible buses limited their usefulness.

> *There are accessible buses coming but at the moment you have to ring them up and say which bus stop at what time. It's too hard. (Jim, 30, living with cerebral palsy)*

But it was not just physical accessibility which made people reluctant to use public transport. There were also difficulties in dealing with aspects of their disability, for instance, balance problems or continence. Some people had experienced harassment which made them reluctant to use public transport services. As one blind woman said, '*You are very vulnerable to injury, being a victim and you have to take this into account and be wary.'*

> *I can't catch buses because I lose my balance. When I lose my balance I get disorientated again and I end up in a screaming mess. (Diana, 54, living with ABI)*
>
> *He wouldn't use public transport especially with his bowel trouble. He feels awkward because we don't know what is going to happen. It could be part physical and part psychological. It all gets a bit tricky. (Tess, 75, caring for her son living with intellectual disability)*
>
> *I don't like buses, I use taxis to come to work. I got teased, 'what are you doing fat cow' and because of my disability I tend to fall and because of my eyes. (Sally, 32, living with intellectual disability)*

A number of wheelchair users described difficulties with air travel. Airlines will only carry certain kinds of wheelchairs and they have to be dismantled and reassembled at the other end. As well as the time involved this can contribute towards costs associated with wear and tear.

> *I flew to Melbourne last year for a friend's wedding and the whole experience was terrible. They had a hoist at the airport but no-one knew how to use it so that was useless. The size of the wheelchair can be a problem because these days certain size wheelchairs are not accepted on the planes. On the way back home I had as much difficulty getting on the plane with different issues. (Tim, 22, living with quadriplegia)*
>
> *I have to make sure the airline will in fact take the chair and won't damage it. When I get there it takes them anything from three quarters to an hour to put it together. So I'm another hour behind everybody else. Jetstar will take the booking but they are not happy about it and I've had staff telling me I should have*

> *a carer with me. They are really good with me here as they are used to me and they know I like to supervise it being pulled apart and put back together again. (Mary, 57, living with physical disabilities)*

8.4.3. Using Taxis

For those who cannot use public transport or a private vehicle taxis become an essential part of the picture especially in rural and regional areas. Not all wheelchair users require a WAT and some can transfer to a seat in a standard taxi. For others a WAT is essential and those people in urban centres like Hobart, Launceston and Burnie had reasonable access to them. Many reported receiving an effective service which was highly valued and this was particularly the case where they had been able to form a relationship with a particular taxi company or driver who understood their needs. They also appreciated the subsidy available through the transport access scheme and the recent introduction of 24-hour wheelchair accessible taxis.

> *I can't use a bus so I use taxis all the time. It's a lot easier because they've got to know me and when I ring up they say is that you Jim and I don't have to go through all my details. With other people who don't know me they can't understand what I'm saying and they say can you spell your name and it's very difficult on the phone. In a week I probably spend $40-50 maybe more. I really have to think about where I am going because of the cost. (Jim, 30, living with cerebral palsy)*

> *Fortunately I get the transport access scheme. That helps and means I only have to pay 40% of the fare. I also get a $70 allowance a fortnight off the state government to help with the cost of taxi fares. But you are only eligible for that $70 if you work or volunteer 32 hours a month. So for those who are not active in the community and who don't volunteer, they won't be able to get the payment so the cost of their transport is just astronomical. (Jack, 47, living with cerebral palsy)*

But often those reliant on taxis were critical of the expense, the availability including late or non arrival and the safety and comfort of travel. Some interviewees expressed caution about the drivers' knowledge of safety procedures when securing wheelchairs into vehicles. A blind woman described taxi drivers who had tried to charge for transporting her guide dog saying that it might be sick in the taxi. She had also had experiences where drivers had taken her 'the long way round'.

> *The taxi fares are exorbitant. You have to order taxis well in advance, about three weeks. And some days you can't get them at all. Fridays are particularly difficult. It has improved since they've allowed more players. Some of the cabs have rear entry and I find that very claustrophobic, most uncomfortable. (Janine, 60, living with physical disability)*

> *I have used wheelchair taxis but they are only accessible if you don't have a large wheelchair because you won't get it in the taxi. I would have to dismantle parts off it so I could get in and so that would be more hassle than it is worth. (Ron, 44, living with quadriplegia)*

The cost of having to use taxis for regular activities, voluntary work or employment meant careful budgeting. People on the DSP could not afford $30 for a round trip and for some people it was easier just to stay at home.

> *If I am going to go over and do my work at the charity it is going to cost $20 a week so there is my Mobility Allowance spent. Everything has to be budgeted and a taxi fare comes out of the food money. (Diana, 54, living with ABI)*
>
> *If you have been assessed by doctors or Centrelink as able to get a job or get involved in the community through volunteering, you are eligible for the mobility allowance. If you had to pay an average of $20 a day just to get from your home to your place of employment or where you volunteer then there's $100 a week. (Jack, 47, living with cerebral palsy)*
>
> *I go by taxi sometimes when I can afford to but basically I will go down the street with my carer twice a week for two hours and that is my life each fortnight. I am either here in this unit or in the garden and that is my life. I would like to have more money in order to be able to go to Burnie occasionally. (Kevin, 50, living with vision impairment)*

As one person said, '*It's quite soul destroying at times so often it's easier not to bother doing anything.*'

8.5 Summary

Most people we spoke to felt that the lack of affordable transport imposed severe restrictions on their lives. It impacted on their ability to participate in the broader community, removed any spontaneity from their lives and served to exacerbate and reinforce the social isolation that many were already experiencing.

> *You don't go out. You try not to get involved. People invite you somewhere and say bring a plate or bring a bottle of wine which is usually about $20. Or they say we're going to tea come and have tea with us. They will buy the wine and stuff and then say your share is $30. You can't go anywhere, how can you go anywhere? How can you go to a concert, how can you afford it? People come to your house and expect things. I don't buy milk now unless I know someone is coming because I've cut back on the milk. You can't say to someone bring your own toilet paper and milk when you come. I'm not part of the community, I can't function. (Sarah, 53, living with ABI)*

Overcoming the physical, financial, attitudinal and psychological barriers to participation meant engaging in a constant battle which drained people's energy. Some found it easier just to give up:

> *I became more and more distressed and intimidated by life experiences as a person with disabilities. Over time as you have doors and opportunities constantly slammed in your face and denied, coupled with increased feelings of worthlessness and lowered value you simply give up, become compliant and accept your fate. Once this process has taken place it is very difficult to bring about renewed empowerment. This is poverty in all its manifestations. (Steve, 31, living with blindness)*

9. THE COSTS OF CARING

The growth in home based care relies heavily on the availability of carers to provide it and most of those who require help with self care, mobility or communication receive it from family and friends. Primary carers are those who provide the most ongoing assistance with core activities and there are 22,000 primary carers in Tasmania (ABS, 2004). Together with South Australia, Tasmania has the highest percentage of the population living in households providing care due to the greater percentage of the population aged over 65 years (AMP.NATSEM, 2006). Nationally thirteen per cent of the population are providing informal care and women are three times more likely than men to be in this role. The majority are aged 35 to 54 and caring for a partner, son or daughter (AIHW, 2005).

We spoke to twenty carers across the State. This included four people who, as well as caring, were also receiving the DSP in their own right. It also included two people who were caring for more than one person. Twelve people were providing care in their own home while others were providing care in the home of the person with disabilities.

9.1 Becoming a Carer

Acquiring caring responsibilities can be a life changing experience. Plans that carers might once have had about their futures have to be revised and they can find themselves managing complex care regimes in tighter and deteriorating financial circumstances.

> *When you first start you haven't a clue what you're doing. He tripped on the stairs and ended up at the bottom. My sister in law and I flew to Melbourne. You just don't know where you are, what you're expecting or what you're going to see. And when you see the head brace and neck brace and the tongs into the head, all the drips you think where am I, is this the real world? It's really traumatic. It hits you so quickly, it's mind boggling, you can't imagine how you're going to do it and now I think how did I do it? It was an incredible learning curve. You had to learn bowel care, physio, you have to learn everything yourself. I left him a couple of times to come home and felt terrible but you just have to have a break. People say a thing like that brings families closer together, forget it. That's the biggest lie. It's not true. (Faith, 61, caring for her husband living with quadriplegia)*

> *It has changed my life completely because he doesn't work, he doesn't remember things, he doesn't cope with crowds, he has panic and anxiety attacks. He also doesn't cope with noises because they create pain in his head. He goes through cycles with things which is a common thing with a head injury. I think the biggest thing for him is not being employed and the finances change. He felt that he had lost his sense of who he was. For a while it actually created a gap with my children due to his behaviour which they didn't understand. (Ellen, 52, caring for her husband living with ABI)*

> *I had to go and get counselling because I found it very hard to go onto a carers' pension and accept the reality of what the rheumatologist had said to us and what the results were. That \was a really big thing because it's a whole change of lifestyle. What upset both of us is what we thought we were going to be doing just went by the wayside. (Lily, 61, caring for her husband with physical disability)*

Some had found it hard to accept the realities and the limitations it imposed. As one mother said, '*It's a big emotional burden especially when it's your child. It is very intensely emotional.'* Many suffered from feelings of guilt and depression. They commented on the difficulties of maintaining any kind of social life or time for their own interests. The organisational practicalities could also be daunting and they described the shock of the adjustment and the reserves of energy and patience required to keep going.

