Ensuring a good life for people with a disability and their families

Carers Australia's response to the Productivity Commission's Draft Report on Disability Care and Support

Carers Australia
May 2011

About Carers Australia

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness, chronic condition or terminal illness or who are frail and aged.

Carers Australia believes that all carers should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimal health, social and economic wellbeing and to participate in family, social and community life, employment and education.

Carers Australia's members are the eight state and territory Carers Associations

Acknowledgement

Carers Australia wishes to thank Carers Victoria, particularly Gill Pierce and Ben Ilsley, for the preparation of this submission on behalf of Carers Australia. We also wish to acknowledge the input provided by the other state and territory Carers Associations, which together has provided a strong base on which to develop this final submission.

Title: Response to the Productivity Commission's Draft Report on Disability Care and Support

Date: May 2011

Carers Australia
Unit 1, 16 Napier Close
Deakin ACT 2600
Telephone 02 6122 9900
Fax: 02 6122 9999
Email: caa@carersaustralia.com.au

Copyright © 2011 Carers Australia

Table of Contents

1 INTRODUCTION

Carers Australia and the state and territory Carer Associations welcome the release of the Productivity Commission's Draft Report on Disability Care and Support. We are heartened by the Commission's focus on the need for sustainable funding to provide lifetime care and support for people with a disability and their families. In estimating that a doubling of current funding would be needed for a new system, the Commission has demonstrated a keen awareness of the current problems in the disability services system which is 'inequitable, underfunded, fragmented and inefficient'. The current system gives people with a disability and their families little choice and no certainty that they can access appropriate levels of support when they need it.

People with a disability and their families have struggled within a severely rationed system. As a consequence they experience poor levels of health and wellbeing, reduced opportunities to participate and fewer life chances. Promised housing and support options which were anticipated to accompany deinstitutionalisation and community integration of people with a disability have only ever been partially realised.

People with a disability and their families are excited about the possibility of real change. They have high expectations of a National Disability Insurance Scheme (NDIS) in the future. At the same time, some carers and people with a disability with whom Carers Australia has consulted retain doubts that such extensive change will obtain government support. They have experienced many government inquiries with negligible outcomes. These include the report of the Senate Inquiry into the Commonwealth, State and Territory Disability Agreement (2007); the Federal House of Representative's Carer Inquiry (2008); the 2009 'Shut out' report; the Disability Investment Group's Way Forward Report (2009) as well as other state based inquiries.

The Commission has demonstrated that it is a strong advocate for significant change. Its far reaching recommendations have the potential to ensure that:

- people with a disability and their families for the first time will have access to the level and quality of care and support that they need
- access to care and support will be nationally consistent for people and families with similar levels of need
- people with a disability and their families can have real choice between suppliers of services and can determine their preferred mix of services through phased-in self-directed and self-managed funding
- caring is more equitably shared between informal carers and formal services
- caring and employment can be combined
- poor health and wellbeing for people with a disability and their families can be addressed through improved levels of individual and family support
- people with a disability and their families can plan together for a positive future that is more predictable
- there can be real progress in the access of people with a disability to appropriate housing and support in the community, and
- disability and family supports are reconceptualised as an investment in people and as an economic benefit.

In preparing this submission we have had the benefit of extensive consultation with carers, including:

- two group consultations with a total of 124 caring families in inner and outer metropolitan Melbourne
- an electronic survey of families who were engaged in national consultation workshops concerning a long term disability care and support scheme in August 2010, and
- 240 registered participants in the Carers Australia's sessions on the Implications of the NDIS for families and carers at the National Disability and Carer Congress, held in Melbourne, 2-3 May 2011.

Within these groups there were many and varied opinions. We believe that we have captured the main themes evident in these consultations in the content and recommendations of our submission. A summary report of the consultations will be forwarded to the Productivity Commission as soon as it is completed.

2 CRITICAL PRINCIPLES FOR A NATIONAL DISABILITY INSURANCE SCHEME

Carers Australia considers that a number of additional key principles should guide the design and practice of a National Disability Insurance Scheme. These include:

2.1 Eligibility for care and support should extend both to people with a disability and to their carers: the scheme should be person centred and family focused

The Productivity Commission has demonstrated that the rationing of disability services in Australia has shifted too many of the costs of care onto families. The costs to carer health and wellbeing can be high: financial security can be severely compromised.

Caring families recognise the interconnectedness of family needs with those of the person needing support and assistance. Many agree that adequate services and supports for the person with a disability would lead to a better life for all family members. Adequate services would ensure that the person with a disability and their caring family can participate in community life in ways that are consistent with their age peers. However, both caring family members and the person with a disability need support and assistance to make this a reality.

Most, but not all people with a disability have strong and mutually supportive relationships with their families; relationships which are frequently the most enduring in their lives. Many family members continue to provide support and assistance for the person with a disability and contribute to their lives whether they continue to live together or not.

Interdependence with family is the reality of the lived experience of most people with a disability and their families. In 2003, 97.5% of people with severe and profound limitations who were under 65 lived in the community. Of these, 84% of people with severe and profound limitations lived with family; 10% lived alone, and 3.2% lived with unrelated people, probably friends[1].

Despite the scale of recommended reforms, there will be a continuation of reliance on informal care.

A feature of the Productivity Commission's proposals for a NDIS is that they are person centred. A family focused principle is not systematically applied.

2.2 The diversity of needs of people with a disability and their carers should be recognised and accommodated through differentiated policies, programs and practices

For some time there has been a policy emphasis on the rights of people with a disability to maximise their potential, to live independently in the community, to participate equally as citizens in employment, social life and community affairs - with adequate support according to their needs. Carers Australia thoroughly supports this view.

But people with a disability are diverse. Such a policy emphasis has difficulty in addressing the practical application of participation and citizenship for adults whose disability is such that they are not self-determining and cannot make major daily life decisions. In these situations the support and assistance of family is crucial to choices about services and in life plans.

Carers Australia believes that there has been insufficient attention paid to evidence based models of community participation or community living for this group of people. The effectiveness of some services is reduced by a lack of variation in service system responses for people with different disabilities, particularly in relation to those with decision making disabilities. There has been little policy or practice attention to the importance of family relationships, or to understanding the positive roles of caring families and friends for adults with significant decision making disabilities. These have key implications in terms of delegated responsibility in decision making and in relation to the need for partnerships with services providers.

Similarly, the needs of carers and their families are diverse. Their needs may be related to the different types and level of disability of their family member, the structure, size, characteristics and background of the family, the availability of informal support, and to carer health and wellbeing or other factors. Many families need additional support and assistance to sustain family care.

2.3 Services for people with a disability should be integrated with services that support their families and friends

Currently the disability services system in Australia is fragmented into services which support the person with a disability, and separate services which provide support to their carers. A discussion paper commissioned by Carers Victoria[2] explores the origins of this divide. It outlines the different perspectives of the carer movement on the one hand, and the disability rights / community living movement on the other.

Carers Australia holds the view that disability reforms in Australia should aim to reduce the divide between services for people with a disability and services for their caring families. The perspectives of people with a disability and the perspectives of their families can be combined and broadened to better recognise critical higher order policy, funding and practice questions. There is potential for Australia to lead the way in the development of a person centred and family focused disability services system. It can make more efficient use of limited funds by reducing duplication and fragmentation of services and improving the continuity of care.

2.4 Informal caring should be shared to ensure a good life for all

The decreasing 'carer ratio' creates an urgent policy challenge concerning how people with a disability will be supported in the future, how family caring can be shared and how unpaid family care can be delivered without too great a cost to family carers.

Increasingly sharing of care between formal and informal resources (paid and unpaid care) is required. In addition, strategies to encourage the sharing of care within and between family members, regardless of gender, can reduce the costs of caring to individuals and improve the quality of the care provided.

2.5 Principles included in the *Statement for Australia's Carers*

The *Carer Recognition Act* (2010) contains a *Statement for Australia's Carers*. It outlines 10 key principles that establish how carers should be considered and treated by Commonwealth agencies and organisations funded to support carers. Two of these principles are of particular relevance to this inquiry:
- Principle 5: Carers should be acknowledged as individuals with their own needs within and beyond caring, and
- Principle 9: Carers should be supported to achieve greater economic wellbeing and sustainability and where appropriate should have opportunities to participate in employment and education.

Carers Australia recommends that:
The additional key principles outlined in 2.1-2.5 should guide the design and practice of a National Disability Insurance Scheme.

The application of these principles is reflected in Carers Australia's submission below.

3 COVERAGE OF A NATIONAL DISABILITY INSURANCE SCHEME

3.1 What the Productivity Commission proposes

The Productivity Commission estimates that outside Tiers 1 and 2, around 360,000 people will be eligible for individually tailored funded supports from the NDIS. Eligibility will be determined functionally by demonstrated need for support and assistance. Supports will be targeted to increase social participation and improve quality of life.

The need for taxpayer funded supports will be assessed and the nature and level of supports and individual budget will be determined (Recommendation 3.1). The scheme will focus on those with the greatest need for care and support which cannot be reasonably met outside an NDIS or via other services systems.

The Report states that people eligible for early intervention are included within the 360,000 people in Tier 3 (recommendation 3.2). However, the Draft Report's recommendation 11.1 creates some ambiguity about this. It states that NDIS funding for early intervention should be additional to that allocated to clients for their ongoing care and support which may mean that estimated eligible numbers are 280,000. It is also not entirely clear as to whether the Commission is using the term early intervention as a services type, or whether it refers to the earlier provision of care and support to some people with a disability. The distinction is an important one. Clarification of these matters by the Productivity Commission is needed.

There are larger estimates of numbers of people with severe and profound core activity limitations who are under 65 (680,000 SDAC, 2009). Of these, 310,000 people require at least daily assistance with core activities. The notion of ‘permanent disability’ (recommendation 3.2) excludes some people who are regarded by SDAC to have severe or profound activity restrictions, but who may not need continuous or ongoing care and support. This is in relation to people with chronic illnesses which result in functional limitations. Their activity restrictions are episodic or shorter term. The Productivity Commission considers that their needs may be best addressed by the health and mental health systems. However, it does not clearly elaborate the estimated numbers of people in these categories.

Admirably, the Productivity Commission also recognises that the 40% of people with an intellectual disability who do not come within the SDAC classification of ‘severe and profound activity restrictions’ nonetheless have ongoing care and support needs. It acknowledges that people with an intellectual disability may still have limitations in their capacity to participate in society - a consequence of non-core restrictions such as learning difficulties, limits to decision making, and interaction and relationship difficulties.

Carers Australia recognises that there are people from other diagnostic groups who share such limitations. These include for example, some people with a psychiatric disability, an acquired brain injury or autism spectrum disorder. Equity of access suggests that their need for support and assistance should be addressed within Tier 3b of the NDIS.

Carers Australia supports the view expressed by Maree Dyson[3]. The application of a diagnostic category (intellectual disability) is discriminatory and will lead to market distortion. It should be replaced by ‘primary brain impairment’ to be inclusive of and provide equity of access to care and support for some people with an intellectual disability, cerebral palsy, acquired brain injury and autism spectrum disorder. The issue of psychiatric disability is discussed further below.

Carers Australia recommends:
That people eligible for NDIS (Tier 3b) include people with primary brain impairment who need significant support to participate in the community.

3.2 The eligibility of people who currently use Disability Employment Services

Carers Australia is unclear about the Commission’s treatment of specialist employment services. Draft recommendation 3.3 suggests that people whose needs are only in relation to mainstream employment and housing should be supported by non-NDIS services. Draft recommendation 4.5 suggests that mainstream employment services should be outside the scheme but specialised employment services and disability specific school to work transition programs are to be included.

It is unclear whether the Productivity Commission means that most people who currently use NDA Open Employment Services (Employment Services Support or Disability Management Support) will be eligible for ongoing care and support through the NDIS. This may be an issue concerning the respective definitions of ‘mainstream’ and ‘specialist employment services’.

Examination of available data[4] indicates that of 87,217 people with a disability who accessed Commonwealth funded Disability Employment Services in 2008-9, 48.1% required assistance with Activities of Daily Living (ADL) and would be eligible. However, 31.6 % required assistance with Independent Activities of Daily Living (IADL) and Activities of Work, Education and Community Living (AWEC). The largest groups are believed to have a psychiatric disability, an acquired brain injury or an intellectual disability. Current eligibility criteria (tier 3 b) would exclude all but those with an intellectual disability.

We consider that specialist employment services refer to the 21,712 people accessing Supported Employment through Australian Disability Enterprises in 2008-9. Of these 79.2% required assistance with Activities of Daily Living and 20.2% required assistance with Independent Activities of Daily Living and Activities of Work, Education and Community Living. Most are likely to meet the eligibility criteria for NDIS care and support.

