The Senate

Community Affairs References Committee

Disability and Ageing: lifelong planning for a better future

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Executive summary

This report examines the planning options and services available now and in the future to assist people with a disability, and their carers, plan for the long-term. In particular, it seeks to assist carers to find an adequate answer to the question: 'What happens when I / we can no longer care?'

Evidence taken by the committee suggests that the challenges facing the disability sector are substantial and that the existing system is not operating effectively. People with disabilities, carers, service providers and governments all agreed that there are many inadequacies in the choice, funding and support options available for people with a disability.

Beyond this, witnesses have also suggested that the deficiencies in the disability service sector have produced a crisis-driven culture which fosters dependency and which limits innovation. It has produced circumstances where families have become accustomed to receiving low levels of support and where it has become commonplace for family members to care for a person with a disability until they are unable to do so. This suggests that while reform is clearly needed within the disability service sector, cultural change is also required, both within the bureaucracy and service sector, in order to establish planning cultures and behaviours that sustainably support people into the future.

Given that Australia is anticipating significant population ageing, which will be accompanied by a commensurate reduction in the availability of informal care and support, the committee is deeply concerned by evidence suggesting that little sustainable planning is taking place. Many carers are so consumed by their day-to-day caring role that they have not even begun to start thinking about planning. Others find the planning challenge considerable and need support to manage what is a complex and multifaceted task.

In the report the committee focuses on whole-of-life planning, rather than simply service planning. It documents why it is critical that whole-of-life planning take place before proceeding to consider some of the major practical barriers to planning, including: access to information, accommodation support, availability of respite, appropriateness of assessment tools, and the difficulty of navigating the disability / aged care interface. Thereafter the committee examines some of the planning support schemes that have been developed in the non-government sector. In acknowledgment of these innovative planning schemes, the committee recommends that the government look to increase its support of these organisations. In so doing, the committee also recommends the establishment of national guidelines to give clear direction on how these organisations might be constituted and how they should account for increased public funding. The committee envisages that these guidelines would also represent the beginning of an integrated and coordinated national approach to planning.

Recommendations

Recommendation 1

The committee considers that there is a need for a clear transition process to facilitate uninterrupted funding when people with a disability move between states, and recommends the Department of Families, Housing, Community Services and Indigenous Affairs work with the states and territories to seek to resolve issues related to portability as a matter of urgency.

Recommendation 2

The committee considers it critical that effective planning support be available for people with disabilities transitioning from education to employment and from employment into retirement. The committee recommends that the Department of Families, Housing, Community Services and Indigenous Affairs provide retirement planning support options for people employed in Australian Disability Enterprises.

Recommendation 3

The committee recommends that the government look to identify people with disabilities as a special group who may age earlier than other members of the population and should therefore have access to a range of aged care services at an earlier age.

Recommendation 4

The committee recommends that the Department of Health and Ageing review the assessment tools used by the network of Aged Care Assessment Teams (ACAT) to take into account the needs of people with a disability who are ageing prematurely.

Recommendation 5

The committee notes the National Disability Agreement requirement for states and territories to consider one-stop-shops for disability services. The committee recommends that the Commonwealth, in consultation with the states and territories, establish its own presence and representation at one-stop-shops. The committee considers that one-stop-shops must be capable of directing enquiries towards whichever service is most appropriate, whether that service is provided at a state, territory or Commonwealth level. Further, the committee endorses Recommendation 22 of the *Who Cares...? Report on the inquiry into better support for carers*, calling for the establishment of a dedicated Carer / Disability Unit at Centrelink. This dedicated Unit should be accessible via disability services one-stop-shops.

Recommendation 6

The Committee recommends that the Department of Families, Housing, Community Services and Indigenous Affairs improve its website to make information about disability services and planning support more up-to-date, comprehensive and navigable. In so doing, the Department should establish a working group, which includes carers, people with disabilities and disability services organisations, to seek feedback on matters of design, utility and accessibility.

Recommendation 7

While the committee would like to see improvement in the quality and accessibility of information on government websites for people with disabilities and their carers, it also mindful of the limited reach of new technologies. In acknowledgement of this, the committee recommends that all levels of government should consider effective non-web-based tools for the communication of critical information on disability and planning services. The working group suggested in Recommendation 5 should also be engaged for this purpose.

Recommendation 8

The committee is seriously concerned by evidence suggesting that as many as 25 per cent of carers are not linked in with Centrelink and therefore are not receiving payment to which they are entitled. The committee therefore recommends that Centrelink review its communication strategy with respect to carers and engage local disability service providers more directly.