> *You have your good days and bad days. You have to live with it and there's nothing you can do about it. You just have to make the best of it, you can't change them back to what they were. You just have to live with it. It takes time and patience, a lot of patience. (Cindy, 54, caring for husband living with physical disabilities)*
>
> *Sometimes I could scream because I would just like to get away every now and then but what would happen - it is a vicious circle. It has changed me and impacted on me so that I have no life at the moment. (Doreen, 74, caring for her grandson with cognitive difficulties)*
>
> *Once when I did go away I left family and friends and carers with a list of what's in the fridge to eat, what you don't do, where the medication is. It nearly drove me absolutely mad. So unless he goes to respite I'll never go away because I cannot leave all the information and the meals. It was exhausting organising that. So I'll stay at home. (Faith, 61, caring for her husband living with quadriplegia)*

Not all carers were negative about their experiences and for some people the process of caring had reinforced family relationships. They however were in a minority.

> *I think it has made me. I would say that probably if we hadn't have had Luke, our marriage might not have been together. I think that we just grew up and we seemed to accept it together and we never blamed each other. I think it had a detrimental effect on our children especially our daughter. The other two children I have found are non-judgmental and very accepting of others which is great. (Caroline, 50, caring for son living with intellectual disability)*

9.2 Support for Carers

There are two main forms of support for primary carers –financial support from Centrelink and respite services to provide a break from the caring role. The Carers Association is also an important source of information and support for carers in Tasmania and many participants in this research had highly valued their assistance. However generally interviewees described financial, physical and psychological costs resulting from a lack of support.

9.2.1 Financial Support

The income support system provides:

- **Carer Payment** for those whose caring responsibilities prevent them from substantial workforce participation. The recipient must be providing constant care permanently or for an extended period to a person with a severe disability. It cannot be received as well as another income support payment and the person being cared for must be receiving a pension or satisfy income and asset tests. The recipient is not required to live with the person being cared for but must be providing constant care in a private home. Currently it is $499.70 for a single person per fortnight.

- **Carer Allowance** to those who provide daily care in a private home to a person with a disability. Care must be provided in the home of the carer or care recipient. The allowance is free of income and assets tests and can be paid in addition to the Carer Payment or other payments. It is $94.70 for a fortnight.

There are over 13,000 people on carer payment/allowance in Tasmania with the majority being female and aged over 40 years. These figures underestimate the caring population because not all carers claim government benefits.

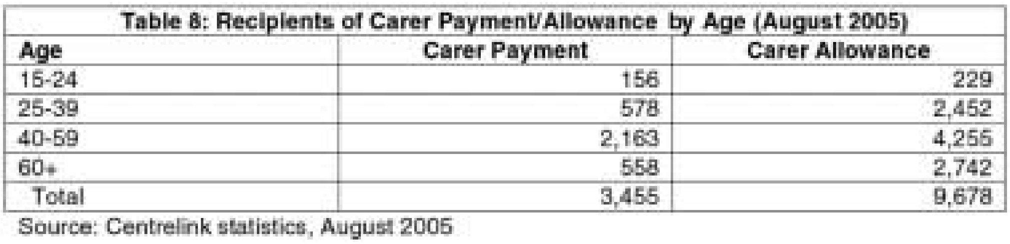

Table 8: Recipients of Carer Payment/Allowance by Age (August 2005)

Age	Carer Payment	Carer Allowance
15-24	156	229
25-39	578	2,452
40-59	2,163	4,255
60+	558	2,742
Total	3,455	9,678

Source: Centrelink statistics, August 2005

There has been a steep rise in the numbers receiving Carer Allowance and Carer Payment. This is explained by population ageing, greater awareness of the payments, and more people with disabilities being cared for at home.

From July 2006 those who apply for carers allowance will no longer be able to claim for a year's worth of payments but will only be able to backdate claims for 12 weeks. This will have a severe impact on carers. They often do not know that the payment exists for some time after the start of their caring responsibilities (National Welfare Rights Network, 2006). Lack of awareness is even greater for those who do not receive a Centrelink benefit already. It can also take a considerable time to obtain a diagnosis or ascertain the nature of any condition. If they are aware of the benefits they may be reluctant to claim because it means taking on the identity of a carer and accepting the caring role in the longer term. This was certainly true of those in our sample, some of whom had not claimed or delayed claims for these reasons:

> *When I rang up to say I was prepared to go onto the carers' payment, John (Centrelink officer) said are you alright? I said I've just come to terms with the fact that our whole lives are changing. He said do you need counselling and I said no but it's still a hard step to take. (Lily, 61, caring for her husband with physical disabilities)*
>
> *I don't get a Carer's pension for him or anything because we don't know if he is going to be able to improve and be able to work at some stage. I haven't applied because we are hoping he is going to come out of this and one day be able to work. (Doreen, 75, caring for her grandson living with cognitive difficulties)*
>
> *I am entitled to the carer's payment but I have had so much to deal with in regards to my son that I keep putting that off so I am losing by not following through on that. I am really pushed just dealing with the day to day stuff. (Madeline, 53, caring for her son with ABI)*
>
> *I had problems getting the carers allowance. The reason I knew it existed was from my first case manager. I had been caring for about 15 months and only just*

> *been back paid nine months. It was slow getting into action after I filled the forms out. They should have paid me the whole amount for 15 months instead of just nine. (Jane, 38, living with cerebral palsy and caring for her partner, Kit, 62 living with epilepsy)*

Recipients were critical of the lack of financial recognition for those who were caring for more than one person and what the future held in terms of their financial security especially as they had often missed out on superannuation schemes. One woman who had been caring for her daughter with an intellectual disability for 23 years found that when her daughter moved into a group home she lost her daughter's DSP and mobility allowance, the carers allowance and the carers' payment. She was now receiving Newstart Allowance and earning an additional $60 per week in part time work. Overnight her household income had fallen from $1,285 to $530 - a drop of 59%. She now found it difficult to afford the additional costs when her daughter came to stay at the weekends or when she wanted to take her out. She went to bed early to save on heat and had sold things to make ends meet. Her daughter found this hard to understand. Another was concerned about her insecure financial future after years of caring.

> *I get the carers allowance which pays the house insurance and the car. Then I get the carers payment. I got nothing for caring for mum. If you are caring for one or more people you only get the one payment. That is injustice. In England a carer is on a full payment like a nurse and they are on that for life. They are not means tested, asset tested or anything else. That's how much they value them. They don't get taxed on the pension at all but we do. We are asset and means tested here. If Gary dies they will put me on a widow's pension for six months and then I've got to go back onto Newstart. You've got to be kidding me for all the years I've worked and saved the government millions. (Cindy, 54, caring for her husband with physical disability)*

Service providers commented that the impact on household finances could operate as a barrier for people with disabilities being able to access their own independent life and accommodation.

Given that the majority of primary carers are middle aged or older, ageing is a major issue for sustaining levels of informal care in the community and carers expressed concerns both about meeting future care needs and about ensuring their own and their adult children's financial security. How to ensure adult children with disabilities benefit from a parent's estate is a big issue.

> *My parents are my only family and my mother is almost 70 and it's a worry. I live in supported housing with Housing Tasmania but if she leaves me her house they will say I don't need the housing anymore. Also there's the cost of maintaining a house, the garden and rates. I don't pay rates now and the price is sky high. So what happens when they pass on? How can I deal with the finances? We are getting advice now but it's quite complicated. My mum thought she could pass the unit onto me but she found that once the person passes on it's stipulated that the unit is sold. I could move into that new unit but what would happen to all my services? That's a big worry for many people with disabilities when they can no longer rely on their parents. (Jim, 30, living with cerebral palsy)*

The Federal Government has announced that from September 2006 private trust funds will not be subject to social security income testing or the usual gifting rules if they are set up for people with severe disability by a parent or a family member. This means that the income from a trust will not affect eligibility for the DSP. The trust will be limited to $500,000 and will also be able to gift up to $500,000 to a son or daughter with a severe disability without the usual rules applying.

9.2.2. Respite Services

Although respite is seen as vital when family are the primary carers there are few respite options in Tasmania. Respite can range from providing carers with a few hours off to the provision of a residential service for days or weeks. Services include:

- **Commonwealth Care Respite Centres,** which aim to provide a single point of contact for carers to obtain information and services. There is an office in each region in the State and smaller outreach offices. They identify needs and assist carers to access services so that they can maintain their caring role. They take referrals for short term, one-off and emergency respite and link people into mainstream services for ongoing support. Fees are payable at HACC rates. They also have brokerage money that enables them to purchase respite for clients when necessary.
- **Disability Services** run centre based respite across the State providing regular respite for families and to cover emergencies. The centres are unable to meet demand and when family care breaks down regularly become crisis accommodation which then excludes respite clients. They were originally designed for people with intellectual disability which means that others can find them inappropriate for their needs. Disability Services can also provide on-off funding for home respite.
- **Nursing homes** provide the bulk of respite services for those with severe or profound disability. This is not necessarily appropriate for younger people with disabilities particularly those who need to be able to continue with their normal activities during respite.
- **Day options/centres.** These provide day time occupation for people with disabilities with fees payable at HACC rates and give carers a break. Again many have been designed around the needs of older people or those with intellectual disability which means that others find them inappropriate.

Under the Commonwealth State/Territory Disability Agreement there is now a bilateral funding offer to all jurisdictions for additional respite for older carers. This means that those aged 70 or more caring for a son or daughter will be eligible for up to four weeks respite a year. Carers aged 65-69 who need to spend time in hospital are eligible for up to two weeks respite a year.