Equity of access indicates that the majority of all of these service users will need to be eligible for NDIS and the support it will provide for people with a disability and their families. People in Disability Employment Services need access to housing and support services, community access support and supported holidays or vacations. People who work in Australian Disability Enterprises need access to alternative retirement support or community participation programs and to housing and support services. The needs of the ageing parents of this group also require consideration.

Adoption of an eligibility category of ‘primary brain impairment’ for tier 3 b would allow appropriate inclusion of many people from Disability Employment Services. The position of people with a psychiatric disability is considered below.

3.3 Should people with a psychiatric disability be included in a Disability Care and Support Scheme?

Carers Australia notes that the Commission has made a specific request for more information on this issue.

3.3.1 What is psychiatric disability and what is its relationship with mental illness?

The World Health Organisation (WHO) defines disability as follows:

‘Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in their involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives’.[5]

The WHO has produced an International Classification of Functioning, Disability and Health (ICF) that provides more detail about how these concepts can be understood and applied[6]. Applying its definition, people with a psychiatric disability will encounter activity limitations and/or participation restrictions as a result of the interaction between their mental illness (impairment) and society[7].

The relationship between mental illness and psychiatric disability is not simple in a causal way. While it is necessary to have a mental illness in order to have a psychiatric disability, not all people with a mental illness will have a psychiatric disability. In spite of prominent community awareness campaigns stating that mental illness is like any other illness and can always be treated, this does not tell the whole story. There are clear limits to the effectiveness of clinical treatment for some individuals. In addition, mental illness has a quite different social context to physical illness. The result of these factors is that medical treatment will not always prevent the development of a psychiatric disability.

To illustrate this, a person with schizophrenia may be accessing clinical treatment and using the most up to date anti-psychotic medication at the appropriate dose. For some, but not all people, this will hopefully reduce their primary symptoms, for example, their hallucinations or delusions. The medication may also create side effects which have physical and cognitive manifestations. Secondary symptoms such as loss of motivation may be treatable or compounded by side effects. A person may lose daily living skills such as self-care, shopping, budgeting, cooking, or if onset is early, may not develop them at the time that their age peers do. Relationships with friends, family members and community members are likely to be adversely affected because of poor communication skills, unusual behaviours or because of the stigma of mental illness. Education and employment may be interrupted, resulting in low incomes. This in turn, for many, affects access to appropriate housing. The stigma of having a mental illness prevents participation in the usual community activities we take for granted.

Thus, even with excellent clinical intervention (pharmaceutical and/or psychological treatments), a person may still be unemployed, isolated, have problems maintaining housing and have difficulties with activities of daily living; that is, they have a significant disability. But there are also people with a serious mental illness who can manage their illness, function well and participate in the community to a great extent. It is not simple to predict who might develop significant difficulties and who might recover more fully. Personal and financial resources, formal and informal supports and good fortune will all help but not guarantee favourable outcomes.

3.3.2 What do people with a psychiatric disability need?

People with a psychiatric disability have the same range of needs as the general population. However, in general they will need additional supports to assist them to recover and participate in the community. There is strong evidence that the following are needed:

Clinical treatment. This may be through specialist services or through the primary health system, such as General Practitioners.

Stable and affordable housing. As mentioned above, specific barriers can make this extremely difficult to attain. There is strong evidence that recovery from mental illness is almost impossible without suitable stable housing and support. This results in repeat admissions to psychiatric or emergency departments and other associated and compounded difficulties.

Psychosocial support with a recovery focus. This is discussed further below

Employment support. People with psychiatric disability face many barriers to finding and retaining paid employment[8].

Income support.

Many people will need all of the above, working in a co-ordinated way. Co-ordination in itself can require resources.

3.3.3 What does recovery mean?

An understanding of the term ‘recovery’ is crucial in meeting the needs of people with a psychiatric disability. It refers to the rebuilding of one’s life and adjusting to the experience of having a mental illness. The relationship between recovery and psychiatric disability is a close one in that recovery can counter the negative impacts of mental illness and so prevent or reduce psychiatric disability.

There are some other important distinctions to note. Firstly, recovery is not the same as cure or remission. For many people with psychosis, for example, their illness will not be cured. However, they can learn how to manage their illness, build a robust self-identity, relearn skills, repair or develop new relationships and find new meaning and roles. This in turn can lead to returning to education or employment, maintaining their housing and so on. Secondly, recovery is an individual process which cannot be achieved by anyone else. At the same time, because this process involves relationships with others, recovery is very difficult to do in isolation and without support. For people with a psychiatric disability, who may have experienced trauma through their illness and admission to hospital, and who have encountered significant loss, empowerment and an emphasis on choice is essential. Although these concepts also underpin good quality support for people with other forms of disability, it can be argued that this is more so for people with psychiatric disability. If an approach which aims to merely maintain a person’s skills is used, it is very likely that a person with psychiatric disability will continue to lose function and skills. Even those people with the most long term and profound psychiatric disability require a recovery based approach.

3.3.4 Specialist Psychiatric Disability Services

There are services in Australia which specialise in working with people with a psychiatric disability. Nationally, the FaHCSIA funded Personal Helpers and Mentors (PHaM’s) program has gathered momentum since the COAG Mental Health initiative in 2006 [9]. This provides individualised support for people living in the community. DoHA has also been delivering the Day to Day Living program that is community based day programs, since that date. At the state level, investment in services has been variable. The Victorian government chose to target this group through the Commonwealth State and Territory Disability Agreement (CSTDA). This formed the basis for the development of a Psychiatric Disability Rehabilitation and Support Services (PDRSS) sector. Other states use a much smaller proportion of their CSTDA (now National Disability Agreement) allocation for this group[10], but may use other funds to provide some services.

There are more than 90 PDRSS’s in Victoria, the majority of which are delivered through non-government organisations (NGOs) specialising in Psychiatric Disability. Other PDRSS’s are delivered through Community Health Services.

The Victorian government funds PDRSS’s through particular service types. While Victoria cannot claim to have a perfect system of psychiatric disability support, it may be useful to list these as a way of informing the Commission of some of the different models of support already available. A list of these models appears in Appendix 1.

3.3.5 Where do families fit in?

Only 35 % of people with a mental illness in the last 12 months received any formal care for that illness[11]

This lack of access to services can come at a very high cost to families who often provide vigilant and empathic support themselves but are, in turn, affected by having a person with a mental illness in their family. Once psychiatric disability has developed, negative impacts on the family can continue for many years.

Although generic data about carers is available, there is a severe shortage of data about the numbers and characteristics of people caring for people with a mental illness or psychiatric disability. Anecdotally, people caring for a person with a psychiatric disability[12]:

- experience their own mental and physical health problems
- are likely to experience poverty as a result of the low workforce participation of themselves and the person with a mental illness
- are less likely to receive carer payment or carer allowance than those caring for people with other disability types, and
- may be less likely to cohabit with their family member, although they may still provide substantial support and assistance on an outreach and/or episodic basis.

Some of these negative impacts have particularly profound implications. For example, having a young person with a mental health problem makes it more likely that family breakdown occurs because of additional stresses. Thus the young person loses not only their source of support, but also their housing. A study into mental health and homelessness showed that in these cases, family breakdown is a more reliable predictor of youth homelessness than the existence of a mental health problem.[13]

Family members often report that they need information, education, and training for themselves about mental illness and psychiatric disability to provide effective care. However, the most prominent and consistent wish expressed by family carers is for services for the person with a psychiatric disability to be improved and more available and to be delivered in a family inclusive way.

3.3.6 How many people with a psychiatric disability need ongoing care and support?

Unfortunately, there is no single data source available to provide a quick figure on this. However, the AIHW's paper, 'Disability and its relationship to health conditions and other factors[14]'(2004) provides a comprehensive analysis and discussion of the limitations of different data sets.

For example, the Australian Bureau of Statistics (ABS)'s Survey of Disability, Ageing and Carers (SDAC) is the primary source of data about persons with a disability. However, its methodology places severe limitations on the data it collects in relation to this group of people. Firstly, it requires a person to disclose or identify with having a mental illness or psychiatric disability. The stigma associated with either of these terms makes this problematic. Secondly, the test used by SDAC to determine severity of disability uses the need for assistance to perform the following core activities; self-care, mobility and communication. As highlighted in Carers Victoria's 2010 submission[15], this test is more suitable for physical or sensory disabilities and is inadequate for determining the extent of intellectual or psychiatric disability (or other cognitive disabilities such as Acquired Brain Injury). As a result, numbers of people with a psychiatric disability captured by SDAC are low - 50,600 people with severe or profound disability (SDAC 2003, persons of all ages but not including Dementia and Alzheimer's Disease).

An alternative source of data is available through the National Health Survey. This highlights that there are very high numbers of people with a mental illness in Australia, well over 1.6 million people under 65 years of age[16].

The massive discrepancy between the two sets of figures highlights both methodological differences and the fact that the two surveys are trying to collect different data: one is collecting health data, the other disability. A third data source, the Burden of Disease Study (1998)[17] attempts to find utility from these differences by overlapping the two studies. Hence, it seeks to determine how many people with specific health problems have a corresponding disability and to what extent. It shows that some medical conditions are much more likely to result in higher degrees of disability than others and that some conditions are more likely to be associated with more than one disability type. For example, persons with schizophrenia are highly likely to have a severe or profound disability and employment restrictions and more than one kind of disability. Persons with depression can also be severely or profoundly disabled, but are more likely to have employment restrictions only. Using this data source, there were 13,000 severely or profoundly disabled people with schizophrenia, for example, and 44,300 with depression. This does not include other forms of mental illness which could result in psychiatric disability.

The Disability Investment Group (DIG) has undertaken further analysis on this issue[18]. By mapping SDAC data onto Burden of Disease data, they discovered that there would be 67,695 people with mental health problems aged 15-64 who would have a severe/profound core activity limitation. This does not include those people with a less severe psychiatric disability who nevertheless would need some care and support. DIG estimated the total number of people with psychiatric disability needing support to be 206,000[19].

3.3.7 How many people with a psychiatric disability currently receive support?

The Productivity Commission's Draft Report uses current CTSDA/ NDA data as an approximate starting guide to possible numbers of people eligible for a care and support scheme. This indicates that 23,292 (not including employment support which includes a larger number) people with a psychiatric disability receive accommodation or community support services through this agreement. A larger number, 33,946, received employment support only.[20]

Not only are the numbers of people with a psychiatric disability included low relative to incidence, but, as previously mentioned, these figures are skewed by the fact that Victoria serves 13,636 people with a psychiatric disability from this agreement out of a national total of 23,292 (not including employment support which includes a larger number). Both concerns are a result of differing conceptions by different states of whether psychiatric disability is included in the NDA or not.

Data from the Commonwealth funded Targeted Community Care (Mental Health) program which serve this group (PHaMS etc) are not included under the NDA and may represent additional supported individuals. It would be a worthwhile exercise to collect this data with a view to the design of a care and support scheme - with the caution that some individuals are likely to be double counted across programs and jurisdictions. As a preliminary indicator, about 10,000 people were supported by the PHaMs scheme in the year 2009-10[21].

3.3.8 What is proposed in the draft report?

The Draft Report suggests that, as a whole, 360,000 people of all disability types would access a new scheme, comparing favourably with the 172,000 people presently using non-employment support under the current NDA. However, Carers Australia suggests that the scheme as proposed will effectively screen out many people with a psychiatric disability from accessing it. Although the term 'disability' would not necessarily deter people with a mental illness from applying (as partially evidenced by an over demand for PDRSSs), the requirement of a person having a permanent disability would. The concept of a permanent disability is antithetical to the concept of recovery from mental illness or psychiatric disability, and excludes people with chronic but episodic conditions. As previously mentioned, the core activity restrictions used by SDAC to determine severe or profound disability are not highly relevant to many people with psychiatric disability. Although there is strong evidence that people with a psychiatric disability receive more benefit from earlier intervention, this group are not one that is mentioned under this category.

It is envisaged that these design details would result in fewer than the possible lower threshold of 50,600 people accessing the scheme, as informed by SDAC. Although more detailed analysis is required, it is not immediately clear that this number is significantly greater than the status quo of people with a psychiatric disability currently receiving community support.

3.3.9 Should psychosocial support be provided through a disability scheme or health services?

The Draft Report discusses this issue in some detail. It suggests that mental health-disability interfaces are complex and potentially problematic. In particular, it asks the question as to 'the extent to which the NDIS *should* (Carers Australia italics) address the poor performance of the mental health system and provide support to people with a mental illness'.