Recommendation 9

Within the framework of life-long planning, the committee recommends that the government facilitate the provision of specialist financial and legal advice to people with a disability and their carers to assist them with planning decisions, including the decision to utilise a Special Disability Trust. This advice could be made available via:

- **Commonwealth funded financial and legal planning workshops specifically targeted to address the issues that arise in disability planning;**
- **The provision of specialist advice through an established Disability / Carers' Unit at Centrelink; and / or**
- **Commonwealth funded independent legal services specialising in disability services, potentially operating in conjunction with non-government service organisations, and nationally registered on a list accessible to people with a disability and their carers.**

Recommendation 10

As Aboriginal and Torres Strait Islander people with a disability face particular barriers accessing planning services, the committee recommends that the Office for Aboriginal and Torres Strait Islander Health undertake research to identify how planning support can best be provided to them.

Recommendation 11

As people with disabilities living in regional and remote areas face particular barriers accessing planning support, the committee recommends that the Department of Families, Housing, Community Services and Indigenous Affairs provide additional funding and resources to develop planning services in these areas. The committee also recommends that the Department establish a working group of people with disabilities, their carers and regional disability service organisations, to provide advice on how additional funding should be utilised.

Recommendation 12

The committee recommends that the government, through the Department of Families, Housing, Community Services and Indigenous Affairs, work with the states and territories to establish a succession planning framework. The framework should:

- **Make clear the importance of long-term planning;**
- **Provide guidance on the critical aspects of long-term planning;**
- **Take into account the individual differences of families;**
- **Support a range of approaches to planning.**

Recommendation 13

The committee recommends that as part of the succession planning framework the government establish nationally consistent guidelines on lifelong planning. It is recommended that these guidelines consider matters such as: registration, constitution of boards, management of funds, governance arrangements, transparency, reporting requirements, and the role of paid facilitators.

Recommendation 14

The committee recommends that the succession planning framework be the first step in the development of an integrated and coordinated national approach to planning. In making this recommendation, the committee stresses that the framework should balance the need for individualised or tailored planning support with clear standards of governance and accountability.

Recommendation 15

The committee recommends that in its next Budget the government allocate funds to assist with the development of disability planning. It is suggested that this funding be made available to:

- **Organisations currently involved in planning;**
- **Individual families seeking to purchase planning services from providers;**
- **Other disability service organisations that intend to develop lifelong planning services for families.**

The committee recommends that this funding be made available on a recurrent basis.

Chapter 1

Introduction and conduct of inquiry

Referral of inquiry

1.1 On 25 November 2009, the Senate referred the following matter to the Community Affairs References Committee for inquiry and report by 2 September 2010:

> Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

1.2 When the Governor-General prorogued the 42nd Parliament on 19 July 2010 the committee was yet to hold public hearings for the inquiry. The committee therefore determined that it was unable to provide a comprehensive report and that it would reconsider matters related to the inquiry in the event that it was re-referred to the committee in the new parliament.

1.3 On 30 September 2010, the Senate re-referred the matter to the committee for inquiry and report. However, the re-referral included changes to the committee's terms of reference. The new terms of reference were as follows:

> Access to options for and services to assist people with a disability and their carers to plan for the future, including:
>
> (a) Inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers;
>
> (b) Ways to ensure the continued quality of life for people with a disability as they and their carers age;
>
> (c) The types of options and services that could be developed to help people with a disability and their carers to plan for the future; and
>
> (d) Any other matters which would assist carers to find an adequate and appropriate answer to the question: 'What happens when I / we can no longer care?'

1.4 The reporting date for the inquiry was 31 March 2011; this date was subsequently extended to 21 June 2011.

Conduct of inquiry

1.5 In accordance with usual practice, the committee advertised the inquiry in *The Australian* and on the internet. The committee also wrote directly to a number of organisations and individuals inviting submissions to the inquiry. In total, the committee received 87 submissions: 76 submissions were received during the 42nd Parliament and 11 during the 43rd Parliament.

1.6 The committee also determined that submissions received during the 42nd Parliament would continue to be considered. Additionally, those who submitted to the inquiry during the 42nd Parliament were invited to re-submit in the event that they wished to update or amend their earlier submission, responding to the new terms of reference.

1.7 The committee held five public hearings: Canberra (8 November 2010); Melbourne (29 November 2010); Sydney (30 November 2010); Toowoomba (1 December 2010); and Canberra (18 February 2011). The committee took evidence from people with disabilities, carers, organisations representing people with disabilities, peak bodies, service providers, and state and federal government departments.