Although older people did not necessarily object to going into aged care facilities for respite, younger people did. Carers in our sample commented on the shortage of appropriate respite options, the guilt they had to overcome to use them and the planning required to book in which removed any spontaneity:

> *He never went for 11 years. They used to say Faith you've got to start somewhere. The first time he went, talk about a guilt trip, you feel so guilty. I came home, rang them up again bawling my eyes out. I was a mess for days. The second time I was a bit better and by the third time he's smiling. So you get used to it. I use it twice a year. There should be somewhere for younger people before they turn 65. He had to go to the old homes and there was no-one to talk to. He doesn't like it and he goes for my sake. He likes the staff but there's no one to talk to. It's a huge effort to get him there because of what you've got to*

> *take. But him going there, mentally, it's a holiday for me. (Faith, 61, caring for her husband living with quadriplegia)*
>
> *I got him assessed because I do need respite. He said, 'they can come and give me an evaluation but I'm not going into a nursing home'. There are no respite centres for people between the ages of 18 and 65, nothing whatsoever and that's nationwide and it's criminal. The most important thing is we, the carers, love our carees but we do need respite. (Lily, 61, caring for her husband living with physical disabilities)*
>
> *We enquired about putting Luke into full time care but the cost was astronomical. It was going to cost us about $1,300-$1,400 for a couple of weeks. So I contacted disability services to see if they could get me some sort of respite and that was so hard to get. In the end my brother in law took holidays and took Luke for me. The respite care was very limited and they told me I should have started organising respite care up to eighteen months beforehand. (Caroline, 50, caring for her son living with intellectual disabilities)*

The fact that no services are guaranteed places additional strain on carers and also creates a reluctance to complain about services.

> *I get worried because nursing homes can refuse a high care patient if they don't want it. They can say no and I tell him please don't do anything wrong. He's not demanding but he's high care and needs lots of care. He will go without things he'd ask for at home but it does frighten me that they could say no. That's a horrible feeling. (Faith, 61, caring for her husband with quadriplegia)*

9.3 The Impact of Caring

The costs of caring are both personal and financial. Although most carers are of working age they have lower rates of employment and lower than average incomes due to their caring role. The Carers Association explored the costs of caring and carers incomes (Carers Association, 1997 & 1998). They found that carers faced restricted employment opportunities due to caring responsibilities, substantial extra costs due to disability and caring and low levels of financial assistance and in some cases no financial assistance. This meant that they were at risk of severe hardship and poverty. Carers in our sample had certainly had difficulties in maintaining employment alongside their caring role.

> *I had a job in a nursing home and I thoroughly enjoyed it. I did it for a few years but it was evening time and too difficult with the night girls. If he had one of his turns I can't leave them alone with that. You never know and every day can be different. So I don't like to leave him. I liked the job but it was too much for me. (Faith, 61, caring for her husband living with quadriplegia)*
>
> *Once Sue started on dialysis, no matter what time of the day it was, it clashed with my work so much I decided to pull the pin. Then when I was driving the taxi it worked out well because I could tie it in with Sue going to dialysis and because I wasn't away for any length of time. But it stopped and I haven't really done anything since then. (Laurie, 54, caring for his wife living with renal failure)*

As well as losing income from paid work, carers were also covering many of the additional costs generated by the disability. This might include paying for insurance, providing meals or buying clothes and shoes. It could also include covering the basics like rent and power bills and one mother had remortgaged her house in order to pay for the dental treatment her son required. Carers allowances and payments were often used to cover disability related costs like aids and equipment, medication or personal support costs and carers were also dipping into their savings. This is consistent with a survey (Carers Association, 1998) which found the costs reported by carers represented 26% of all weekly household expenditure.

> *It does impact on us because we are finding it hard to manage because his dad cannot work full time and I can't do full time work. Sean is managing quite well but for us it has changed things a lot. We don't mind working less so we can be here for Sean but it certainly has impacted on us. I am on a pension and I would not have expected to be on one yet. (Trish, 52, caring for her son living with quadriplegia)*

Disability impacts on relationships and families find they commonly experience psychological, medical, social and emotional difficulties associated with their caring role. For example the divorce rate among people with MS is astronomical due to both cognitive and physical changes and depression and there is a high risk of carer breakdown. It is usually considered inappropriate for spouses to undertake personal care and certainly not bowel care. However many do by default and this can have a negative impact on relationships:

> *I help my wife out as much as I can because she is working long hours so therefore I try and do as much as I can with the help of my carers. I don't like my wife to do my care, I never have and I never will. There is a lot of strain on our marriage with me being in the position I am in. The more I can take away and that I can do, it keeps our relationship better. (Ron, 44, living with quadriplegia)*

The Australian Unity Wellbeing Index (Cummins, 2005) has looked at the effects of care giving in the family home on the well being of the primary care giver and others. It showed that living in a household with someone who requires care reduces personal well being especially if there is no partner. Those caring for people with severe disability are at extreme risk of being highly stressed, clinically depressed and with a subjective quality of life way below the norm. A survey (Carers Association, 2000) found that as a result of caring well over half suffer a decline in their physical health and one third are physically injured. Sixty percent experience major negative effects on their life opportunities and paid work and seventy percent reported low energy levels. Over half believe they have worse emotional and mental health.

> *You do hundreds of hours for nothing and others come along and get paid for it. I might as well divorce him and be a live in carer and get the money. (Faith, 61, caring for her husband with quadriplegia)*

9.4 Summary

ABS data on informal care has been used to estimate the dollar value of the work of informal carers (Access Economics, 2005). It showed that the replacement value (i.e. if carers' services were replaced by formal services) would be $30.5 billion. Despite the value of informal care it has been demonstrated (ABS, 2004) that 37.2% of all primary carers felt that they needed more support in their caring role. This was certainly reflected in our research. And they felt not only unsupported but also exploited.

There is a lot of publicity about how much money the carers save the Government and we are keeping people who need care out of institutions. Also we are keeping people out of hospital and keeping them healthy and keeping them going well, then it is saving on all the other services that would be required if things were allowed to get to a crisis point before there is any intervention. (Deb, 74, caring for daughter living with multiple disabilities)

We are saving the Government quite a lot of money by keeping our loved ones at home. There is not enough support and there is a lot of bickering that goes on and too much red tape. The carer's allowance is only $90 a fortnight. If you divide that by 24 hours a day and 7 days a week we are only getting around 15 cents an hour to look after our loved ones. It is absolutely ridiculous. More acknowledgement and financial compensation is required. The money we receive for all the different needs including respite is just not fair, it really isn't. (Pamela, 61, caring for daughter living with cognitive difficulties and husband living with Parkinsons)

10. MANAGING THE BUDGET

Finance rules the lives of people living on a Disability Support Pension. It can dictate daily activities, impact on access to services and entrench poverty through social isolation and extra expense. There is very little disposable income to vary day-to-day events or improve the quality of life and this means living a very constrained existence. As one person said, '*You have to be rich to afford to be disabled.'*

The implications of living on government benefits have been well documented in the research literature and it is well know that people with disabilities face additional costs. However there is little clear evidence about the true extent of these costs. This lack of information means that levels of financial benefits and local services are determined using limited evidence and the extent to which they offset additional costs is unknown. This section examines the range of additional costs people with disabilities face, how they manage their household income and to what extent they are living in hardship.

10.1 Additional Costs

This report has already described a myriad of additional costs associated with living with a disability. These are not only financial but also physical, emotional and psychological. They include the costs associated with acquiring and maintaining essential aids, equipment and personal care, costs associated with accessing services and a social life and in finding appropriate accommodation, day time occupation, employment and health. Living in a rural or remote location also imposes additional costs especially for transport and getting access to the full range of services. These are the more visible and recognised costs and services have been provided to offer some assistance in meeting them. However on top of these there are the more invisible costs faced by people with disabilities which are not subsidised through service provision and which they have to meet from their DSP.

The nature of any disability can generate substantial individual costs and generally those with the greatest needs have the highest costs. It may mean having to pay for clothes or shoes to be specially made to fit a particular body shape. It could mean particular dietary requirements or investing in aids not covered by the Community Equipment Scheme or other subsidy schemes. Individuals might need to cover the additional costs associated with using a washing machine more frequently or providing tea or coffee for support workers coming into their home.

> *Because of how I sit, a lot of the normal cut jeans don't fit me and also my size is difficult. So a lot of the time I have to buy material and get trousers made and I have to meet these costs from my pension. (Mat, 22, living with cerebral palsy)*
>
> *I need to wear clothing that stretches and I am lucky because my mum can sew but it means you have to access the right fabric and design a pattern to actually suit you, especially when I am at work. Shoes are also an issue because I have circulation issues and my feet have a lot of spasticity. In winter they get frostbite and there are only certain types of shoes I can wear. (Stephanie, 32, living with MS)*

As chapter six demonstrated affording communication equipment can be especially difficult. Computers are a lifeline for many people. They allow them to keep in touch with the world, go shopping, control their finances and do their banking. But there is very little assistance available either to purchase them, get onto the net or to update software unless people are in work or studying. As one person said, '*If you need extra software to accommodate your disability there are some schemes but who knows about them?'*

There are also the additional costs generated by coping with particular behaviours or by having to pay someone to do the tasks most people would be able to do for themselves, for instance, having to invest in a tumble dryer because of being unable to hang washing on the line or an electric can opener in order to eat tinned food. Inappropriate behaviour, like that which can be associated with an ABI, can generate wastage costs through not being able to shop cost effectively or burning everything that is cooked.