The early vision for an NDIS acknowledged that people with a disability often missed out on the support they needed because of geographical anomalies and state-commonwealth cost shifting. There are parallels here for people with a psychiatric disability. The discussion of which jurisdiction 'should' provide services must not disadvantage the people who need them.

A medical model of treatment for mental illness has its limitations in terms of both its efficacy and its scope. In some ways, it is unrealistic to expect the health system to help people with a mental illness to address their housing, employment or relationship needs. Recovery as previously defined is both a personal and social process. It requires a considerable conceptual shift to recognise this paradigm within a medical system. In many ways, the service design and practice required sits more comfortably within a social model of disability.

Even though there is clear evidence that housing and supporting people with a psychiatric disability pays for itself in reduced health, homelessness and prison costs, it has proved almost impossible for different government departments to recognise these cost offsets and pool funds. In Victoria, PDRSS's are budgeted for within the health budget. As such they must compete for resources within the mental health budget which in turn competes within the larger health budget. PDRSS funding has plateaued at 10-11% of Victorian mental health funding for the past 10 years, in spite of massive demand for services.

Possible interface issues between a NDIS and the mental health system should not be a barrier to including people with a psychiatric disability within the scheme. In Victoria, the PDRSS sector has encountered these issues for many years. Although they require continuous work to ensure that services are co-ordinated, this is not an impossible task. In many ways the example given in the Draft Report, that of someone with chronic schizophrenia is one of the less problematic examples. People in this situation receive clinical treatment from their GP and/or a medical team through their Area Mental Health Service. They receive regular psychosocial support through one or more services provided by a PDRSS. Regular case management meetings are held jointly to ensure that the treatment-support package is cohesive. In many ways, Prevention and Recovery Care Services (PARCs) provide a good example of what is possible through the use of a hybrid model of care.

3.3.10 Will future mental health reforms meet the needs of this group?

This issue was mentioned in the Draft Report and subsequent public hearings. There is speculation that the proposed National Health and Hospital Reforms (NHHR) might duplicate the efforts of an NDIS. Likewise, the current federal government has made a commitment to mental health in its second term and has tabled this intention at COAG meetings. Also not far below the surface is a different concern that, because the funding needs of mental health are so large, to include psychiatric disability in a NDIS could produce a total scheme cost so large that government would be deterred from embracing it.

The Government’s 11 May Budget has clarified the situation somewhat. The Budget contains a $2.2bill mental health reform package, $1.5bill of which is new money. Some $281mill over five years is for community support for adults with a mental illness through PHAMs, Mental Health Respite and Day to Day Living programs. There is also $343mill over 5 years to co-ordinate care for 24,000 people with severe, disabling and persistent mental illness. To a considerable degree these and other services are services that might be provided under a NDIS. Certainly they only go part of the way to address unmet need. For example, there are considerably more than 24,000 people with severe psychiatric disability who need support. But the Budget has made a good start. The additional spending could be integrated into a NDIS and diminish the net cost of a scheme that includes people with a psychiatric disability. Carers Australia urges the Productivity Commission to incorporate people with a psychiatric disability into its planning for a NDIS.

3.3.11 What are the options for the Productivity Commission?

Carers Australia recognises that the Commission faces difficult decisions. It must attempt to provide the reforms that are so badly needed while also recommending a scheme that is economically viable, politically acceptable and equitable.

Carers Australia considers that it is imperative that the Productivity Commission’s final report makes it clear to what extent people with a psychiatric disability will be included in a NDIS. There is a history of this group of people being theoretically included in some programs but not in practice. Examples of this are the Home and Community Care Program and Carer Payment and Allowance for those providing care. In some ways, ambiguity is a worse outcome for people with a psychiatric disability as a group than a clear exclusion as it can preclude future investment from other sources.

Eligibility ambiguity is also a risk for the integrity and viability of the scheme as a whole. It is likely that if this issue is not addressed, some people with a psychiatric disability will understandably attempt to access the scheme through existing categories, creating distortions. A person could, for example, emphasise physical needs and minimise psychosocial ones within Category 3a, or emphasise or seek an intellectual disability diagnosis for Category 3b, or mount a case for early intervention or large identifiable benefits from support (3c and 3d).

We have attempted to summarise the options available.

Option 1: Equitable inclusion of people with a psychiatric disability

The needs of this group are as urgent and far reaching as any other disability group. A NDIS provides an opportunity to resolve many existing problems for this group and their families: problems which arise from State-Commonwealth complexities, geographical variation in service availability (‘postcode lottery’), and lack of resources.

This option would be an effective way of making sure that people with more than one disability type do not fall through the cracks. It would preserve the integrity of the scheme by not discriminating on the basis of disability type.

This option would require additional data analysis to determine the potential number of people with a psychiatric disability who may be eligible. The overall number of people eligible for a NDIS would increase. Analysis should include the range of support needs for this group.

The Commission could consider the pooling of existing funding from the states in addition to Commonwealth Mental Health Funding (PHAMS, Mental Health Respite Program, Community Program, Day to Day Living).

In order to ensure that people with a psychiatric disability are included in practice as well as in theory, the scheme’s eligibility and assessment criteria would need to be broadened to address the needs of this group. This could be achieved in a number a ways. Assessment tools for Category 3(a) could be designed to be inclusive of social functioning and participation difficulties, consistent with the ICF. The ‘Intellectual Disability ‘ category (3b) could be retargeted to be inclusive of all people with primary brain or cognitive impairments, regardless of the source of disability. The scheme could also make provision for people with a psychiatric disability to be included under the early prevention category (3c), in some ways a natural fit for a group whose functioning can quickly decline without purposeful support. Similarly, people with a psychiatric disability could fit neatly into a ‘large identifiable benefits’ category. Eligibility should be based on assessed functioning, not psychiatric diagnosis.

The Commission would also need to consider the workforce implications of including this group. The proposed NDIS should support a recovery focussed approach. This will require different recruitment, training and supervision practices than for other forms of disability support, which will in turn need to be reflected in unit pricing structures.

Option 2: Inclusion of a small group of those with the most severe psychiatric disabilities

In some ways, this is what the Draft Report proposes to do, although it does so by applying indicative figures for scheme coverage rather than a more intentional system of rationing.

It should be recognised that, even if a small number of people with a psychiatric disability are included, for those individuals, their lives and those of their families will be enhanced immeasurably by receiving the support they need. Rationing of services to those who need them the most should be based on assessment criteria with clear rationales. There may be some merit in targeting people with dual disability (psychiatric and intellectual) who commonly miss out on support from either service.

Increased rationing is likely to heighten eligibility threshold and assessment issues.

Workforce considerations would still apply.

It could be speculated that meeting the needs of a smaller group of people with a psychiatric disability could come at the expense of the larger group. That is, inclusion of some people with a psychiatric disability within the NDIS could make it less likely for state governments to address the needs of ineligible people.

Option 3: A Delayed or staged inclusion of people with a psychiatric disability

This option would buy time, during which a NDIS is established. This could also provide more time in which to assess possible future health reforms.

In the meantime, however, alternative sources of investment and reform for this group could also stall, in anticipation of inclusion by NDIS. In effect this would put a brake on advocacy for the needs of this group of people.

Option 4: Not including people with a psychiatric disability in an NDIS.

This option would have the advantage of avoiding a possible source of cost increases for the scheme. Challenging (but possible) mental health system - NDIS interfaces would not need to be developed or encountered, apart from for some people with dual disabilities.

On the other hand, it also discriminates on the basis of disability type, something that the proposed NDIS was keen to avoid. In this way, integrity of the scheme as a whole is compromised.

Consistent with previous comments, if people with a primary psychiatric disability are not actively included in the scheme, it will be important for this to be explicit to avoid any unintended consequences of ambiguity.

Carers Australia recommends:

- **That people with a psychiatric disability are explicitly included in a NDIS on the grounds of equity and consistency.**

- **That the Productivity Commission conducts a more detailed analysis of existing data about the numbers and characteristics of people with a psychiatric disability.**

- **That while Carers Australia recognises that inclusion of people with a psychiatric disability in the scheme could appreciably increase its costs, this is not a reason to fail to engage adequately with the subject.**

3.4 Are there people needing lifetime care and support whose needs are hidden in the current system?

Many people with a long standing disability are not users of services funded under the National Disability Agreement or the Home and Community Care program but are likely to be eligibility under a NDIS. They include:

- people (often with either an intellectual disability or acquired brain injury) who were 'deinstitutionalised' in earlier decades to live in Supported Residential Services (SRS's) or Boarding Houses, or who are homeless
- people with pre-existing disabilities who do not access NDA services; a consequence of unsuitable or unavailable services in past years, and
- families from culturally and linguistically diverse backgrounds who do not access formal services but provide informal support to family members with a disability. NDA services users are less likely than the total Australian population to be born outside Australia (11% compared with 22%).

Carers Australia recommends:
That the role of local NDIA case managers includes an outreach function to encourage vulnerable groups currently 'outside funded services' to engage with the NDIA, in particular those in unstable or unsuitable housing.

3.5 The issue of eligibility and early childhood

A number of states and territories currently deliver early intervention support to a wide variety of children with developmental delay. They separate the delivery of early intervention and family support services for children under 6 from specialist disability services. They are reluctant to use a disability label too early, when early intervention has the potential to restore functioning to an age appropriate level.

Evidence based early intervention for very young children with a severe or profound disability is proposed to be a key role of the National Disability Insurance Agency. Negotiations with state instrumentalities will need to consider how further fragmentation of the delivery of early intervention services can be avoided. It will also be important to consider how the Commonwealth funded early intervention programs (Better Start and Helping Children with Autism) can have an improved interface with existing early intervention infrastructure.

4 ASSESSING CARE AND SUPPORT NEEDS

4.1 The diverse needs of carers

The Draft Report proposes an assessment framework to establish what 'natural supports' can 'reasonably and willingly be provided' by unpaid family carers, consistent with circumstances and lifecycle stage (5.8). It also recommends a separate assessment for carers who provide a 'substantial share of the care'. This assessment will focus on the sustainability of caring, and the carer's own support needs, as well as on respite assistance. We welcome this attention to the needs of family carers but believe that the development of objective measures of 'substantial care' across different condition types is likely to be challenging.

Caring families have diverse needs and circumstances. Their need for support is not always directly related to the extent of care provided. There is an expanding evidence base about the poor health and wellbeing of some carers[22]; financial disadvantage, significant proportions of primary carers with disabilities or chronic illnesses themselves[23]; higher rate of depression and anxiety than the general population[24]; social isolation and a lower rate of participation in employment.

The Cummins Report[25] emphasises that carers in comparison to other groups have the lowest health and wellbeing, average a moderate rate of depression and their wellbeing commonly decreases with increasing hours of caring. The most disadvantaged carers are sole parents.

4.2 High needs families

Grounded knowledge and practice have demonstrated that there is no absolute correlation between the nature and severity of a disability; the extent of unpaid family care provided and the needs of a caring family for higher levels of support. A wide variety of variables are relevant to considering the sustainability of family care and the nature of supports needed to prevent the risks of carer ill health, family breakdown or premature or unwanted out of home care. Families at risk who may require significant support include:

4.2.1 Families of people with significant decision making disabilities

There will be high numbers of people potentially eligible for NDIS who may have decision making disabilities (around 60% of users of services funded under the National Disability Agreement). There is a need to develop individual care plans in partnership with families where decision making disabilities are present.

Individualised person centred planning, particularly for those with decision making disabilities should:
- recognise the autonomy of individual adults with a disability on request but
- generally be undertaken in partnership with caring families, and
- encourage joint planning, explicit consideration of the roles of formal and family care and the negotiation of any differences.

4.2.2 Families with multiple care responsibilities

High caring loads can exist within or between generations. In 1998 the ABS Survey of Disability, Ageing and Carers[26] estimated that 20% of primary carers provided assistance to more than one person. The Australian Institute of Family Studies (2008) found that 13% of surveyed recipients of Carer Payment or Carer Allowance supported and assisted 2 or 3 people with a disability. These include families caring for two or more children with a disability, with or without other children; and families caring for one or more children with a disability and one or more disabled adults. Family members with multiple care responsibilities were found to have poorer mental health, physical health and vitality.[27]

4.2.3 Sole caring parents

Sole caring parents are considered to be at higher risk [28] in general, with increased risk for those who are socially isolated and lack informal support.

- 34% sole carers in a 2005 study considered relinquishing care, and [29]
- a small numbers of carers do relinquish the care of their son or daughter because the care load is beyond family resources. They are generally offered inadequate family support and assistance. The irony is that substitute care families are generally offered a higher level of formal support.

4.2.4 Ageing parents

Increasing numbers of elderly parents continue to care for adult sons and daughters with a disability. Many are widowed; others care for their son or daughter and their spouse with frailty or dementia. Many have disabilities or chronic illnesses themselves. We support the inclusion of this group in initial NDIS priorities.