Related inquiries

1.8 The Productivity Commission is currently conducting an inquiry into Disability Care and Support. This is intended to examine the costs, benefits and feasibility of alternative approaches to funding and ways of delivering long-term care and support for people with severe or profound disabilities. The Commission will present its final report to government by 31 July 2011. Information on the Productivity Commission's inquiry can be found at:

http://www.pc.gov.au/projects/inquiry/disability-support.

1.9 The Draft Report of the Productivity Commission, released on 28 February 2001, made a series of important recommendations:

- There must be a shift from a welfare to an insurance philosophy;
- Responsibility for the funding of long-term care and support should be the responsibility of the Commonwealth;
- A three-tiered National Disability Insurance Scheme (NDIS) should be established;
- Funding for the NDIS should come from consolidated revenue via a guaranteed formula;
- A new federal agency—the National Disability Insurance Agency—be established to oversee the NDIS;
- The proposed NDIS support scheme would be portable across state and territory borders (as would the assessment of need).

1.10 The committee endorses in principle the recommendations contained in the Productivity Commission's Draft Report. The committee agrees that a National Disability Insurance Scheme would provide significant new resources as well as flexibility and choice for people living with disability. The committee also notes that submitters and witnesses to the inquiry expressed their broad support for a national disability insurance scheme, arguing that an NDIS would provide much needed reform and a mechanism for the creation of individualised support packages.[1] The committee notes however, that until the government responds to the Productivity Commission

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[1] For example: People with Disabilities Australia, Committee Hansard, 30 November 2011, p. 55; Professor Christine Bigby, Committee Hansard, 29 November 2011, p. 21; Catholic Health Australia, *Submission 35*, Recommendation, p. 6.

report, the states and territories must continue to fulfil their obligations under the National Disability Agreement (NDA).

1.11 The committee also notes that the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) recently engaged Allen Consulting Group to undertake an *International Review of Future Planning Options* for carers of people with disability. The purpose of the project was to identify and analyse international approaches that encourage private financial provision and supported future planning. Eight countries, in addition to Australia, were included in the research: Canada, United States, United Kingdom, Ireland, New Zealand, Finland, Sweden and Germany. Released in 2009, the report recommended that the Australian government consider: the implementation of financial savings accounts for children with disability; a government-funded matched saving component be added to Special Disability Trusts; and implementing a future planning program similar to that of PLAN in Canada.[2]

1.12 The committee also notes the recent parliamentary inquiry undertaken by the House of Representatives Family, Community, Housing and Youth Committee into support for carers. *Who Cares...? Report on the inquiry into better support for carers* identifies strategies to increase the capacity of carers to make choices within their caring roles and to support carers in effectively planning for the future. The Senate Community Affairs References Committee notes that, among its recommendations, the House committee recommended that the Minister for Human Services direct Centrelink to establish a dedicated Carer / Disability Unit with staff to provide specialist advice to carers and care receivers, including those with complex care and family issues (Recommendation 22). Further, that the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing undertake pilot studies to test the potential for the Australian Government's funding for carer respite and in-home assistance to be re-allocated directly to carers through 'individualised funding programs' (Recommendation 35).

Scope of inquiry

1.13 Much debate around disability support focuses on questions of funding, policy settings and regulation, or the macro-level planning offered by government. In its consideration of the costs, benefits and feasibility of a national disability insurance scheme, the Productivity Commission seeks to contribute to higher-level disability reform. The committee has not considered matters related to the establishment of a national disability insurance framework. Rather, it is concerned with the planning that takes place below, alongside or in concert with this macro-level planning. That is, the planning provided by parents, relatives, spouses, friends and other members of the community, who monitor the quality of care, the availability of services and who seek to make provision for the future. Specifically, the committee seeks to identify ways to

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[2] International Review of Future Planning Options: http://www.fahcsia.gov.au/sa/carers/pubs/Documents/international_review/default.htm (viewed: 12 May 2011). PLAN is an organisation that is involved in assisting families caring for a person with a disability plan for the future: http://www.plan.ca/.

support individualised planning through the provision of funding and professional services to assist families develop life-long and sustainable care plans for the future. In so doing it seeks to assist carers find an adequate and appropriate answer to the question: 'What happens when I / we can no longer care?'