> *I don't cook for myself, I can't use the stove. I've set fire to myself twice. I have to buy everything prepared or eat cold food unless I can microwave it. If I don't get foods made up I don't have anything because with my head injury I don't know how to prepare and with the chronic pain in my face I can't chew so everything has to be in little pieces. If I buy the chopped up foods where you would pay $5 for a packet of spuds that is $7 for my meal, just for the potato salad. These are the expensive things that happen. I've locked myself out of my car in town and had to get mobile people to come and pay that out of my disability pension. I got up one morning and went outside in my dressing gown with the phone in my pocket and shut myself out. I had to ring round to get someone to come while I sat out the front of the house in the middle of winter. I've spent hundreds and hundreds of dollars on spectacles. I either lose them, sit on them, can't find them. (Sarah, 53, living with ABI)*
>
> *Because of my disability if the dog goes wandering or gets out of the door I can't catch up with her so I had to have those gates put on and that cost about $500. My neighbour next door (who also has a disability) he's got a dog and the contractor who mows the lawn has refused to do it because of the mess they have to clean up from the dog. But it costs him $40 to pay for someone to come and mow his lawn. (Jack, 47, living with cerebral palsy)*

Many people were facing higher regular bills for power because of the way in which immobility increased the need for both heating and air conditioning. They reported bills of up to $500 for the winter quarter and a reliance on family help to meet the cost.

> *My parents had to help me meet the cost of this winter's bill. It was about $550 and there's no way I could afford it or pay it back on my own. $550 for three months is an awful lot of money. In the summer months sitting down I get hot so I have to make sure this air conditioner is on all the time. So that is going fifteen hours out of twenty-four each day. (Jack, 47, living with cerebral palsy)*
>
> *Because of my MS I need to keep warm so I had to buy a heat pump. I have to keep it high during the winter. I also can't get too hot because I can't cool down so I have to put it on reverse cycle for cool air. So there are additional costs for me to keep the temperature right. (Stephanie, 32, living with MS)*

A telephone can be an essential tool for survival but difficult to afford.

> *A telephone, that really is your safety net so I have to have one. My last telephone bill was $256. It's your network for those friends you do have. (Janine, 60, living with physical disability)*

> *I've got an ordinary mobile phone and most of the facilities I can't use because they are all menu driven. If I want a phone that downloads a program which can talk to me like my computer I would have to buy quite an expensive mobile phone, plus the program which would cost $400-500. One of the new generation mobile phones could be $700-800 or more just to do the ordinary things on a mobile phone that everyone else does. (Anna, 56, living with blindness)*

And for a number of people their biggest expense was maintaining and running a car, again vital for allowing them to retain reasonable mobility.

10.2 Managing Finances

Given the additional pressures on the DSP how were people managing? There was a big difference between those with some additional income and those who were entirely dependant on the pension. Sources of extra income were superannuation, savings and part-time employment. Those with some extra money were in a much better position than those without. It gave them some discretionary income and cushioned them against additional costs.

> *If I didn't have this second income, there is no doubt in my mind that I would have to rely on the emergency relief providers because I have to eat three times a day. You can't escape that when you are a diabetic. (Gary, 47, living with intellectual disability)*

For most people it was only careful budgeting which allowed them to make ends meet.

> *We manage. It's not easy but I'm very good with budgets and money and I've been taught to be. Our biggest expense is the car. I ask for a pay advance two weeks before and then I pay that. What I normally do is put the money away in the account and leave it there. We manage and some fortnights are tighter than others. With bills I may not be able to pay in full but I've always paid something on time. The power bill, that's due next week, I've paid half of it now and the other half two days after it's due. We are not desperate only because I'm careful. I hate this time of year because I know all the big bills are coming. (Denise, 52, and her husband both living with cerebral palsy)*

> *When I got sick I got rid of the cheque account, credit cards, everything went. What I do is, as soon as things turn up, I pay which makes me short in the pocket. There are penalties involved and I can't even afford a $5 penalty on my phone. So I over-exaggerate some bills and pay them twice somewhere along the line especially with the phone and the rates because they have penalties if I don't pay them. (Sarah, 53, living with ABI)*

Not having access to the credit and loan facilities which are available to the population generally could be a considerable disadvantage in meeting additional costs and managing on a small budget.

> *Somewhere there should be a way where people with disabilities can actually get loans easily. Because they are only on a DSP some financial institutions won't allow them to take out a loan and they won't even allow them to have a credit card. One of the things they ask you when you get a credit card is how much money are you earning a year and some won't allow those earning under $15,000. That excludes everyone with a DSP unless you're earning a little bit of extra. If they could get a small personal loan they could upgrade their wheelchair or in a blind person's case their reading machines and software knowing they could budget and pay it back. It means people can't have what they need. (Anna, 56, living with blindness)*

A number of people used direct debit for essential payments like bills and the rent and this saved a lot of stress and anxiety. However they did have to do without things which other people would take for granted and prioritise. This could mean prioritising petrol money over food or cashing in a prescription instead of paying for a taxi to visit a friend. As one person said, '*I survive and make ends meet but there is no such thing as a luxury.*'

> *It is very difficult and it is only because of my planning and the assistance I get from my family that I am able to do half the things I do now. Basically it takes a lot of discipline and a lot of pre planning on my part. Sometimes I am left with $100 a fortnight to play with which is not much. (Mat, 22, living with cerebral palsy)*
>
> *We just make ends meet. You struggle. You have to have the phone in case anything goes wrong with him. That's around $100 a month. We don't spend money on ourselves, we don't go out. We pay for our petrol fortnightly. We don't go out for meals. The finances do become very very stretched at times. (Sharon and Mike, 60s, both living on DSP and caring for their grandson living with multiple disabilities)*
>
> *The only thing I don't go without is food. I do have to cut the food bill down. I love going to the movies. We used to be able to go out every week for a meal, every week for twenty years but now we're lucky if we do it once a month. I love going out for a meal. We love going to the pictures but that costs $40 by the time you get to the pictures even though we get concessions, the petrol to get there. So we miss out on that. (Denise, 52, and her husband both living with cerebral palsy)*

10.3 Being In Control

Being able to manage your own finances and banking requirements is a key issue for many people with disabilities who can be very vulnerable to exploitation. As one person said, '*The sharks are always circling.*' For those with physical and sensory disability control can be maintained by access to the appropriate assistive technology.

> *As long as you can use a finger, you can use telephone banking and it's very important that you maintain independence and confidentiality as long as you can. I now have a scanner and I can actually read my bank statement and my credit card statement and control it all myself and it's really important that people can do that. It's almost as important as having the money to spend. Some people*

> *need someone to help them understand finances. This is the importance of knowing how much money you've got, how much you owe on various accounts and being methodical and keeping records. You need to be the person who is in control even if you need someone to physically help you. With forms I need someone to help me fill them in even though I can read them. As long as I'm aware of what I'm filling in and I have particular friends I would trust to do that. You get to know who you will give certain tasks to particularly with financial tasks. (Anna, 56, living with blindness)*

Those who are prevented by cognitive or intellectual disability or mental health problems from being able to manage their income may be reliant on staff in group homes, on other service providers, on family or on the Public Trustee to manage it for them. This can work well or it can create difficulties when the wishes and needs of the individual are not fully taken into account. For example service providers have reported problems with staff rather than residents in group homes determining the heating and air conditioning levels and hence the size of the bills which residents then have to pay from their pensions.

The Public Trustee operates a Financial Administration Service for those dependent on the DSP who have assets of less than $10,000 and who have no family or friends willing or able to assist with financial management. The service currently charges $1,070 per annum per client for this facility. For a single adult living independently on the DSP this represents 8% of their income and means that many are excluded from accessing the service.

10.4 Living in Hardship

There were interviewees in our sample who had to cut back on what most people would call essentials. This could include not having enough money for heating or hot water or being regularly dependant on emergency relief and food vouchers - the last form of assistance for people who have fallen through the safety net of the Australian social security system. They also described being always behind on things.

> *I haven't had a hot water service for three years now at home. I can't afford to get a new one, for them to come out and see if it can be fixed. I'm building up a credit with the electrical repairs people and go out there every fortnight and give them $10 in cash. They say you can always owe us and I say no I can't because if anything happens to me I don't want to leave a debt. I have been selling some things, it's come down to that. I sold a beautiful vase of mum's because I needed $500 to pay a vet bill. People said how could I part with it but I needed to pay this bill. (Rose, 62, living with physical disabilities)*
>
> *I have to go to bed all the time to keep warm. I've had to have a new heater put in but after getting this heater I couldn't afford to run it. (Sarah, 53, living with ABI)*
>
> *I've gone without meals. A couple of years ago I didn't eat for eight days and I do use emergency relief. I've been using them too much when I'm not supposed to. I've got some friends to help me out a little bit with food to keep me going for a couple of days and I do run out of money. (Sally, 42, living with intellectual disability)*

All interviewees were asked whether they had experienced a number of events in the previous twelve months due to a shortage of money. As Table 9 highlights well over one third of those with disabilities had gone without meals, not sought health care or not filled a prescription and sought financial help from friends and family due to a shortage of money. At least a third had been unable to adequately heat their home or pay their utility bills on time and a fifth had difficulty in making rent and mortgage payments.