4.2.5 Families who care for people with very challenging behaviours

These may include families who provide care and support for people with attention deficit hyperactivity disorder, autism, acquired brain injury or disinhibited behaviours or for those who are at risk of self-harm.

4.2.6 Families providing high intensity care

Families of people, who are not mobile, require transfers and lifting and have high level health support needs such as ventilation, PEG feeds, tracheostomy care, and seizure management.

4.2.7 Young people with significant care responsibilities

Many young people provide care for a parent with a disability such as an acquired brain injury, or multiple sclerosis. They may also provide care and support for their siblings and aim to hold the family together. Increased family support and assistance may prevent negative outcomes for the young carer.

Carers Australia recommends:
That assessment of the needs of carers be accompanied by the allocation of packages of support to high needs families to sustain family care.

4.3 The supports needed by high needs families

These include specialist disability supports which have the capacity to be both person centred and family focused if they are to assist in sustaining co resident family care.

The Productivity Commission emphasises that 80% of the care provided for people with a disability is provided by their families or friends[30] rather than formal services. In addition, while the Commission intends to ensure that people with a disability have increased opportunities to leave the family home at adulthood, consistent with their age peers:

- currently only 3.5% or people with severe and profound disabilities live in cared accommodation, a proportion that has progressively decreased since 1981
- many people with a disability will choose to remain living with their families in their home communities, and
- many people with significant decision making disabilities do not conceive of care outside their family home.

4.4 Needed family supports

A raft of family supports may be needed to sustain family care. These are supports targeted to support the family to continue home care particularly for:

- high needs families, and
- families at risk of stress, ill health or family breakdown

Family support services include:

4.4.1 Regular in home family support, domestic assistance or behaviour management support

These may be needed to:

- sustain high dependency care in the family home
- support parents with a very challenging and disruptive offspring
- support isolated sole parents with significant family responsibilities
- assist ageing parents with a disability or illness
- support or supplement family functioning where a parent with a significant disability has dependent children, and
- support young people with significant care responsibilities for a parent.

4.4.2 Regular in home respite or community participation support

This support for the person with a disability will allow:

- family space for addressing other relationships and caring roles, and
- promoting increased independence for the son or daughter of an ageing parent.

4.4.3 Family focused transition support which includes

- Carer support/ early intervention at the transition into the caring role to assist families to come to terms with diagnosis of disability; to deal with loss and grief; to learn about the implications of the disability and available services, entitlements and supports.
- Family focused support at key lifecycle transitions. In general at key transition points, both people with a disability and their families anticipate their future needs, collect information and explore available options, learn what will be involved, share the decision making and consider what their new roles and responsibilities may be. Referral and linking of the person with a disability and the family to new services and support options are needed. Transitions for the person with a disability will commonly need to be pre-planned, timely, phased in and supported by families, particularly for children and for adults with decision making disabilities. Case management support for key lifecycle transitions will often be required for both the person with a disability and their family.

4.4.4 Is family support preferable to the concept of respite?

The Productivity Commission emphasises the moral and economic imperatives for the provision of support to caring families. But it has limited its description of family supports to various forms of formal respite and family carer capacity building/training to be delivered through referral from the NDIA to Carer Support Centres. Allocations for counselling and carer training may be included in individual support packages to encourage choice.

The best training and counselling options for caring families are to be appraised as part of NDIA research function. The National Carer Counselling program is recommended to continue – although the Commission emphasises the need for competition and choice.

Respite provision in the disability sector has evolved as a consequence of significant rationing of specialist disability services, both for the person with a disability and for their families. While there are a variety of respite services or activities for people with a disability, (in home, out of home, facility based), a wider variety of specialist services provide a ‘respite effect’ for their partners, parents or families. For example, access to ongoing and adequate personal care, education, day programs, employment, and community participation can provide a ‘respite effect’ for families and positive experiences for the person with a disability. This can reduce the need for formal, traditional respite programs and replace the notion of relief of carer burden with positive opportunities for community participation by the person with a disability which equally benefit the family.

Emphasising respite as a service type disguises a range of needed supports for the person with a disability and for their family. A new conceptual framework would see the notion of respite replaced by a variety of regular ongoing and adequate disability and family supports, chosen according to the needs and preferences of both the person with a disability and their family.

These include normalised opportunities such as:
- regular participation by the person with a disability in out-of- hours community recreation and leisure activities, with or without support
- regular access by the person with a disability to participation support from social and friendship networks
- opportunities for supported camps, holidays and travel with friends
- active in home/out-of-home support with a hobby or interest to allow family time for other activities
- host family care such as Interchange, and
- vacation and out-of-school or centre hours care.

Out of home group holiday (respite) arrangements will also be required to ensure a break for some families providing high intensity care. They must operate on the principles of a positive experience for the person with a disability and beneficial outcomes for their family.

Carers Australia recommends:
That eligibility and needs assessment processes and care plan development are both person centred and family focused and these should include consideration of the support needs and choices of caring families.

Significant family needs would be reflected in an entitlement to a family focused package of support, developed according to the needs, preferences and choices of caring families and targeted to sustaining family care.

The eligibility of carers for a tailored package of support when the person with a disability refuses to access specialist disability services requires consideration.

Carers Australia recommends:
That the NDIS includes a mechanism for caring families to access support independently of the person with a disability.

There will always be a need for episodic and emergency care and support arrangements for people with a disability to accommodate illnesses and death in caring families, and episodic changes in family needs. Such changes may require a reappraisal of the support needs of the person with a disability and their family, and the provision of additional support until a new equilibrium in formal and informal care arrangements can be achieved.

Carers Australia recommends:
A quarantining of funds to ensure the timely availability of resources for tailoring increased episodic and emergency care arrangements, chosen according to the preferences of the person with a disability and their family. This may be for a short or longer term period until equilibrium is restored.

4.5 People with a disability

Carers Australia supports the proposal to assess the nature, frequency and intensity of the needs of the person with a disability in a way that is individual, independent, objective and benchmarked. We support the intention for assessment to flexibly consider functional based measures as well as condition based measures where relevant. The use of the International Classification Framework (WHO) will provide a positive assessment framework. We are keen to ensure that the toolbox encompasses consideration of psychological and social capacity of the person with a disability for participation in education, employment and social activities. These factors are particularly important for adolescents and adults with an intellectual disability, acquired brain injury or autism who may face learning and decision making disabilities and need ongoing guidance, encouragement and emotional support. The proposed incremental development of the toolbox over time is likely to contribute to improved evidence based assessment practices.

Carers Australia recommends:
That disability needs assessment encompasses a consideration of the capacity of the person to participate in education, employment and social life.

4.6 Eligibility assessment tools

While there has been work done by DoHA and FaHCSIA on a Carer Eligibility and Needs Assessment tool (CENA) this is yet to be in the public domain. While the CENA may have considerable usefulness, a tool to assist exploratory assessment of the family situation should be included in the Toolbox, as a means of gaining better understanding of the person in his or her family situation. It is acknowledged that not all people with a disability have caring families and that the autonomy of the person with a disability to choose whether or not to involve families must be preserved.

Comprehensive carer needs assessment is essential to the delivery of person centred, and family focused care. It is essential to ensuring that preventive support and assistance is provided where necessary to ensure the health, wellbeing and quality of life of both the caring family and the person with a disability. It is an essential means of ensuring adequate support to sustain family care.

Carers Australia, through its Member Associations has developed conceptual models for holistic assessment of the needs of individual care situations. One of these is outlined in the two figures below.

Figure 1: Holistic Assessment of the care situation

This figure [31] illustrates how the needs of the family carer and the person with a disability can be equally considered. It is a means of considering the support services needed by both. In addition it provides a means of exploring differences in the needs, priorities and aspirations of the family carer(s) and those of the person with a disability. Differences can be acknowledged and negotiated within the needs assessment and funding allocation process.

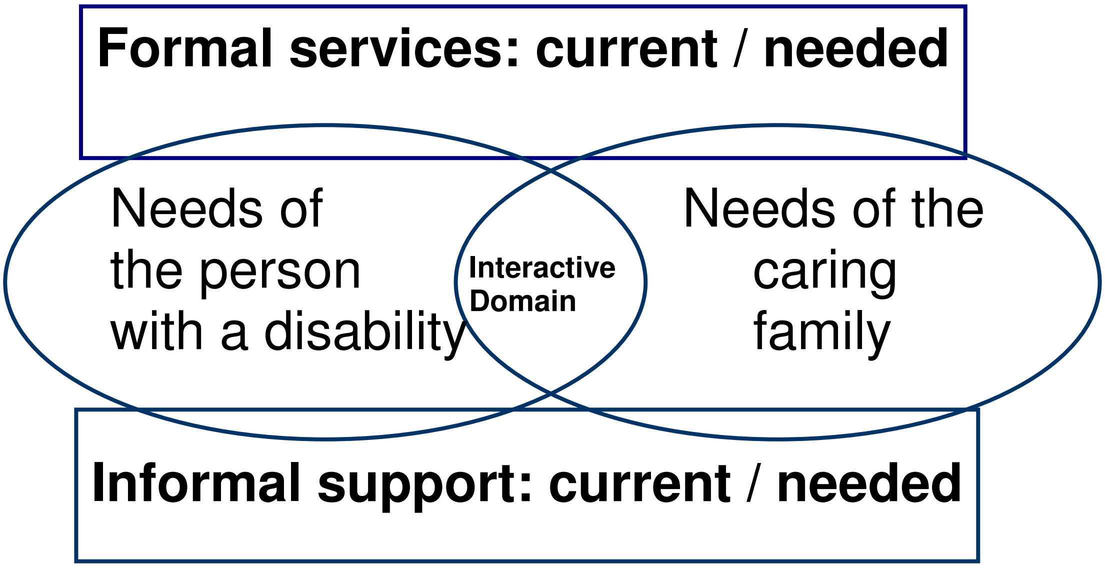
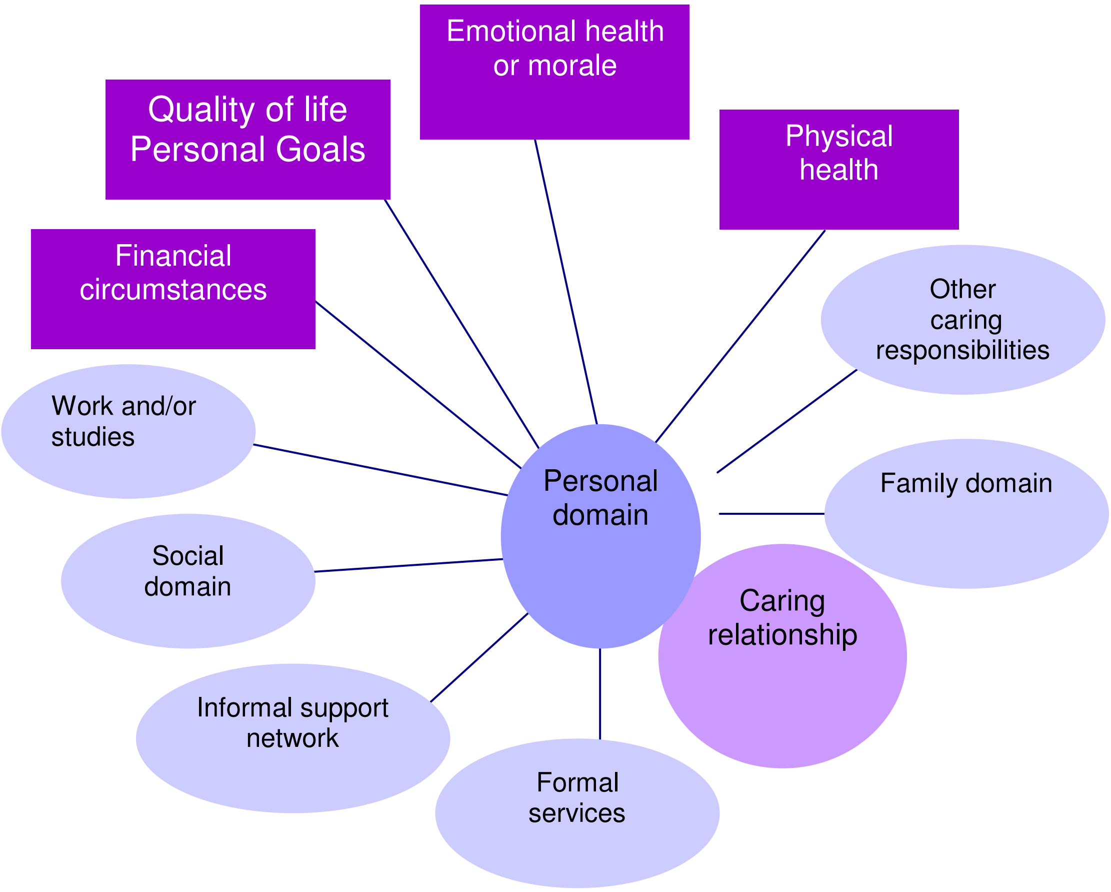


Figure 2 Assessment of Family Carer Needs

This figure[32] illustrates the components of a comprehensive assessment of family carer needs.