Rates of disability and current funding arrangements

1.14 The main source of information about rates of disability and the number of carers of people with a disability is the 2009 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers. The ABS data indicated that 4 million people or 18.5 per cent of Australians reported having a disability.[3]

1.15 The prevalence of disability in Australia has fallen 1.5 percentage points since the last ABS survey in 2003. In 2003, 20 per cent of Australians had a reported disability. After removing the effects of different age structures the age standardised rate also fell by 2.1 percentage points. The rate of profound or severe limitation in the core activities of communication, mobility and self-care declined, from 6.3 per cent in 2003, to 5.8 per cent in 2009. Much of the decrease in the prevalence of disability between 2003 and 2009 is due to a decline in the proportion of Australians disabled by physical health conditions, such as asthma and heart disease.[4]

1.16 The ABS also estimated that there were 2,632,100 carers in Australia who provided regular or sustained care to another person. This represented 12.2 per cent of the Australian population. Almost a quarter of these carers (771,400 people) were 'primary carers', that is, they provided the most care to another person with a severe or profound core activity limitation.[5] These statistics reinforce the urgency of the planning challenge. They reinforce that in the next decade many carers will either die or find themselves unable to care. As the size and capability of the informal care sector declines, it is essential that the community finds alternative ways to support people with disabilities.

1.17 In 2009–10, the Commonwealth Government provided funding of approximately $1.7 billion to the disability sector, while state and territory governments provided funding of approximately $4.5 billion.[6]

1.18 The National Disability Agreement (NDA) came into effect on 1 January 2009. Under the NDA, the Commonwealth has responsibility for the provision of employment services for people with disability and income support. State and territory governments have responsibility for delivering other specialist disability services including: accommodation, respite, community support and community access services.

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[3] 2009 Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers: Summary of Findings*, 2010, p. 3.

[4] 2009 Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers: Summary of Findings*, 2010, p. 3.

[5] 2009 Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers: Summary of Findings*, 2010, p. 10.

[6] Productivity Commission Draft Report, *Disability Care and Support*, Volume 1, p. 2.

1.19 Under the NDA, over the next five years, the Australian Government will provide $5.3 billion to assist state and territory governments to deliver specialist disability services. Of this, $408 million will go to assist with the National Disability Reform Agenda. Some of the key reforms under consideration include:

- Improved access to disability care including consideration of systems that provide a single point of access;
- Nationally-consistent assessment processes and a quality assurance system;
- A renewed focus on early intervention and planning to ensure that clients receive the most appropriate and timely support;
- Improving the capacity of service providers to better develop and train care workers;
- More consistent access to disability aids and equipment;
- A commitment by all levels of government to work together to better measure the level of unmet demand for disability services; and
- Continued work on reform of roles and responsibilities in relation to community mental health, disability services and aged care.[7]

1.20 Funding and the legislative and policy frameworks surrounding disability will be explored by the committee further in Chapter 3.

1.21 The committee also notes the National Mental Health Reform package in the Federal Budget 2011–12. The committee supports the establishment of a National Mental Health Commission and endorses the allocation of $571.3 million, over five years, for a single point coordinating clinical and social support services for people with severe and debilitating mental illness. The fact that comprehensive multidisciplinary assessments will be provided for health and non-health needs, to establish tailor-made care plans, is an important reform that would also be of value to the disability community.[8]

Structure of report

1.22 In the following chapter the committee will examine the challenges facing the disability sector. It describes the current disability sector as being underfunded, difficult to navigate and crisis driven. The committee then proceeds to consider the implications that this has for disability planning.

1.23 In Chapter 3 the committee will consider the legislative and policy frameworks currently in place to provide national disability support. The chapter will examine the division of responsibility between Commonwealth and state and territory governments and the interaction between the disability and aged care sectors. This chapter will also examine some of the relevant rights frameworks, in particular, the

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[7] Council of Australian Governments website, www.coag.gov.au/coag_meeting_outcomes/2008-11-29/docs/20081129_national_disability_agreement_factsheet.pdf (viewed: 29 January 2011).

[8] *Budget National Mental Health Reform 2011–12*, http://budget.australia.gov.au/2011-12/content/download/ms_health.pdf , p. 5.

United Nations Convention on the Rights of People with Disabilities (CRPD). This will be followed by consideration of Australia's national carer recognition legislation and the national carers recognition framework. Chapter 3 will also document the forms of planning support offered by Commonwealth and state and territory governments.

1.24 Chapter 4 will give specific consideration to planning issues. It will consider why lifelong and sustainable planning is important and how planning might be done to support the various transitional life stages—school, work and retirement—but also, that it consider matters such as social engagement, recreation and each individual's ambitions for the future. Chapter 4 will also consider premature ageing for people with physical and intellectual disabilities.

1.25 Chapter 5 follows up on the discussion in Chapter 2, examining the challenges facing the disability sector, to consider the evidence identifying the major barriers to planning. In so doing, it documents the barriers to planning for different disability groups, Aboriginal and Torres Strait Islanders, non-English speaking people and people living in regional and remote areas.

1.26 Chapter 6 will provide a discussion of the important planning work that is currently taking place in the non-government or community sector and make recommendations to improve disability planning across Australia.