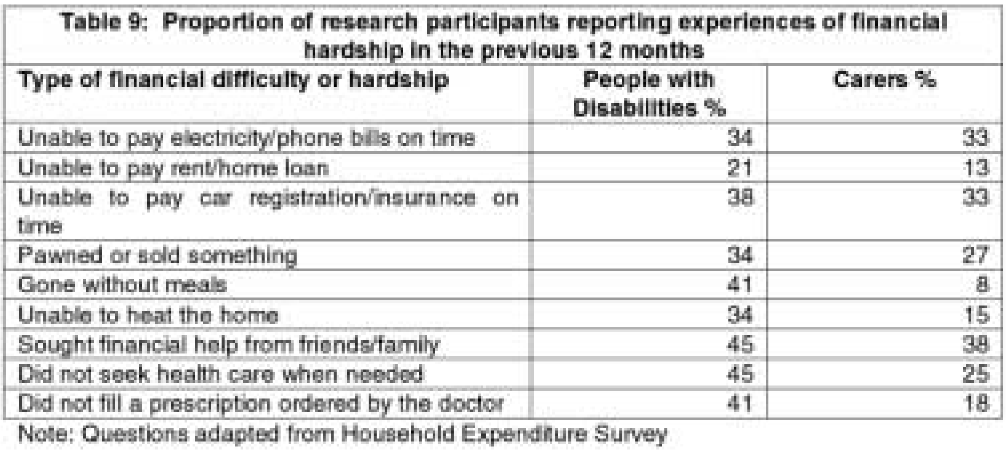

Table 9: Proportion of research participants reporting experiences of financial hardship in the previous 12 months

Type of financial difficulty or hardship	People with Disabilities %	Carers %
Unable to pay electricity/phone bills on time	34	33
Unable to pay rent/home loan	21	13
Unable to pay car registration/insurance on time	38	33
Pawned or sold something	34	27
Gone without meals	41	8
Unable to heat the home	34	15
Sought financial help from friends/family	45	38
Did not seek health care when needed	45	25
Did not fill a prescription ordered by the doctor	41	18

Note: Questions adapted from Household Expenditure Survey

Carers were also experiencing financial problems and over a third had been forced into making late payments for utilities and car registration and had been reliant on financial help from their family.

Table 10 outlines a typical budget for someone with a severe disability living in the community and reliant solely on DSP. It uses average rents in public housing, average expenditure on medication and assumes the receipt of HACC funded personal support capped at $10 per week. It demonstrates the inability of the DSP to cover anything more than the very basic costs of living leaving recipients with little or no discretionary funds at all: a total of $32 a week to spend on all other aspects of their life. Costs are likely to be higher for those surviving in the private rental market.

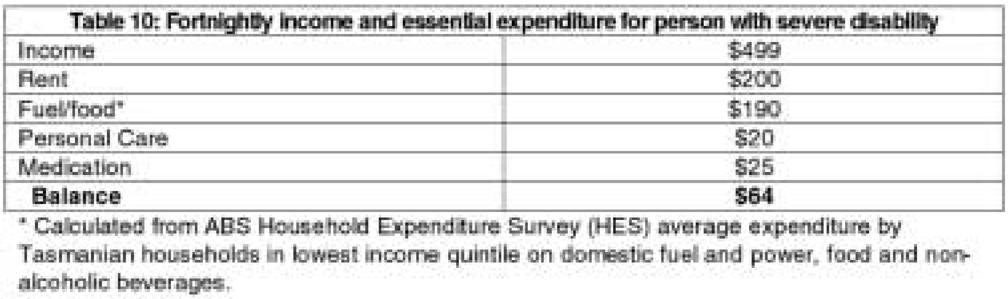

Table 10: Fortnightly income and essential expenditure for person with severe disability

Income	$499
Rent	$200
Fuel/food*	$190
Personal Care	$20
Medication	$25
Balance	**$64**

* Calculated from ABS Household Expenditure Survey (HES) average expenditure by Tasmanian households in lowest income quintile on domestic fuel and power, food and non-alcoholic beverages.

The Australian Bureau of Statistics Household Expenditure Survey data shows that Tasmanians in the lowest income quintiles on average spend $200 a fortnight on the following essential goods and services: clothing, personal care products, health and transport. This level of expenditure is not affordable to people with the budget outlined above. Neither does it take into account any additional expenditure on continence needs, maintaining a telephone or internet connection or any costs associated with having a social life and/or participating in the community.

11. CONCLUSIONS

Acquiring and living with a disability is always a major life event. Unfortunately in Tasmania it is too often also accompanied by financial hardship and exclusion from participation which imposes an additional and unnecessary burden. It is this burden which government at both a Commonwealth and State level has failed to adequately address through policy.

11.1 In Summary

This research has shown that the situation for many people with disabilities and for their carers is difficult and in some cases desperate. They daily have to cope with inadequate incomes which force them underneath the poverty line and which cannot provide them with the lifestyle and choices which other people take for granted. At the same time the supports available to offset the additional costs of disability are inequitable and inefficient. Not only do those suffering from similar medical conditions get very dissimilar treatment and access to widely varying levels of support but the service system itself is fragmented, complex and bureaucratic and most programs are under-funded. Although unpaid carers remain the main providers of assistance people with disabilities will at various times require services across the spectrum. Services however are provided by a range of different departments, policies and programs with little coherence and rationed by means tests, eligibility criteria, administrative rules and funding arrangements that vary across programs. There is little or no integration of information and care planning across disciplinary boundaries like health, education, disability services, employment and training or income support. This results in a duplication of assessment, delivery and monitoring resources and a large reservoir of unmet need.

The support a person with a disability in Tasmania receives depends on what sort of impairment they have, how they acquired it, where they live and whether they are willing and able to advocate for themselves. Many receive the minimum amount of support they need to survive rather than what is required to have some kind of quality of life. This increases dependence and the need for personal assistance and in the longer term it fuels a demand for premature entry into high cost nursing home and intensive care. As research elsewhere has shown a failure to provide a person centred system with a personalised response to individual needs can create additional needs and therefore additional demands on services (Edge, 2001). The constant fight to get the services required and the processes involved prolong difficulties and exacerbate poverty as well as impacting on self esteem and identity. It also promotes a perception of services being an individual responsibility and the disadvantages stemming from disability as an inevitable outcome of impairment rather than socially constructed barriers which can be addressed through appropriate social and economic policies. So although there is no one solution to meeting the needs of everyone living with a disability what is clear is that the costs of not addressing these issues are high.

Tasmania should be able to afford essential services for disabled people without long waiting lists and debates about which department is responsible (ACROD, 2005). Strategies are required to overcome the finance related barriers and create enabling environments so that people can participate and contribute. Currently however, despite the Disability Framework for Action, disability is not high on the political agenda and many politicians remain ignorant about the financial burden it imposes and about their own chances of acquiring a disability during their life.

Any change requires action at a number of levels - in legislation, in policy reform and in attitudinal change in the community to create a groundswell of opinion which can demand better services.

11.2 What People Would Like to See

Everyone who participated in the research was asked what they would like to see the government do for people with disabilities and for carers. They put forward a wide range of suggestions about how the lives of people with disabilities could be improved. Their priorities were:

- **information** about what services are available and how to access them using a one-stop-shop approach so that consumers only have to make one enquiry rather than several. This should include providing information in different formats as well as telephone and internet advice facilities.

- **a full recognition of the additional costs** of living with a disability and more assistance to meet them and enable people to participate in voluntary work, employment and socially.

- **a person-centred approach** with services tailored to meet the needs of individuals through a big expansion in individual support packages. This would allow people to facilitate their own lifestyle choices and also access social support to counter the common experience of social isolation.

- **home respite and respite options** which don't involve accessing aged care facilities.

- **improvements to the physical accessibility** of public facilities.

- **more timely and comprehensive rehabilitation support** particularly with the emotional aspects including personal and peer support counselling.

- **more accommodation choices** particularly core and cluster models located in areas with good access to services.

- an increase in the range and level of assistance available to acquire **aids and equipment** especially for employment and study purposes.

- **raising the profile of people with disabilities** so there is an increased awareness and compassion about their needs and more effective inclusion in decision-making processes.

What people wanted more than anything else was a coherent service system. This meant access to the support they required to function based on entitlement and not seen as an added extra or whether they had the energy to fight for what they needed.

> *To take a more holistic approach to people. I get really sick of having to tell my details over and over again to get a basic service. My disability will never go away and if anything it will only get worse but there's no recognition of any of that stuff, no recognition of really looking at what supports a person has. It's awful to feel you have to beg for everything and that you're not the priority everybody else is and the fact that you have to wait for everything for so long. It's all this piecemeal stuff: do you get your services from HACC or from Disability? It's the flexibility around how things are provided and what sort of lifestyle you lead. I would just sometimes like one thing to be really simple and straightforward. (Mary, 57, living with physical disability)*
>
> *People with disabilities should not have to fight every inch of the way. Society should be able to say okay this is what you need and so that is what we will give you. It should be factored in as part of our daily life and how we do business, not stuck on the outside and trying to find extra money. We shouldn't have to be fighting for basic rights. (Trish, 52, caring for her son living with quadriplegia)*

11.3 Recommendations

This research has demonstrated that the circumstances and experiences of many people with disabilities in Tasmania fall well below what is acceptable and that too many lead impoverished and restricted lives. The situation is not all bad and participants reported incidences of excellent service from individual providers, support workers and health practitioners. They welcomed the introduction of individual support packages and the recognition of the additional costs of social participation with the introduction of a Companion Card. There is also an appreciation of the potential of the Disability Framework for Action and the new Disability Bureau to instigate change. Yet the gap between the opportunities available to disabled people and those available to non-disabled people remains huge. This research has generated a number of recommendations about how to respond to that gap and improve the quality of people's lives.

The burden falling on carers can also be enormous and completely change their lives, severely reduce their incomes and have a big emotional impact which can affect their ability and willingness to access support services. Given the replacement value of informal care in the formal sector, assisting carers to care should be given the highest priority. At a time when the number of carers is projected to fall while the working age population of people with disabilities is projected to rise it will become imperative to counter the disincentives to care. Their support needs are therefore also reflected in the recommendations.