The domains of a comprehensive assessment of family needs

Oval shapes represent interactions between the family carer's life and caring experiences:

- ***Personal domain** includes the family carer's demographic details including marital status, cultural background and language(s) spoken*
- ***Caring relationship domain** includes the history and quality of the personal and care relationship as well as caring tasks and responsibilities*
- ***Family domain** includes relationships with other family members including family members who provide direct support for both the person with a disability and for the primary carer (if any)*
- ***Other care responsibilities domain** includes care of older people, other children and adults with a disability, mental or chronic illness as well as regular care of children or grandchildren*
- ***Work and/or studies domain** includes current employment/study commitments or goals to undertake these*
- ***Social domain** includes friendships, community involvement and recreational/leisure interests*

- ***Informal support network domain*** *includes neighbours, colleagues, community and faith based groups, and*
- ***Formal services domain*** *includes satisfaction of the person with a disability and the caring family with the supports currently used (if any)*

Rectangle shapes represent the family carer's personal resources and responses to the caring role:

- ***Physical health domain*** *includes any health condition, disability, chronic illness or injury risk which may affect the capacity of the carer to provide support and assistance*
- ***Emotional health or morale*** *domain includes satisfaction, confidence and sense of control in the care situation as well as any feelings of depression, anxiety, grief and guilt*
- ***Quality of life and personal goals domain*** *includes the hopes, plans and worries about the future.*
- ***Financial circumstances domain*** *includes costs of disability/ caring, access to concessions and benefits and any legal or financial arrangements.*

The establishment of 'reasonable and necessary' formal supports for the person with a disability and 'reasonable and willing' levels of informal support must take account of the needs and circumstances of the family and carers. Needs and choices are interconnected; generally families are 'in it together'.

Carers Australia recommends:

- **That the NDIS offers separate needs assessments for people with a disability and for their families, noting that many families would choose a combined process.**

- **That the NDIS incrementally develop a reliable, validated and rigorous family assessment tool as a component of the tool box.**

4.7 Reassessment and review of support needs

The Productivity Commission outlines a system for timely reassessment and review around major lifecycle transitions (Section 5.8). A person centred and family focused approach would take greater account of other key transition where changes in formal support may be needed such as:

- increasing formal and informal support needs which occur in some progressive or degenerative disabilities
- decline in carer health and wellbeing (short or long term) or the health and well being of the person with a disability
- behaviour changes which require intervention
- episodic changes and reductions in key informal family support (such as siblings moving interstate, parent divorce), and
- changes in access to key services – such as loss of employment or day programs – which require families to regroup and reorganise.

Carers Australia recommends that:

Both people with a disability and their carers should be able to request timely and responsive reassessment as a consequence of change or predicted changes in individual or family circumstances.

5 SPECIALIST DISABILITY SUPPORTS

The Commission has included a comprehensive list of specialist disability supports, targeted to the person with a disability. Further definitional clarification is needed in the final report. This includes particularly the boundaries between specialist accommodation support, domestic assistance and personal care.

5.1 Specialist accommodation support

This is defined as group homes or alternative family placement, encompassing support for clients to carry out essential tasks of daily living. Does it include the following?

- Co-resident homes or co-tenancies (free board in return for support and guidance)?
- independent living with drop in staff support (mornings and/or evenings) to provide guidance and support with daily living?
- 'Living nearby' clusters? Independent living with access to staff support located nearby?
- Lead tenant arrangements – a dispersed group of apartments close to a staffed, tenanted apartment?
- Non active overnight staffed care?

The meaning of independent living within the disability sector encompasses the above options, as well as domestic assistance, according to the needs of individuals and households. While people with a physical disability may live independently with the support of needs based personal care and domestic assistance, people with intellectual and other decision making disabilities can require ongoing emotional support, guidance, encouragement, and prompting through regular access to paid care.

5.2 Domestic assistance

This is defined as services to enable people to live in the community and live on their own. It includes meal preparation, domestic tasks, banking, shopping, and organising day to day tasks. Such a functional definition perhaps omits the affective supports such as motivation, encouragement and emotional support that may be required by people with decision making disabilities to live more independently.

6 CARER SUPPORT SERVICES

In Carers Australia's response to the Productivity Commission's draft report on the Caring for Older Australian's Inquiry, we argued strongly in support of the Commission's proposal to develop Carer Support Centres. These Centres have the potential to bring about significant improvement in the experience and lives of carers. Carers Australia therefore supports the related recommendation in the Commission's draft report on Disability Care and Support where following an assessment of a carer's needs, the NDIS may

> 'Refer people to the Carer Support Centres and to the National Carers Counselling Program (Rec 13.3).'

We would reiterate here, however, that if the potential of these centres is to be realised several conditions for their funding and operation need to be met. The Centres should:

- provide a broad range of supports, broader than those currently provided by the Commonwealth Respite and Carelink Centres (CRCCs). This should include carer counselling, carer advocacy, peer group support, education and training, respite services, in-home support and an alternative care program for employed carers
- be resourced to provide ongoing preventative support and assistance, particularly for intensive caring situations, instead of focusing solely on the relief of stress and burden
- support all carers, including carers of people with a disability (as indicated in the Productivity Commission's Disability Care and Support draft report). Carers should be able to access support, regardless of whether the care recipient receives services or is eligible for services under either of these two schemes
- be effectively linked with Medicare Locals, Local Health Networks, mental health services, and relevant bodies in the disability sector (e.g. the proposed National Disability Insurance Agency and assessors)
- receive significant and ongoing funding to ensure their sustainability and capacity, and
- be effectively governed, and operate and perform consistently in all jurisdictions.

Carers Australia therefore repeats its recommendation from its response to the Caring for Older Australians draft report:

That the Commission should ensure that the proposed Carer Support Centres are adequately resourced to provide a broad range of services and supports to all carers.

7 INDIVIDUALLY TAILORED SUPPORT PACKAGES

7.1 Individualised funding

The Commission recommends individualised funding through person centred and directed care rather than block funding to services providers. Most people with a disability will be allocated a package of entitlement to support and a choice of providers.

Carers Australia gives qualified support to the intention of individualised, person centred care. This will allow people with a disability and their families greater freedom, choice and control with their services and supports. Within limits they can choose the services they receive, who will provide them and when. It is an empowerment model which shifts control away from providers and towards people with a disability and their families.

Our caution comes from the knowledge that international evidence about the long term cost effectiveness of self-directed and self- managed care is limited. For skilled individuals, there is considerable evidence that better value for money can be obtained through self-management. The use of a financial intermediary can also minimise or reduce the costs of operational overheads.

However, the evidence of cost effectiveness at a systemic level may not be conclusive[33]. The small numbers of evaluation studies are fraught with methodological problems, and have a short term focus. Most appear to focus on individualised funding for one disability services type rather than individualised funding for a variety of services. Most studies have not explored cost and benefit issues over the long term.

The Commission anticipates that self-managed care will be possible initially for a minority, subject to some accountability controls and some funding being tied to essential services. Self-management capacity will be assessed and support offered with the development of the necessary skills.

Carers Australia has reviewed the national and international literature on consumer directed care[34] and broadly supports the models proposed by the Commission. Internationally the take up rate of self-managed care has been slow and mixed between different target groups. People with physical and sensory disabilities have a higher take up rate; older people, people with an intellectual disability and their families are more reluctant[35]. Third party managed care (where an individual budget is managed through a financial intermediary) is more attractive to many.

7.2 Self-managed care

Carers Australia supports the following recommendations of the Draft Report:

- **Assessing an individual's or family's capacity to self-manage their care.** Stability in the care situation and 'readiness' must be precursors to self-directed or self-managed care[36]. Feelings of loss, grief and confusion can be features of an initial disability diagnosis. They can be accompanied by the need for discussion, information provision, encouragement and emotional support to determine a course of action. For many people with a disability and their families, case managed early transition support together with care management by an intermediary will be essential until an equilibrium is reached.

- **The establishment of clear boundaries around essential services (admissible and inadmissible).** There will be a need to control and regulate the boundaries of essential services[37] and to manage risk.

7.3 Employment of family members

Carers Australia expresses caution about the direct employment of family members. Internationally, the direct employment of family members to provide care services and the question of whether family carers should receive payment out of individual budgets is a contentious one.[38] It can ensure responsive support is available for geographically or culturally isolated people. It can also risk commodifying informal care and blurring its boundaries with formal care.[39]

In New Zealand[40] the direct employment of family members has at times contributed to reducing the independence of the person with a disability and encouraging family reliance on payments. In the United Kingdom, family carers expressed concern about conflict of interest in being paid to care.[41]

Direct employment of family members will need to be an option for a minority of people with a disability and their families such as rural and remote families or CALD and

Indigenous families. In these circumstances, employment of family members or friends eventually through an agency and their access to supervision and support could be considered. Approval and review practices are needed for participating families.

There are other macro issues to consider here. It is likely that families opting to directly employ one or more family members are already disadvantaged, whether geographically, culturally or economically. For this reason, there are a number of tests that should be applied when evaluating this part of the scheme. These might include whether family members are more or less socially excluded as a result of receiving payment for care. This should apply to all family members (the person with a disability and other family members) and should be on a population and longitudinal basis as well as an individual and short term one. “Social exclusion” should be measured across community participation and economic domains.

In addition, Carers Australia is interested in the implications for long term social policy goals of the scheme. For example, would paying family members interfere with the long term goal of increasing society’s and the market’s capacity to provide care? Would paying family members distort the market in the long term by disguising workforce supply shortages?

Carers Australia recommends:

That employment of close family members is generally limited to situations of intermittent care by non-resident family members.

Carers Australia endorses the proposed distinction between:
- employment and payment arrangements for flexible incidental care, and
- full employer responsibilities for large packages which employ support workers for substantial amounts of time.

This is a positive compromise which can increase choice and promote the engagement of family and friends for limited care roles, thus broadening recruitment possibilities for paid care. It has the potential to avoid the emergence of a grey economy of lower paid workers[42]; although in Victoria above award payments are a common feature of the direct employment program.[43] Clear practice guidelines will be needed.

Carers Australia also endorses:
- the Commissions proposed trial and evaluation of the employment of family members under self-directed funding, and

- the potential for pooling funds from individual funding packages across disability and aged care services.

There is potential for self-directed or self-managed care to reduce services fragmentation for families such as ageing parents with a disability or chronic illness. Support packages respectively for the parent and the person with a disability have the potential to be pooled and managed via the same intermediary organisation.

7.4 Self-managed care and the market

Self-managed care and consumer empowerment and choice are anticipated to stimulate competition and innovation in the market. However, there are market distortions in community care in the form of supply imbalances for some high needs groups such as adults with cognitive difficulties and very challenging behaviours; and people with profound and multiple impairments. ‘Cherry picking’ within the community care market has been demonstrated in relation to provider reluctance or refusal to provide services to the most vulnerable.

The proposed National Disability Insurance Agency will monitor service needs and gaps. There is a proposed innovations fund.

Carers Australia recommends:
The initiation of new and responsive individual or group programs to fill gaps in the current services system through investment in infrastructure for community and program development.

That the NDIA ensures that there is capacity in the system for identifying, establishing, and supporting the development of new individual or group participation options.

While there are many benefits there are also risks in individualised community access and participation – particularly the risk of isolation. Many people with decision making disabilities may wish to participate in new small group programs such as recreation participation or small group holidays. These may require base funding or transition funding to seed their initial development, and essential outreach and ‘back of house’ work.

There is a place for a continuation of block funding and highly specialised programs in certain circumstances, usually tied to essential services. These include:

- services in low population rural and remote areas where there is a single supplier and little potential competition. Multipurpose services may be required and there may be little interest in cashing out program funds. This may also be applicable to services in some indigenous communities

- essential services such as emergency respite which must be equitably available and should not be left to the whims of the market

- services where coordinated and multidisciplinary expert approaches are required. Examples may include early childhood intervention programs which combine early educational and developmental intervention, family capacity building, family counselling and mutual family support

- complex care situations such as those involving young people with care responsibilities for a parent with a psychiatric disability or acquired brain injury. The coordinated family interventions and family support services required are highly specialised and could be provided via block funded agencies. They may not be readily delivered through individual packages of support

- coordinated multidisciplinary support for ageing parent carers and their sons or daughters with decision making disabilities (a priority group). There is an urgent need to develop an evidence base and practice wisdom concerning best practice in transition planning and support for ageing parents. A comprehensive well resourced and empowering case managed approach is needed which combines:

  - planning for future housing and support through active family engagement and access to quarantined package funds for specialist accommodation support or alternative housing and support
  - funds pooling of care packages to allow the development of chosen living arrangements with friends
  - formal and informal care resources to support the person with a disability
  - implementing/ brokering appropriate housing and support options, and
  - supporting people with a disability and their families with future planning including Wills, Trusts and estate planning, and future representation arrangements.