Planning Framework for Disability Services

A lack of transparency in the allocation of funds to disability support services means that it is difficult to calculate how the money is being spent and what additional funds are required to ensure that waiting lists for essential services are eradicated and growing needs met. Costings are also hampered by the absence of good quality data about future service needs.

Recommendation 1: That the Commonwealth Minister for Families, Community Services and Indigenous Affairs and the Tasmanian Minister for Health and Human Services ensures that the Commonwealth State/Territory Disability Agreement provides a planning framework for the provision of disability services across Australia which takes into account demographic changes, future service needs, changing

expectations of service users and carers, the capacity of service providers and other relevant factors including the need for improvements in the quantity and quality of data collected.

Recommendation 2: That the Tasmanian Minister for Health and Human Services and the Treasurer ensure transparency in the allocation of monies to disability support services by itemising funding and "outputs" in State Budget papers as has previously been done for Children and Families and Housing Tasmania and by establishing a communications strategy to inform stakeholders about what money is available and how it has been spent.

Dealing with Immediate Need

A substantial injection of funds is essential to respond to the acute unmet need demonstrated by long waiting lists for services and to ensure that everyone has their basic needs met.

Firstly, investment is required in capital expenditure. At the time of writing there were 26 people with moderate to high level support needs waiting for long term supported accommodation options. Although the appropriate mix of accommodation options would need to be determined costings do exist for group homes which can be used as a baseline. The construction costs of group homes housing four individuals each are approximately $444,000 per home. An additional seven group homes would therefore be required to eradicate the waiting list at a total cost of $3.1 million, excluding land purchase.

Recommendation 3: That the Tasmanian Minister for Health and Human Services and the Treasurer allocate one-off funding of $3.1 million to build seven new group homes for people with disabilities.

Secondly significant funds are also required to meet the outstanding acute needs of clients. The ongoing operational costs of a group home run by a non-government organisation are approximately $385,000 per annum. Seven new group homes will therefore require ongoing operational funding of $2.6 million. At the time of writing there were also 262 people waiting for individual support packages requiring 3,000 hours of support per week at a cost of $32 per hour. To meet this need would cost $5 million. Ninety two people are waiting for day options at an average cost of $15,000 per person per annum. To eradicate the waiting list would require $1.4 million. Finally the Community Equipment Scheme estimates that $800,000 is required to meet current client need at existing standards of service delivery.

Recommendation 4: That the Tasmanian Minister for Health and Human Services and the Treasurer provide an additional $9.8 million per annum to meet the ongoing support needs of those removed from the waiting lists.

No waiting lists are maintained for people needing respite care. This makes it difficult to specify the cost of satisfying the substantial unmet need for respite.

Recommendation 5: That the Tasmanian Minister for Health and Human Services ensures that routine data is collected about unsuccessful requests for respite care in order to monitor the levels of unmet need for respite services.

Improving the Service System

There is also a need to ensure adequate levels of funding which can respond to growing levels of demand in this area and improve the quality and quantity of services. Adequate funding would go some way towards addressing the significant inequities that exist between the support available to those who are compensable under insurance schemes and those who are not. There are concerns that without building in growth funds there will be a return to waiting lists and no resolution of the crises which exist in the system.

The Social Policy Research Centre at the University of New South Wales estimated that the national demand for disability services grew at approximately 2.3% per annum between 1996 and 2000. ABS projections quoted by Disability Services in Tasmania (Disability Services, 2005) estimated that increased support requirements nationally will result in a growth in demand of 3% to 8% per annum. Given the high proportion of the population with a disability and the age of the Tasmanian population the following recommendation adopts the 8% projection.

Recommendation 6: That the Tasmanian Minister for Health and Human Services and the Treasurer commit 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 and the needs of an ageing population. Within this funding increase the following should be prioritised:

- ***development of a range of accessible and appropriate respite options with the goal of achieving a benchmark of four weeks annual leave and ten days sick leave for full time primary carers by 2020;***
- ***increased access to domestic assistance and to personal support to promote independent living and social and community participation;***
- ***increased funding to the Community Equipment Scheme to meet current demand and allow for an increased limit on expenditure for individual items;***
- ***provision of a range of day options for people with disabilities which are appropriate to their needs in terms of age, type of disability and geographical area; and***
- ***increased range of long term supported accommodation options.***

Income Support

People with disabilities have to make stark choices to ensure their income stretches to meet basic needs. Although state benefits and services are meant to offset some of the additional costs of living with a disability the weekly incomes of those entirely dependant on the Disability Support Pension fall far below the amount needed for an acceptable quality of life. This shortfall should be addressed through a combination of improved benefit levels, enhanced service provision, environmental improvements to boost accessibility and better access to employment.

Recommendation 7: 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 8: That the Commonwealth Government through the Minister for Families, Community Services and Indigenous Affairs restore provisions to backdate the Carers Allowance for 12 months from the date of the claim.

Recommendation 9: That the Tasmanian Premier direct the Department of Premier and Cabinet's Social Projects Unit to research the effects of the welfare-to-work reforms on people with disabilities and other groups affected by the reforms to assess outcomes in terms of gaining sustainable employment and the impact on Tasmanian community and health services.

Disabled people can experience numerous difficulties in accessing Commonwealth Government benefits from Centrelink. These are associated with administrative procedures and processes and levels of disability awareness among Centrelink staff.

Recommendation 10: That the Minister Families, Community Services and Indigenous Affairs direct Centrelink to conduct comprehensive disability awareness training with all Centrelink staff annually and produce clear guidelines about working with people who advocate for people with disabilities.

Recommendation 11: That the Minister for Families, Community Services and Indigenous Affairs direct Centrelink to develop an information kit outlining the support available for those transferring from compensation payments to Centrelink benefits.

A major concern for both people with disabilities and their carers was how to ensure their future financial security. They wanted to see information available about the options open to them to ensure that their assets were managed for the benefit of their offspring who had disabilities and long term care needs. This requires complex legal and financial decisions covering the laws involving trusts, superannuation and Centrelink requirements.

Recommendation 12: That the State Government through the Attorney General require the Department of Justice to produce information about the options available to people with disabilities and their families to plan for their future financial security.

Employment

Access to employment can be the key to breaking a cycle of deprivation yet people with disabilities face high levels of discrimination in finding and retaining paid work. They are also expected to participate in the labour market without reasonable levels of assistance to offset the additional costs involved including expenditure on aids and equipment and transport. The cumulative effect of these costs can make employment unfeasible. Much of the current assistance available to smooth the transition into work is about improving the individual employee rather than about supporting employers to remove disabling barriers.

Recommendation 13: That the Commonwealth Minister for Employment and Workplace Relations secure funding to improve employer incentive schemes, assistance with disability-related employment costs and disability awareness programs to encourage employers to employ people with disabilities.

Recommendation 14: That the State and Commonwealth Governments act as role models by reviewing their own employment practices so that people with disabilities are employed in the public sector at a similar rate to their numbers in the working age population.

Recommendation 15: That the State Government commit to ensuring that a quota of 10% of new traineeship positions in the public service is targeted towards people who are long-term unemployed and within this broad definition a quota is identified for people with disabilities who are long-term unemployed.

Recommendation 16: That non-government organisations review their employment practices to ensure that they do not erect barriers to the employment of people with disabilities. This should include reviewing the administration of pre-employment medical checks and the requirement for driving licences.

Support Services in the Community

There are a wide range of support services available to assist people in living independently in the community including home-based personal care, aids and equipment and supported accommodation. But there are serious gaps both in the levels of support available and the way in which services are delivered. These include the absence of information about what assistance exists, the skills and attitudes of service providers, the existence of co-payments which can represent large sums in small budgets and the lack of consistency in how and to whom services are delivered. All in all the right to independent living is compromised by State Government budget constraints and an inability to provide a comprehensive person-centred approach to service delivery.

Recommendation 17: That the Tasmanian Minister for Health and Human Services introduce a streamlined service system which addresses multiple entry points to community care for people with disabilities, uses a common assessment tool, has a common approach to data collection and can provide case management services to those who require them.

Recommendation 18: That the Commonwealth Minister for Families, Community Services and Indigenous Affairs and the Tasmanian Minister for Health and Human Services abolish the co-payments for HACC services in order to remove financial barriers to accessing services.

Recommendation 19: That the Tasmanian Minister for Health and Human Services ensure that all workers in the disability sector, related services and health service staff have access to good quality disability awareness training conducted by trainers with disabilities.

Recommendation 20: That the State Government immediately amend the Disability Services Act to ensure that cognitive impairment is specifically identified in order to ensure those with acquired brain injury have equal access to services.

Recommendation 21: That the Tasmanian Minister for Health and Human Services put strategies in place to ensure that those population groups with high needs enjoy the same level of access as the general population to disability services and that barriers to Indigenous and culturally and linguistically diverse communities are removed.

One of the most significant needs identified by the research was for better information about rights and entitlements to support and help for people with disabilities across the spectrum of services, including services provided by non-government organisations. Many wanted to see a disability support information service provided as a one-stop-shop, with face-to-face access to an adviser and with information available in a range of formats and which would be automatically available to people with disabilities and their carers on discharge from hospital. One way of ensuring a state-wide accessible service would be to locate it within Service Tasmania. The possibility of staffing the service with service co-ordinators from Disability Services could also be explored.

Recommendation 22: That the Tasmania Minister for Health and Human Services establish a disability support information service within Service Tasmania which can provide a one stop shop about rights and entitlements to support and assistance across the spectrum of services.

Assistive Technology

People's lives can be transformed by having access to appropriate assistive technology. Yet this research has demonstrated that the current cash limited and means tested subsidies commonly do not allow people to meet their basic needs for communication, mobility or continence or to update or maintain equipment and they are forced into the ignominy of fundraising. The inadequacy of the assistance for purchasing or modifying accessible vehicles, for assistive home modifications and for updating computer equipment are particularly large gaps in the system. This is despite the fact that aids and equipment can reduce expenditure on health and social care in the longer term.

There are also particular concerns about younger people with disabilities living in residential aged care who are currently barred from accessing the range of disability support services. Anglicare believes that more appropriate housing options should be sought for this population as a matter of urgency and in the interim that they should have full access to the disability support services that they need.

Recommendation 23: That the Commonwealth and State Governments ensure that younger people with disabilities currently living in residential aged care have access to the Community Equipment Scheme and to the range of other disability services.

Recommendation 24: That the Tasmanian Minister for Health and Human Services fund the No Interest Loans Scheme (NILS) to undertake a 12 month pilot offering loans to people with disabilities for items of equipment not available through the Community Equipment Scheme to assess demand and cost.

Housing

People with disabilities do not have the same choices and opportunities in housing as non-disabled people. They may find themselves housed a long way away from their families, support networks and services, in aged care homes or with people they have nothing in common with. They may have to devote large amounts of discretionary income to living in more expensive areas so they can access services or to modify their accommodation so it fits their needs. The preferred supported housing option for many people with disabilities and for their carers is a core and cluster model where a core central building has communal facilities and support while residents are housed in their own units. This enables them to access support whilst maintaining high levels of independence.

Recommendation 25: That the State Government fund the capital cost and operating budget of a core and cluster housing model in each of Tasmania's three regions for people with disabilities with low to moderate support needs.

It can be difficult for people with disabilities to become home owners. Shared equity models enable low income households who would otherwise be unable to purchase a whole dwelling to gain some equity in their housing by purchasing a part of it with the Housing Authority owning the remainder. This offers the opportunity for affordable entry to progressively owning the whole house.

Recommendation 26: That the State Government fund Housing Tasmania to develop shared equity models specific to the needs of people with disabilities, including those with ageing carers who possess assets.

Recommendation 27: That the State Government fund Housing Tasmania to conduct research to establish how far the needs of people with disabilities are met in the public housing environment in terms of access, affordability, a modified environment and the promotion of social participation.

Models exist of partnerships between national non-government organisations and major banks to enable low income households to access loans at reasonable rates of interest. Such a model could be replicated between the Tasmanian Government and a financial institution.

Recommendation 28: That the State Government develop a model to improve access to home modifications and independent living for people with disabilities or carers who own or are 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 and/or brokerage of the design and management of proposed modifications

Recommendation 29: That the Tasmanian Minister for Health and Human Services reviews the charges and fees in supported accommodation and group homes to ensure that they are uniform across the State.

Transport
Research participants demonstrated the overriding importance of accessible and affordable transport in allowing them to participate in work, education, volunteering, a social life and in community activities. They highlighted the current inadequacy of concessions in meeting transport needs particularly in more rural areas and for accessing specialist health services. The lack of assistance with undertaking vehicle modifications is also a significant issue.

Recommendation 30: That the Tasmanian Minister for Health and Human Services define wheelchair accessible vehicles as 'equipment' to allow individual support package recipients to use the funding for support hours they have not used (banked support hours) to contribute towards the costs of modifications to vehicles.

Recommendation 31: That the State Government fund two pilot projects to explore ways of better co-ordinating Community Transport, wheelchair accessible taxis and non-government organisations to provide a more effective transport service. It is recommended that these pilots should be located in a rural/remote area and in a metropolitan area.

Recommendation 32: That the Tasmanian Minister for Health and Human Services increase funding to the Patient Transport Access Scheme so it meets the actual costs of transport, accommodation and meals for people with disabilities accessing specialist health services.

Health

Although disabled people have higher mortality and morbidity rates than non-disabled people health services are not always responsive to their needs. Their access to mainstream services, preventative health programs, alternative therapies and medications can be compromised by additional costs and the attitudes of health practitioners.

Recommendation 33: That the Commonwealth Government restores the Medicare safety net threshold to $300 for Disability Support Pensioners.

Recommendation 34: That Medicare is funded to subsidise the costs of prescribed medical items such as neck braces, surgical stockings and bandages for Disability Support Pensioners.

Recommendation 35: That the Tasmanian Minister for Health and Human Services abolish the co-payment for general treatment in the public dental system.

Recommendation 36: That the Commonwealth Health Minister and the Tasmanian Minister for Health and Human Services ensure that patients attending GP surgeries have access to adjustable height examination beds.

Recommendation 37: That the Tasmanian Minister for Health and Human Services establish procedures to ensure a planned hospital discharge for people with disabilities. This should include:

- ***ensuring accommodation arrangements are adequate;***
- ***confirming transport arrangements;***
- ***assessing the carer's capacity to care;***
- ***informing relevant service providers in the community; and***
- ***distributing an information kit to patients and carers outlining the disability service system and appropriate support agencies***

Promoting the Civil Participation of People with Disabilities

The needs of people with disabilities should be afforded the highest political priority and all politicians need to have a greater awareness of the issues. This requires a strong consumer lobby or disability movement in Tasmania to advocate for a better deal and to make decision makers accountable. Tasmanians with Disabilities have performed this role but under funding over a number of years has affected their ability to undertake representations. People with disabilities and their families should be leading the way in promoting a cultural shift in attitudes to disabled people, in informing policy decisions about resources and in the governance of services. Currently they are too often seen as consumers rather than people who can contribute and opportunities to raise issues and concerns about the receipt of services are compromised by a fear of losing access to those services. The value of having disabled people and families represented on the Disability Advisory Council is acknowledged but there should also be other options for ensuring their voices and experiences are heard and their expertise used by government.

At a minimum a peak disability consumer organisation should consist of a full time executive officer, full time administrative support, part-time policy officer and a resource centre. It should also have the ability to operate as an umbrella organisation for smaller disability organisations. It should aim to:

- promote the rights of all people with disabilities to be involved in national and state policy, planning and service decisions which affect their health and well being;
- promote a just and equitable distribution of resources to redress inequalities between people with disabilities and other population groups and ensure full participation; and
- encourage the development of disability services which are effective in enhancing the capacity of people to participate as fully as possible in the community and are responsive to consumer needs and preferences; community-based and managed; respectful of human rights; culturally relevant; universally accessible; cost effective.

Recommendation 38: That the Premier through the Minister for Health and Human Services immediately commit $200,000 per annum to ensure the existence of a peak state-wide consumer organisation which is funded to represent the interests of consumers of disability services and covers the concerns of people with all types of disability.

REFERENCES

Access For All Alliance, 2006. *National results of a survey into the barriers confronted by tourists with disabilities.*

Access Economics Pty Ltd, 2003. *Transparency of State and Territory Budgets.* Report prepared for the Commonwealth Department of Family and Community Services: Canberra.

Access Economics Pty Ltd, 2004. *Clear Insight. The Economic Impact and Cost of Vision Loss in Australia.* Access Economics.

Access Economics Pty Ltd, 2005. *Acting Positively: Strategic Implications of the Economic Costs of Multiple Sclerosis in Australia.* For Multiple Sclerosis Australia.

Access Economics Pty Ltd, 2005. *The Economic Value of Informal Care*. For Carers Australia. Canberra.

ACROD, 2005. *Budget Priority Submission 2006-07*. State Budget Process. Hobart.

AMP.NATSEM, 2006. *Who Cares? Income and Wealth Report*. Issue 13. NATSEM.

Australian Bureau of Statistics, 2004. *Disability, Ageing and Carers, Australia: Summary of Findings 2003*. Cat No 4430.0 ABS: Canberra.

Australian Bureau of Statistics, 2005. *Australian Social Trends 2005*. Cat No 4102.0. ABS: Canberra.

Australian Bureau of Statistics, 2005. Household Expenditure Survey 2003-04. ABS: Canberra.

Australian Institute of Health and Welfare, 2002. *Unmet need for disability services: effectiveness of funding and remaining shortfall.* Cat No DIS 26. AIHW: Canberra.

Australian Institute of Health and Welfare, 2003. *Disability: the use of aids and the role of the environment.* Cat No DIS 32. AIHW: Canberra.

Australian Institute of Health and Welfare, 2003. *Disability Prevalence and Trends*. Cat No DIS 34. AIHW: Canberra.

Australian Institute of Health and Welfare, 2005. *The seventh biennial welfare report of the AIHW*. Cat No Aus 65. AIHW: Canberra.

Australian Institute of Health and Welfare, 2005. *CSTDA/NMDS (unpublished) funded service users, age group by primary disability group. Tasmania 2003-04.*

Australian Institute of Health and Welfare, 2005. *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples.* AIHW Cat No IHWE 14; ABS Cat No 4704.0.

Australian Institute of Health and Welfare, 2005. *National Social Housing Survey*. AIHW: Canberra.

Australian Council of Social Service (ACOSS), 2005. *Who is worse off? The regional distribution of people affected by the Welfare-to-Work Policy.* ACOSS Info 381.

Australian Council of Social Service (ACOSS), 2005. *Ten Myths and Facts about the Disability Support Pension (DSP).* ACOSS Inform 362. Jan 2005.