- block funding may also be appropriate for some day programs, particularly for people with a significant intellectual disability or those with a psychiatric disability. While we support the thrust to increase community access and participation for people with a disability, the value of group programs in the provision of mutual support, non-judgemental acceptance and the development of social relationships with peers needs to be acknowledged. Assumptions about choice, self-determination, and community participation make little sense when they are applied to adults with significant decision making disabilities who have difficulty with communication and making major life decisions[44]. Differentiation of the pathways of different disabilities into policy and practice is required.

Carers Australia recommends:
That block funding for essential services be retained as a funding option, for highly specialised and tied interventions and to address the needs of rural and remote communities.

8 AIDS AND APPLIANCES

Carers Australia supports the importance attributed to the timely provision of aids and appliances to support home care and enhance participation and independence. Aids and appliances can deliver considerable cost savings[45]. Currently considerable out of pocket costs are borne by people with a disability and their families (73% according to the Australian Institute of Health and Welfare[46]). Gap costs are too great, and many people with a disability need multiple items and elements to effectively address their needs.

A recent study by Deakin University[47] demonstrates:

- There may be multiple elements to an assistive technology solution (multiple aids and equipment, multiple environmental modifications and episodes of care). These need to occur together in individually tailored hard devices and soft (assessment and trial) assistive technologies, and environmental interventions.
- Many effective assisted technology solutions require both customised and generic devices used interdependently. Many generic solutions are not included on listing of eligible devices.

Return, refurbishment and reissue of equipment can provide considerable savings to an Aids and Equipment scheme.[48]

9 GOVERNANCE ARRANGEMENTS FOR THE PROPOSED NATIONAL DISABILITY INSURANCE AGENCY (NDIA)

In its August 2010 submission to the Disability Care and Support Inquiry, Carers Australia noted that in consultations it had conducted with carers a clear concern was expressed about a feared insensitivity of an `insurance' organisation to the needs of people with a disability and their carers.

As part of the governance arrangements for the NDIA, the Productivity Commission has recommended an independent commercial board, comprising people selected for their commercial and strategic skills. The perspective of people with a disability and their carers would be provided by way of an advisory council, comprising representatives of disability and carer amongst other groups. In addition there would be an appointment panel which would nominate candidates for each board vacancy. The panel would include people with ‘a clear interest in disability policy issues’.

Carers Australia accepts that membership of the board should not be representational but based on the skills and experience of individual members. It supports the proposal for an advisory council, which would include a carers’ representative. A problem with the recommended governance arrangements, however, is that they do not rule out the possibility that no member of the board had either a direct experience of disability or caring or a background in related areas of policy (the board selection criteria recommended at 7.28 seem narrower than implied by the discussion at 7.25).

If the board is to have empathy for the objectives of the NDIS and if stakeholders are to have confidence in the NDIA, we believe it is essential that at least some members of the board have disability or caring experience or a policy background. One way to achieve this would be to make this experience or background an essential qualification for some of the board positions.

Carers Australia recommends:
That the experience of disability or of caring, or a policy background or work experience in related areas, should be an essential qualification for at least some of the Board positions on the NDIA.

The Productivity Commission has recommended that the NDIA directly manages complaints and disputes through an independent arm. Generally external complaints processes are desirable to ensure an objective and unbiased approach and to ensure public confidence. However, the internal management of risks is considered necessary to protect the integrity of the scheme.[49]

Critical to the transparent operation of the NDIA will be the roles of individual and systemic advocacy undertaken by peak consumer representative bodies on behalf of their constituents.

10 ISSUES AT THE INTERFACE OF THE NDIS AND MAINSTREAM SERVICES

Disability care and support must be a whole of government responsibility. Carers Australia supports the intention of Memoranda of Understanding between mainstream services providers and the National Disability Insurance Agency. The coherent collection of data about the nature, frequency and intensity of the support needs of eligible people may provide a means of leverage and reporting for improved program planning in mainstream instrumentalities. It will be important that the NDIS advocate for and supplement mainstream services for people with a disability rather than substitute for them.

10.1 In education

It is important that mechanisms and opportunities for the NDIA to leverage appropriate levels of funding for education aids, based on need, in early childhood and educational settings. This is a critical area of concern for family carers.

10.2 Interface with aged care

Carers Australia supports the Commission's proposals concerning people with a disability of age pension age having the option of continuing to use NDIS provided and managed services or moving to the aged care system. The co-payment requirement for people above age pension age is likely to be manageable. People with a disability who are over 65 are more likely to be financially disadvantaged.

The issues for people with long term disabilities who are ageing are becoming more apparent after years of implementing community living policies. In common with the rest of the community, people with disabilities are living longer, but may experience ageing differently. They rarely receive the supports they require. The Commission must address the issues at the interface between recommendations to reform the care of older Australians and disability care and support. People with a disability and their carers will need guidance and support to be able to make an informed choice as to whether needs are best met through the disability system or the aged care system.

Assessment and support services in both systems need to be flexible enough to:

- Sustain care relationships through enhanced access to aged accommodation and support when there is interdependence between an older family carer and a person with a disability.
- Pool packages of entitlements to care and support received by an ageing carer and by a person with a disability so that support to the care situation is coordinated and less disruptive to people's lives. Use of a single intermediary is likely to assist.
- Enhance access to aged care assessment for people with disabilities who experience premature ageing with improved guidance for assessment services in determining ageing related conditions in people under 67 years. Joint assessments between the NDIA and ACAT or Gateways may be considered.
- Enable older people with disabilities living in disability supported accommodation to 'age in place'. This may require increases in individual support packages to support participation or care at home.
- Ensure access to rehabilitation and support services for older people who develop a psychiatric disability.
- Improve access to Aged Psychiatry Assessment and Treatment Teams (APATTs) for support with responding to behaviours of concern.

10.3 Interface with health services

The development of Memoranda of Understanding between the National Disability Insurance Agency and health departments in each jurisdiction will be important in relation to:

- ensuring appropriate health care for people with a disability. It is noted that they are more likely to poorer physical and mental health and higher rates of health risk factors[50]
- minimising cost shifting between health and the NDIS particularly in relation to people with a chronic illness and associated activity restrictions, and
- Minimising cost shifting between health and the NDIS concerning people with a terminal illness.

10.4 Interface with justice systems

The comparatively high numbers of people with a disability who interact with the justice system indicates a need for the NDIA to develop common MOU's with Justice Departments. The focus should be:

- responding to and supporting people with an intellectual or psychiatric disability who enter or risk entering the criminal justice system
- providing early intervention for people at risk, and
- strategies to prevent incarceration or reoffending.

In New South Wales, similar to other states and territories, 54% of female prisoners and 39% of male prisoners had been diagnosed at some point in their lives as having a psychiatric problem.[51] People with an intellectual disability are also disproportionately represented. One study found that while people with an intellectual disability constitute 2-3% of the population, nearly one quarter of people appearing as defendants in six local courts in NSW could be diagnosed as having an intellectual disability, with a further 14.1% being regarded as in the borderline range of ability.[52]

10.5 Interface with housing

Lack of access to suitable, stable and affordable housing consistently ranks as one of the biggest challenges for people with a disability and, in turn, for their families. In many ways, the need for housing and support are inseparable for this group; one cannot succeed without the other. Carers Australia believes that a lack of housing looms as one of the biggest constraints upon successful outcomes for people with a disability and the scheme as a whole.

The Productivity Commission's Draft Report refers to access to social housing as a mainstream issue. The rationale for this is that public and community housing is available to many others in the community and so is not specific to people with a disability. While this is true, it is also the case that access to housing is a disability issue because it is a key component to living in the community and is affected by the low incomes and discrimination encountered by many people with a disability. This is an area in which the market consistently fails people with a disability. The systemic problems of mainstream housing and its shortage in particular, will impact upon a NDIS and must be considered.

The Draft Report does make an exception to the argument that housing is a mainstream issue. It appears that existing forms of supported accommodation currently funded through the NDA will be included in a proposed NDIS. This can be seen as reflecting the status quo of the current housing landscape in which some people with more severe disabilities are eligible for group housing in which accommodation and support are combined. Often people with similar disability types are housed together in this way. However, the vast majority of people with a disability do not live in these housing models; they live with friends or family[53].

There are clear implications here for equity and choice. The trend over the past few years, even taking the more recent Nation Building Program spending into account, is for numbers of social housing dwellings to be in decline. At the same time, the general population is growing, and numbers of people with a disability are proportionately increasing. Purchasing or private rental of housing is unaffordable to many. In addition, even if people with a disability do not encounter discrimination in the private rental market, this tenure type rarely offers the stability they need. The implications for families are clear; many people with a disability have no choice but to remain in the family home. This can have profound negative effects on quality of life and choice of all family members. For more detail on these issues, refer to AHURI's paper, 'The housing careers of people with a disability and carers of people with a disability'.

The Victorian public housing priority system, in common with other State Housing Authorities, does not use the existence of disability as a prioritising criterion, although the need for formal support is taken into account. Rather, provision of public housing is based upon housing need. Although many people living in social housing do happen to have a disability, most people with a disability living in the family home do not qualify because they are seen as being adequately housed. They may of course, apply to go on the general waiting list (or 'Wait-turn' as it is known), if income and assets tests are satisfied. Wait times can then be longer than ten years.[54] [55]

It is no wonder that Shared Supported Accommodation, such as that funded through the NDA, is seen as an attractive option by many people with a disability and their families. Accommodation and support are co-ordinated, but perhaps most importantly, it provides housing security where little exists elsewhere.

Carers Australia takes a pragmatic stance, informed by the views of people with a disability and their families. What is clear, though, is that there is a mismatch between the assessment criteria for SSA and mainstream housing. The former prioritises the need for support over housing choice or, indeed, housing need, the second prioritises according to housing need and is somewhat blind to disability or support needs.

10.6 What should the Productivity Commission recommend about housing?

It is not feasible for a NDIS to fund all housing for people with a disability. Nor would this necessarily be desirable in that motivations to access the scheme could become distorted by housing need.

However, as an insurance scheme, there are strong incentives to influence mainstream housing for people with a disability. The policy needs here can be seen as twofold: the first is to ensure that mainstream housing, of all tenure types, are accessible to people with a disability. The second need, tied to the first but possibly even more important, is to advocate for and promote an increase in supply of affordable housing.

There is work already occurring in these areas which could support a NDIS:

- state housing authorities have agreed with the Commonwealth to develop Common Waiting lists in which public and community housing lists are combined. There is an opportunity here to develop clearer eligibility rationale so that community housing providers are prescribed targets for housing people with a disability on very low incomes

- advocacy efforts have recommended that Commonwealth and State governments plan and invest in affordable housing for people with a disability. There is a need for more population data and its analysis to inform these processes

- there has been some success in advocating that new social housing should be built so as to be universally accessible for people with disabilities. It is important that the Commission supports this. The suggestion in the Draft Report that a NDIS would fund housing modifications in the social housing sector should apply to existing stock only so as to avoid cost shifting by State Housing Authorities, and

- the National Rental Affordability Scheme (NRAS), in which private or NGO landlords receive a financial incentive in return for providing housing at below market rate, holds considerable promise for people with a disability and their families. Carers Australia is unaware of whether data relevant to disability is currently collected. It is therefore difficult to assess whether it is reaching people with disabilities, and if so which types and in which housing markets. With access to data of this type, it may be possible to build a case that landlords receive a larger subsidy if they house people with disabilities.

The Henry review of Australia's Taxation system contains several relevant and potentially useful ideas in this area[56].

- The first is that people with special housing needs eg homeless people, people with disabilities and/or mental health problems, should receive an additional "high need housing payment"[57] with which to approach social housing providers (both community and public housing are proposed). The intention behind this is very well founded; there are financial and structural barriers for community housing providers wishing to house people with a disability[58]. Registered Housing Associations in Victoria are required to grow their housing stock as a condition of registering. However, this runs directly counter to an aim of providing a high proportion of housing for people on the very lowest incomes (eg DSP, Newstart), particularly people who wish to live alone.