Australian Quadraplegic Association, 2000. *'CAAS Survey - a system in crisis'*. Quadwrangle. Winter 2000.

Berthoud, R., Lakey, J., McKay, S., 1993. *The economic problems of disabled people*. Policy Studies Institute. London.

Bradbury, B., Norris, K., Abello, D., 2001 *Socio-Economic Disadvantage and the Prevalence of Disability.* Social Policy Research Centre, University of New South Wales, Australia.

Bricknell, S., 2003. *Disability: the use of aids and the role of the environment*. Disability Series. Australian Institute of Health and Welfare Cat No DIIS 32 AIHW: Canberra.

Bridge, C., Parsons, A., Quine, S., Kendig, H., 2002 *Housing and care for older and younger adults with disabilities.* Australian Housing and Urban Research Institute. Sydney Research Centre.

Brotherhood of St Lawrence, 2005. *Welfare reform and people with disabilities.* Policy Commentary.

Brotherhood of St Lawrence, 2005. *Vital but undervalued. The Personal Support Programme and increasing workforce participation.* Brotherhood Comment. August 2005.

Burchardt, T., 2003. *Being and becoming: social exclusion and the onset of disability*. ESRC Centre for Analysis of Social Exclusion. CASE Report 21. London School of Economics and Political Science.

Cameron, P., 2002. *Condition Report: Low Income Earners in the Tasmanian private rental market.* Anglicare Tasmania, Hobart.

Cameron, P., 2002. *Access to Dental Care for Low Income Tasmanians.* Anglicare Tasmania, Hobart.

Cameron, P., Flanagan, J., 2004. *Thin ice: Living with Serious Mental Illness and Poverty in Tasmania.* Social Action and Research Centre. Anglicare, Tasmania.

Carers Association, 1997. *Caring Enough to Be Poor: A survey of carers income and income needs.* Carers Association of Australia.

Carers Association, 1998. *Caring Costs. A survey of tax issues and health and disability related costs for carer families.* Carers Association of Australia.

Carers Association, 2000. *Results of the 1999 National Survey of Carer Health and Well Being.* Carers Association of Australia.

Caust, C., Davis, B., 2005. *Are state run aids and equipment schemes meeting the needs of older people living with disabilities.* Independent Living Centres Australia Inc.

Cavallaro, T., Foley, P., Saunders, J., Bowman, K., 2005. *People with a disability in vocational education and training. A statistical compendium.* National Centre for Vocational Education Research.

Chartered Institute of Personal Development (CIPD), 2001. *Adapting to disability wasn't so* *difficult after all: The change agenda*. CIPD: London.

Coalition of Disability Advocacy Group, 2005. *Joint Statement of Action*. February 2005.

Community Affairs References Committee (CARC), 2003. *A Hand Up Not a Hand Out: Renewing the fight against poverty.* Report on Poverty and Financial Hardship. The Senate, Parliament House, Canberra.

Considine, G., Watson, I., Hall, R., 2005. *Who's Missing Out? Access and Equity in Vocational Education and Training.* National Centre for Vocational Education Research.

Cummins, R., 2005. Australian Unity Wellbeing Index. *Survey 13: The Wellbeing of Australians - Caregiving at Home*. Report 13.0. Australian Centre on Quality of Life. Deakin University.

Disability Services Tasmania, 2005. *Directions for the Provision of Disability Services to 2009.* Final Draft. Department of Health and Human Services: Tasmania.

Department of Health and Ageing, 2004. *The Way Forward. A new strategy for community care.* Commonwealth of Australia.

Department of Premier and Cabinet, 2004. *Social Justice for People with Disabilities in Tasmania: Background Information paper for the Whole of Government Disability Action Framework*. DPAC, Tasmania.

Department of Premier and Cabinet, 2005. *Disability Framework for Action 2005-1010. A Whole-of-Government Framework for Tasmanians with a Disability.* DPAC, Tasmania 2005.

Edge, J., 2001. *Who's in Control? Decision-making by people with learning difficulties who have high support needs.* Values Into Action.

Enablenet, 2005. *Disabled Civil Servants Disappearing.* Disability information on the Net. December 2005.

Frisch, J., 2001. *Towards a Disability Allowance: Offsetting the costs of disability.* Physical Disability Council of Australia. Faculty of Commerce and Economics. University of New South Wales.

Gabriel, M. 2004 *Housing Stress in Tasmania: Recent Trends and Future Projections*. Housing and Community Research Unit, University of Tasmania.

Gleeson, B., 1998. '*Disability and Poverty'* in Fincher, R., Nieuwenhuy, J (eds) Australian Poverty: Then and Now. Carlton: Melbourne University Press.

Goggin, G., Newell, C., 2005. *Disability in Australia. Exposing a Social Apartheid.* University of New South Wales Press.

Graham, S., Stapleton, C., 1990. *The extra costs of participation in work, education or training for people with disabilities: An exploratory study.* Social Policy Research Centre. University of New South Wales. Sydney.

Harding, A., Ngu, Vu., Percival, R., 2005. *The Distributional Impact of the Welfare to Work Reforms Upon Australians with Disabilities.* Report of the National Foundation for Australian Women. National Centre for Social and Economic Modelling. University of Canberra.

Home and Community Care (HACC), 2004. *Home and Community Care Program Minimum Data Set 2003-04 Annual Bulletin.* Australian Government Department of Health and Ageing.

Human Rights and Equal Opportunity Commission, 2005. *Indigenous young people with cognitive disabilities and the Australian juvenile justice systems.* A report by Aboriginal and Torres Strait islander Social Justice Commissioner.

Human Rights and Equal Opportunity Commission (HREOC), 2002. *Report of Wheelchair Accessible Taxi Inquiry.*

Human Rights and Equal Opportunity Commission (HREOC), 2005. *Workability II Solutions. People with Disability in the Open Workplace.* Final Report of the National Inquiry into Employment and Disability. December 2005.

King, S., 2004. *Examination beds in doctors surgeries. National Survey.* Access for All Alliance (Hervey Bay) Inc.

KPMG, 2005. *Audit of Government provided accommodation support services for people with disabilities in Tasmania.* Department of Health and Human Services: Tasmania.

Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Boyle, F., Purdie, D., 2004. *Ask For It: Development of a Health Advocacy Intervention for Adults with Intellectual Disability and Their General Practitioners.* Health Promotion International 19(2):167-175.

Lindsay, M., 1996. *Commonwealth Disability Policy 1983-1995.* Social Policy Group. Background Paper 2 1995-96. Parliamentary Library.

Lister, R., 2004. *Poverty (Key Concepts).* Polity Press. UK.

Madden, K., 2005 and 2006. *Tasmanian Community Survey. Financial Hardship and Employment.* Social Action and Research Centre. Anglicare, Tasmania.

Multicultural Disability Advocacy Association of New South Wales, 2005. *Everybody Needs a Home.* MDAA.

Myriad Consultancy, 2005. *WAT Review Advocacy Group Consultation.* Research Report. DIER: Passenger Transport Policy Branch.

National Welfare Rights Network, 2006. *Submission to Senate Affairs Registration Committee.* March 2006.

Newell, C., 1995. *Consumer Reflections on the Disability Discrimination Act 1992.* Australian Disability Review 2, pp 60-65.

Nucleus Group for Office of Disability, 2004. *Survey of New Disability Support Pension Customers.* For Department of Family and Community Services.

New South Wales Department of Juvenile Justice, 2003. *NSW Young People in Custody Health Survey.* Key Findings Report. Sydney.

O'Neill, C., 2003. *Exploring the Cost of Disability: Theoretical Underpinnings and Research Methodology.* Paper delivered at Disabilities Studies and Research Institute, May 2003.

Parrish, M., Schofield, T., 2005. *Injured workers' experiences of the workers' compensation claims process: Institutional disrespect and the neo-liberal state.* Health Sociology Review 14: 33-46.

Phibbs, P., Higham, A., 1999. *Review of the Home Modification Scheme of the Home and Community Care Program.* Ageing and Disability Department. New South Wales.

Prime Ministers Strategy Unit, 2005. *Improving the life chances of disabled people*. Final Report. UK.

Productivity Commission, 2004. *Review of the Disability Discrimination Act 1992*. Report No 30. Melbourne.

Productivity Commission, 2005. *Policy Implications of an Ageing Australia: an illustrated guide to the Financial Review on Ageing Population Summit.* September 2005. Sydney.

Saunders, P., 2005. *Disability, Poverty and Living Standards: Reviewing Australian Evidence and Policies.* Social Policy Research Centre, University of New South Wales, Australia.

Saunders, P., Abelman, L., 2005. *Income Poverty, Deprivation and Exclusion: A comparative study of Australia and Britain.* SPRC Discussion Paper No. 141. Social Policy Research Centre, University of new South Wales, Australia.

Spencer, B., 2005 *A life less lived,* The Age, Review 8. May 7th 2005.

Saunders, P., Sutherland, K., Davidson, P., Hampshire, A., King, S., Taylor, J., 2006. *Experiencing Poverty: The Voices of Low-Income Australians. Towards new indicators of disadvantage project.* Stage 1: Focus Group Outcomes. Social Policy Research Centre. University of New South Wales, Australia.

Tibble, M., 2005. *Review of existing research on the extra costs of disability*. Working Paper No 21. Department for Work and Pensions. UK.

Wilson, E., Oke, N., Vecellio, L., 2005. *Economic hardship and social participation*. SCOPE.

WorkCover Tasmania, 2004. *A guide to workers compensation in Tasmania*. WorkCover Tasmania and Workplace Standards Tasmania.