- The second is that the Commonwealth Rental Assistance (CRA) program is reviewed and targeted more effectively[59]. This would involve benchmarking the subsidy according to local market rents and increasing the amount offered to those on the lowest incomes. Some people on higher incomes would become ineligible. Analysis by housing experts suggests that the feared distortion of the market at the lower end (ie an increase in rents) would not occur because the numbers are insufficient relative to the market.

- Mixed and shared equity schemes in which people with a disability and/or their families purchase homes in partnership with social housing providers hold promise and are in existence now in small numbers. However, the data about how many people with a disability might benefit from such schemes gives a somewhat mixed picture[60] [61]. Many people with a disability and their families are poor in terms of both equity and income, with little prospect of future increases in income. Mixed equity schemes may benefit some families, but further work is needed before it can be seen as an area of significant growth and scaled up accordingly. There are also equity issues to consider here. Families who are in a position to contribute financially may acquire stable social housing sooner than others. On the other hand, if financial investment by families did not receive an advantage, then why should they invest? This issue comes back to the aforementioned macro structural problems: if housing supply does not increase, then people with a disability continue to have to compete with others, regardless of innovative policy.

With specific regard to the suggestions made about housing in the Draft Report, Carers Australia would like to make a few additional comments. The concept of ‘cashing out’ housing and support dollars to purchase or rent a home has intuitive merit. It improves choice and may enable some to achieve stable housing who might not have been able to otherwise. There have been similar proposals recently suggested in the United Kingdom (cf IPPR). However, more detail is needed before the idea can be supported wholeheartedly. For example:

- What financial and bureaucratic structures would be needed to allow this to occur? How would the scheme be funded?
- If some people were able to cash out their public housing dollars, say, what would this mean for other tenants who could not? Would this result in even further residualisation of public housing?
- If the scheme was successful and large numbers of people cashed out their housing, what effects would this have on the market? Without additional supply of housing and increased demand, additional spending power could result in higher prices and rents as demonstrated in the First Home Buyers Scheme.
- If, as suggested, people could top up their cashed out package to live in an area of their choosing, what does this say about the suitability of housing available to people who are not in a position to top up?

Carers Australia recommends that:

A NDIS collects longitudinal data about the housing needs of people with a disability.

In its final report, the Productivity Commission stress the importance to successful disability reform of increasing the overall supply of affordable housing and of improving the access of people with a disability to affordable housing.

11 INCOME SUPPORT

11.1 Carer Payment

One expected outcome of an NDIS would be an increase in workforce participation of people with a disability and their carers with a resulting reduction in government expenditure on Disability Support Pension and Carer Payment. This saving could be used as an indirect cost offset when presenting the scheme to government.

However, with regard to the Carer Payment, the Productivity Commission’s Draft Report takes the notion of ‘offset’ much further when it canvasses the option of the value of the payment being included in the individualised budget of a person with a disability, who could decide to choose alternative care options (Section 4.25).

Carers Australia strongly opposes this option. It suggests a misunderstanding of the nature and purpose of Carer Payment, which is 'a payment for carers who, because of the demands of their caring role, are unable to support themselves by participating substantially in the workforce.' (Centrelink definition). Carer Payment is an income support payment, not a wage for care provided. Entitlement, established by legislation, is determined by Centrelink on application by the carer. The option implies that the question of receipt of carer payment could reasonably be decided without consulting the carer, even though the income it provides may be critical to the wellbeing of the family. Because the care that might be purchased with an amount equivalent to Carer Payment would be much less than full care, there would also be a risk that a carer would continue to provide care, but now unacknowledged and without the accompanying income support.

It is also questionable as to whether the option would produce savings to the Budget to the extent envisaged. The Pension Review Report (2008-09)[62] explained that, because of long term poor attachment to the workforce, many carers move between Carer Payment and other payments such as the Aged Pension, the Disability Support Pension, Parenting Payment or Newstart. A transfer to Newstart (unlike transfers to pensions) would produce savings because it is a less generous payment but this outcome – the further impoverishment of caring families - would be an unfortunate accompaniment to the introduction of NDIS.

Research [63] indicates that the majority of people in receipt of Carer payment wish to have paid employment, but are limited by a complex set of barriers. These include a lack of suitable alternative care, a lack of faith in the quality of alternative care provided, and a lack of flexibility in paid employment. The Productivity Commission report makes recommendations to address some of these barriers and hence a NDIS could make a real difference to the employment prospects of carers. If there is to be a focus on reducing Commonwealth outlays on Carer Payment, Carers Australia believes that the better approach is to create the conditions in which carers can seek and find work. This would be done through the funding and development of alternative care arrangements to support carer workforce participation and the provision of employment support services for long term carers, in addition to changes to the Fair Work Act 2009 as recommended in the Draft Report.

Carers Australia recommends:
That any expected reductions in expenditure on Carer Payment could be considered as a legitimate indirect offset to the cost of a NDIS but is strongly opposed to the option of cashing out Carer Payment into individualised budgets as a means of achieving savings. The better way to produce savings on Carer Payment is to create conditions favourable for carers to seek and find paid work.

10.7 Carer Allowance, Carer Supplement and other payments

Carer Allowance currently has an ambiguous rationale: 'a supplementary payment that may be made available for a carer or parent providing daily care and attention'. Its purpose is interpreted subjectively by carers, either as a form of recognition, or income supplement to meet costs of disability/caring. These are not met currently any other way by either through the income support system or disability services.

Similarly, Carer Supplement Payments are annual payments to carers to assist with the costs of caring for the person with a disability. In the case of children, Child Disability

Assistance Payment and Carer Adjustment Payment (in 2012) are payments for the cost of care, the latter related to a catastrophic event.

The Pension Review report suggested that the costs of disability should ideally be borne through the disability system and paid employment. To quote:

'Once supports for carers to maintain links with the labour market are developed, it may be appropriate to review the role of Carer Allowance. However, the Review considers that a review would require better access to respite, or other forms of care, to help balance work and caring, and targeted assistance to gain employment to be in place. Until then, Carer Allowance will continue to have a role in supporting the provision of informal care'.

It is one of the stated aims of a NDIS to reduce the costs of disability for families. The design, scope and detail of the scheme will all determine the extent to which this occurs.

Carer Allowance is also valued by many carers as a form of symbolic recognition. For this reason, any changes to its design should be made with clarity and sensitivity.

Carers Australia recommends:
That the purpose and design of Carer Allowance is reviewed once the benefits of a NDIS in addressing the costs of disability and the reliance on carers are evidenced.

10.8 Mobility Allowance

This provides direct support to a person with a disability who is involved in activities and cannot use public transport. Essentially it recognises some costs of disability. However, its inclusion in NDIS for eligible people may increase complexity for people in Tiers 1&2 and create a split system.

Carers Australia recommends that:
There may be a rationale for including Mobility Allowance in a NDIS. More work may be needed to consider the equity and complexity implications of doing this.

11 THE NATIONAL INJURY INSURANCE SCHEME

Carers Australia supports the proposal for a harmonised and federated no fault National Injury Insurance Scheme (NIIS) to run initially in parallel with the NDIS. Achieving national consistency across state and territory catastrophic injury schemes is an important precursor to decisions on the longer term interface of catastrophic injury schemes with the NDIS. We thoroughly support the proposed expansion of eligibility to include people with catastrophic injuries to include medical, criminal and general accidents, and the transfer to NIIS of catastrophic workplace claims as necessary in individual jurisdictions.

Consideration is required to ensure that future National Injury Insurance Schemes are developed to ensure:

- planning partnerships with caring families.
- appropriate provision of family support, and
- ongoing monitoring of the health, wellbeing and quality of life of family carers who provide substantial amounts of care.

11.1 Injury Compensation for Carers

It is well established that, compared with the general population, carers have poor health and wellbeing. A national survey of carer health and wellbeing published by the Carers Association of Australia in 2000 reported that well over half of carers believed that caring had made their physical health worse or much worse.[64] A survey of carer health and wellbeing published in 2007 by Deakin University, Australian Unity and Carers Australia found that carers had the lowest level of wellbeing of any group examined.[65] Carers had an average rating on the depression scale that is classified as moderate depression. Over one third of carers were classified as having severe or extremely severe depression. Far fewer carers were free from physical pain or had minor pain compared with the general population and more than twice the proportion of carers experienced high levels of pain. One aspect of poor health and wellbeing is injury sustained in the course of caring. The same research conducted by Deakin University *et al* indicated that most carers were carrying an injury caused by their caring.[66] Research published by the Independent Living Centre of WA in 2006 indicated that over half of carers with a current health condition said they had orthopaedic or spinal problems.[67]

There are a number of recommendations in the Productivity Commission Draft Report that would help to prevent carer injury, in particular increased training opportunities for carers and increased levels of support for people with a disability, including specialist disability supports such as aids and appliances. The report is silent, however, about support for carers once they have sustained an injury.

Unlike people who are injured in the work-place or in motor vehicle accidents, carers who are injured in the course of their caring – for the most part at home - are not covered by injury compensation schemes. This means that apart from the support they get through the public health system carers, by and large, meet these costs themselves. Such costs include the costs of injury management and rehabilitation which can extend over many years. They also include the cost of diminished life-style options and life-time earning capacity. They can be an important contributor to the financial disadvantage that is an all too common corollary of being a carer.

Some carers would benefit under the National Injury Insurance Scheme that is proposed by the Productivity Commission in its Draft Report. Because, however, this scheme would be limited in coverage to catastrophic injuries, at least until after 2020, the large majority of injured carers would presumably not benefit for many years from this proposed reform. CA believes that the situation with carer injury warrants immediate attention. In its final report the Productivity Commission should recommend the introduction of injury compensation arrangements for carers. Means of verification of injury need to be considered.

Carers Australia recommends:
That the Productivity Commission explore and make recommendations about the introduction of injury compensation arrangements for carers.

12 LIST OF RECOMMENDATIONS

Carers Australia recommends:

1. **That additional key principles outlined in 2.1-2.5 should guide the design and practice of a National Disability Insurance Scheme.**

2. **That people eligible for NDIS (Tier 3b) include people with a primary brain impairment who need significant support to participate in the community.**

3. **That people with a psychiatric disability are explicitly included in a NDIS on the grounds of equity and consistency.**

4. **That the Productivity Commission conducts a more detailed analysis of existing data about the numbers and characteristics of people with a psychiatric disability.**

5. **That while Carers Australia recognises that inclusion of people with a psychiatric disability in the scheme could appreciably increase its costs, this is not a reason to fail to engage adequately with the subject.**

6. **That the role of local NDIA case managers include an outreach function to encourage vulnerable groups currently 'outside funded services' to engage with the NDIA, in particular those in unstable or unsuitable housing.**

7. **That assessment of the needs of carers be accompanied by the allocation of packages of support directed to high needs families.**

8. **That eligibility and needs assessment processes and care plan development are both person centred and family focused and that these should include consideration of the support needs and choices of carers.**

9. **Significant family needs would be reflected in an entitlement to a family focused package of support, developed according to the needs, preferences and choices of caring families and targeted to sustaining family care.**

10. **That the NDIS includes a mechanism for carers to access support independently of the person with a disability.**

11. **A quarantining of funds to ensure the timely availability of resources for tailoring increased episodic and emergency care arrangements, chosen according to the preferences of the person with a disability and their family. This may be for a short or longer term period until equilibrium is restored.**

12. **That disability needs assessment encompasses a consideration of the capacity of the person to participate in education, employment and social life.**

13. **That the NDIS offers separate needs assessments for people with a disability and for their families, noting that many families would choose a combined process.**

14. **That the NDIS incrementally develop a reliable, validated and rigorous family assessment tool as a component of the tool box.**

15. **Both people with a disability and their carers should be able to request timely and responsive reassessment as a consequence of change or predicted changes in individual or family circumstances.**

16. **That the Commission should ensure that the proposed Carer Support Centres are adequately resourced to provide a broad range of services and supports to all carers.**

17. **That employment of close family members is generally limited to situations of intermittent care by non- resident family members.**

18. **The initiation of new and responsive individual or group programs to fill gaps in the current services system through investment in infrastructure for community and program development.**

19. **That the NDIA ensures that there is capacity in the system for identifying, establishing, and supporting the development of new individual or group participation options.**

20. **That block funding be retained as a funding option for essential services, for highly specialised and tied interventions and to address the needs of rural and remote communities.**

21. **That the experience of disability or of caring, or a policy background or work experience in related areas, should be an essential qualification for at least some of the Board positions of the NDIA.**

22. **That a NDIS collects longitudinal data about the housing needs of people with a disability.**

23. **That in its final report, the Productivity Commission stress the importance to successful disability reform of increasing the overall supply of affordable housing and of improving the access of people with a disability to affordable housing.**

24. **That any expected reductions in expenditure on Carer Payment could be considered as a legitimate indirect offset to the cost of a NDIS but is strongly opposed to the option of cashing out Carer Payment into individualised budgets as a means of achieving savings. The better way to produce savings on Carer Payment is to create conditions favourable for carers to seek and find paid work.**

25. **That the purpose and design of Carer Allowance is reviewed once the benefits of a NDIS in addressing the costs of disability and the reliance on carers are evidenced.**

26. There may be a rationale for including Mobility Allowance in a NDIS. More work may be needed to consider the equity and complexity implications of doing this.

27. That the Productivity Commission explore and make recommendations about the introduction of injury compensation arrangements for carers.

Appendix 1: Victorian Psychiatric Disability Rehabilitation and Support service types

Residential Rehabilitation Services (RRSs)

These provide an integrated model of accommodation and support for 10-20 individuals. Initially informed by the concept of a therapeutic community, they are intended to assist a person to rebuild the skills they need before living more independently. They represent a throughput rather than permanent model of housing and support. Some RRSs have 24 hour staffing, others Monday to Friday 9am to 5 pm. Victoria also has RSS's particularly for youth (aged 18-25).

The Victorian government is conducting a review of this model. Availability of RRSs is variable across the state but access is always in demand. Although many RRS's help people with a psychiatric disability to achieve positive outcomes, there is some speculation that the popularity of the model highlights the critical shortage of housing and support for this group rather than the benefits of this particular model per se (although there may be important differences here between the needs of adults and youth). Many people with a psychiatric disability, given the choice, would prefer to live alone or with a smaller group of individuals to their choice.

Home Based Outreach Services (HBOS)

These provide individual support to people living in their own homes. They may live with their family or friends, alone or in group accommodation such as rooming houses or, in Victoria, Supported Residential Services (SRS's). Many are supported in caravan parks or other forms of unsuitable accommodation. As with RRSs, support is provided by non-clinicians who are trained in psychiatric rehabilitation. The majority of staff is graduates, many of which trained in the allied health professions.[68]

The amount of support provided is flexible, depending upon the need of the individual, and will fluctuate with their illness and life circumstances. It is constrained by government funding and pricing. HBOS delivers, on average, 1.5 hours of support per week per person, the Intensive Home Based Outreach (IHBOS) version, 3 hours. There are also newer packages of care which are designed to provide joined up clinical and psychosocial support to people with much more complex needs, but these are relatively small in number. Thus, a lack of resources places limits on the numbers of people with profound psychiatric disability who can be supported to live in the community. Some people remain living in highly supported clinical environments which are inappropriate for the long term, creating systemic problems such as 'bed blockages'[69]

In Victoria, HBOS is an important component of the Housing and Support Program (HASP) in which people with psychiatric disability, many of whom had lived for many years in institutions, were provided with public housing and clinical and PDRSS support. Initiated in 1992[70], this program has been highly successful, but has not remained in its original form, primarily as a result of a shortage of housing stock.

In New South Wales, the Housing and Support Initiative (HASI) has been set up in a more robust way than HASP. Formal accords were written between mental health and housing bureaucracies, to ensure program sustainability. The program has been comprehensively evaluated from its inception. It can demonstrate clear and quantifiable client and systemic outcomes, and calculation of the cost benefits of the scheme[71]. Importantly, the scheme is also funded to provide different tiers of support according to different needs of individuals. In this way, HASI can support people with higher needs than those receiving HBOS or IHBOS.

The Commonwealth funded PHaMs program has been largely interpreted in Victoria to be an expansion of the HBOS model, although sometimes with different eligibility criteria.

Day programs

Again, situated in the community and largely delivered through NGOs, these are designed to assist people with psychiatric disability in their recovery. Programs may take the form of a ‘drop-in’, structured group based skills development programs, or more individual approaches. There is an emphasis on providing a welcome space to visit and facilitating access to the broader community. There has been some debate in recent years as to whether services should provide drop in, favoured by some groups of people with a psychiatric disability, or more individualised, non-site based support, which may provide different outcomes and can suit a broader range of needs.[72] Most day programs still provide a mix of options, conditional on funding parameters and constraints.

Respite services

The Victorian State government provides some respite services for people with a psychiatric disability and their families. This can take the form of group holidays or individual time limited one-to-one sessions in which the person with a disability is supported to access leisure activities within the community. This allows family members to meet their own needs. Using a recovery based approach by workers, possible outcomes for the person with a psychiatric disability and their families can be broader than merely providing ‘a break’. The reality is that good practice demands that the needs of both the person with a disability and the caring family are taken into account.[73]

Mutual Support and Self Help programs

In terms of a clinical to community continuum, these services are very much at the community end of the spectrum. They assist people with mental health problems to meet their own support needs through psycho education and group support with other people in similar situations. Some programs are state wide and condition specific eg Eating Disorders Foundation or the Anxiety Recovery Centre. These will often have a strong focus on community awareness and information provision.

Mutual Support and Self Help programs tend to be chronically underfunded. This is both an oversight and a symptom of the fact that the majority of people with a mental illness do not access any help through the specialised public mental health system. FaHCSIA’s Community Mental Health program has been a welcome addition to this area.

Step up, Step down Sub acute services (Prevention and Recovery Care Services in Victoria

These are designed as an alternative to the more intrusive admission to, or premature discharge from acute psychiatric hospital. They are a hybrid clinical-psychiatric disability support model with health services contracting PDRSS services[74].

REFERENCES

---

1 AIHW (2008) Disability in Australia: Trends in prevalence, education, employment and community living. Bulletin 61

2 Fyffe, Pierce, Ilsley and Paul (2010) The Next Steps: Adults with a disability and caring families. www.carersvictoria.org.ay

3 Maree Dyson (2011) Implications of the Reform, paper presented at the national Disability and Carer Congress, 3 May.

4 Productivity Commission (2011) Report on Government Services.

5 WHO (World Health Organisation) 2001. International classification of functioning disability and health

6 Ibid

7 Carers Victoria (2010), Recognizing interdependence: promoting a good life for all, Carers Victoria's submission to the Productivity commission Inquiry into Disability Care and Support.

8 Mental Health Council of Australia (2007) Let's get to work – A National Mental Health Employment Strategy for Australia

9 COAG National Action Plan on Mental Health (2006 - 2011)

10 AIHW Mental health services in Australia 2007-08

11 National Survey of mental health and Wellbeing (2007), ABS

12 Mental Health Council of Australia (2009) Adversity to Advocacy: The Lives and Hopes of Mental Health Carers

13 Johnson, G and Chamberlain, C, Are the Homeless Mentally Ill? RMIT University. A paper presented at the Australian Social Policy Conference, University of New South Wales, 2009

14 AIHW (2004) Disability and its relationship to health conditions and other factors

15 Carers Victoria (2010), recognizing interdependence: promoting a good life for all, Carers Victoria's submission to the Productivity commission Inquiry into disability Care and Support

16 National health survey (2001), ABS

17 Mathers et al (1999)Burden of Disease and Injury in Australia, AIHW

18 Price Waterhouse Coopers (2009), Disability Investment Group, National Disability insurance Scheme, Final Report

19 Ibid

20 AIHW Mental health services in Australia 2007-08

21Targeted Community Care Summary Information Reports (2011) FaHCSIA

22 Cummins et al (2007) Special Report, the wellbeing of Australians; carer health and wellbeing, Deakin University; Gill et al (2007) The health and wellbeing of adult family carers in South Australia; Edwards et al (2008) The nature and impact of caring for family members with a disability in Australia, AIFS.

23 ABS (2003) Survey of Disability, Ageing and Carers Cummins et al, op cit; Gill et al op cit.

24 Edwards et al op cit, Cummins et al op cit

25 Cummins et al op cit

26 ABS (1998) Survey of Disability Ageing and Carers

27 Edwards et al (2008) The nature and Impact of caring for family members with a disability.

28 Cummins et al op cit; , Stollznow (2005) Market Research Report A crisis in caring or a system that works. Prepared for Carers Australia.

29 Stollznow (2005) op cit

30 Productivity Commission (2011) Draft report on disability care and support

31 Carers Victoria (1998) Putting carers in the picture. Improving the focus on carer needs in aged care assessment.

32 Carers Victoria (1998) op cit

33 CarersVictoria (2010) Position statement on Consumer Directed Care, unpublished draft.

34 Carers Victoria (2010) Individual Support packages and self managed care, unpublished draft.

35 Carers Victoria (2010) op cit.

36 Dyson Consulting Group (2010) and Transport Accident Commission (2010) Personal communication.

37 Clements, L. (2008) Individual budgets and irrational Exuberance and Maree Dyson, Dyson consulting group (2010), personal communication concerning NZACC.

38 Glendinning C, et al. Arksey, H., Jones, K., Moran, N., Netten, A., and Rabiee, P., (2009)The Individual Budgets Pilot Projects: Impacts and Outcomes for Carers ; Ungerson, C (2004). Whose empowerment and independence? A cross-national perspective on 'cash for care' schemes, Ageing and Society 24, 2, 189-212

39 Allen, S and Ciambrone, D. (2009)Community Care for People with a Disability; Blurring Boundaries between Formal and Informal Caregivers. Qualitative Health Research, Sage Publications. www.sagepublications.com

---

40 Maree Dyson, (2010) Dyson Consulting Group; personal communication

41 Glendinning, C. et al, op cit.

42 Maree Dyson, (2010) Dyson Consulting Group; personal communication

43 HDG Consulting. (2010) Evaluation of the Direct Employment Project, in process.

44 Fyffe, Pierce, Ilsley and Paul (2010) The Next Steps: Adults with a disability and caring families

45 Audit Commission ((2000) Fully Equipped. The provision of equipment to older and disabled people by the NHS and Social Services in England and Wales. The Audit Commission, London.

46 AIHW (2009) Australia's Health Expenditure, 2007-2008.

47 Layton, N; Wilson, E and others (2010) The Equipping Inclusion Studies: Assistive Technology Use and Outcomes in Victoria. Deakin University.

48 Summers, Michael (2010) National Aids and Equipment Reform Agenda background paper, unpublished. MS Australia.

49 Dyson Consulting (2010) Personal communication concerning risk management for the NZ ACC.

50 AIHW (2010) Australia's Health.

51 Butler and Millner (2003) NSW Inmate Health Survey, NSW Department of Corrective Services.

52 Hayes, Susan (1997) Prevalence of intellectual disability in local courts, Journal of Intellectual and Developmental Disability, 71,73,81.

[53] AIHW (2008) Disability in Australia: Trends in prevalence, education, employment and community living. Bulletin 61

54 Parliament of Victoria Family and Community Development Committee (2010), Inquiry into the adequacy and future directions of public housing in Victoria

55 National Housing Supply Council (2010), 2nd State of Supply Report

56 Australian Treasury (2010), Australia's future tax system. Recommendations 102 to 106

57 Ibid recommendation 105

58 Victorian Auditor-General's Report (2010), Access to Social Housing

59 Australian Treasury (2010), Australia's future tax system. Recommendations 102 -103

60 Allen Consulting Group (2008) Development of a Model(s) for families and Individuals to Invest in Housing provided by the Disability Housing Trust.

61 Pinnegar et al (2008), Innovative financing for home ownership: the potential for shared equity initiatives in Australia, AHURI

62 Australian Government, Department of Families, Housing Community Services and Indigenous Affairs (2009), Pension Review Report

63 Edwards et al (2008) The nature and Impact of caring for family members with a disability, Australian Institute of Family Studies.

64 Carers Association of Australia, National Survey of Carer Health and Wellbeing, (2000).

65 Cummins, R., et al, The Wellbeing of Australians- Carer Health and Wellbeing, Special Report, Australian Unity Wellbeing Index Survey 17.1, (2007), pp4-5.

66 Ibid. p17-8.

67 Independent Living Centre of WA (Inc), Family Carers and the Physical Impact of Caring – Injury and Prevention, Research Report, (2006), pB17

68 VICSERV, Training Needs Analysis Report, (2010)

69 Boston Consulting Group, (2006) Improving mental health Outcomes in Victoria, The Next Wave of Reform

70 Carter, M., Burke, T &Moore, S. (2008) Case Studies in Deinstitutionalisation, Implementing Supported Housing programs in Two Australian States, Swinburne Institute for Social Research

71 Fisher, K. et al (2007) Housing Accommodation Support Initiative, Stage 1 Evaluation Report, SPRC

72 VICSERV (2006) Into Community, Review of Day Programs

73 SANE Australia (1998), Planned Respite Care

74 Prevention and Recovery Care Services, Service Guidelines, Victorian Department of Health