Acknowledgements

1.27 The committee thanks all those who contributed to the inquiry through making submissions, providing additional information or appearing before it to give evidence. The committee is particularly grateful to those who made special travel or respite care arrangements to attend public hearings.

Chapter 2

Challenges facing the disability sector

2.1 Evidence taken by the committee shows that the challenges facing the disability sector are substantial and that the existing system is not operating effectively. People with disabilities, carers, service providers and governments all agreed that there are many inadequacies in the choice, funding and support options available for people with a disability and their carers. The failings of the system have been well documented by the Productivity Commission in its recently released Draft Report on *Disability Care and Support*:

> The disability support 'system' overall is inequitable, underfunded, fragmented, and inefficient and gives people with a disability little choice. It provides no certainty that people will be able to access appropriate supports when needed. While some governments have performed much better than others, and there are pockets of success, overall no disability system in any jurisdiction is working well in all of the areas where change is required.[1]

2.2 In this chapter, the committee will provide an overview of the challenges currently facing the disability support system. The committee provides this in order to consider the implications that this has for planning. For a more complete analysis of the challenges facing the disability system readers should refer to the Productivity Commission's Draft Report, Chapter 2—'Why real change is needed'.

A culture of 'crisis'

2.3 Witnesses appearing before the committee described the disability sector as having a culture of crisis. They said there was little choice about services, substantial unmet need in all areas and significant underinvestment in housing. Witnesses also described a fragmented and uncoordinated disability system: a lack of clarity in funding arrangements and a service system too complex and difficult to navigate. The committee also heard calls for improved data on disability; greater national consistency with respect to policy settings and service provision; and more flexibility and portability with funding and programs. The committee notes that under the NDA the states and territories have made commitments to reform in each of these areas but it believes that the delivery of these commitments has been poor.

2.4 In offering an assessment of the current state of planning in the disability community, the Department of Families, Housing, Community Services and Indigenous Affairs suggested that frequently planning is often only taking place at the moment of crisis. Planning, they conceded, 'has tended to be crisis driven'.[2] While regrettably, the evidence received by the committee has emphasised this point, the committee does not regard 'planning' and 'crisis' as concomitant concepts. Crisis intervention and response is not planning; it is not pre-emptive nor does it adequately

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[1] Productivity Commission, Draft Report, *Disability Care and Support*, Volume 1, p. 5.

[2] FaHCSIA, *Committee Hansard*, 8 November 2010, p. 2.

anticipate future need. The committee believes that the lack of long-term thinking demonstrated by the bureaucracy has contributed to this crisis. The committee also believes that, as a community, we plan in order to avoid crisis and that good public policy is designed to prevent crises from taking place. This report will therefore examine ways to develop planning cultures that avert rather than respond to crisis.

2.5 The notion that the disability sector is 'crisis driven' was reinforced by many witnesses appearing before the committee.[3] It was widely suggested that one only comes to the notice of authorities or support services when a carer can no longer care and when the person with the disability becomes an urgent planning case. For many ageing carers, the situation is desperate and the committee has heard of numerous instances where a carer has relinquished a child in order to receive appropriate care and support. People Without Disability suggested, with respect to the availability of supported accommodation in New South Wales:

> At the moment, if you want accommodation in New South Wales you join a queue. You do not get to the top of that queue unless, really, you are in crisis and the only way to leapfrog the queue is if you are in crisis. That is a sad aspect of our work: families or individuals are often brought to the point where they resort to abandonment or to rendering a person theoretically homeless before there is a response. So certainly there needs to be a significant amount of investment across the range of services in the sector.[4]

2.6 The form of crisis management that has become a feature of the system was also described as having significant implications for disability funding. Dr Ken Baker, Chief Executive of National Disability Services, suggested that funding for the disability sector was reactive rather than proactive: 'One of the perverse features of the current system is that its investment in early intervention is relatively small compared to crisis management'.[5] This suggests a more systemic problem: that the disability system is so underfunded and that governments are so overwhelmed that they can only deal with the challenges that are most urgent.

2.7 These problems are exacerbated by the underinvestment in housing. It becomes very difficult to transition someone out of the family home, for example, and into alternate accommodation, if there are no places available. As a result, there are

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[3] For example: Mrs Joan Hughes, CEO, Carers Australia, suggested that 'we have a crisis driven system', *Committee Hansard*, 8 November 2010, p. 26; Ms Leah Hobson, Australian Federation of Disability Organisations, reiterated the system was 'crisis orientated', *Committee Hansard*, 29 November 2010, p. 6; while Family Advocacy argued 'accommodation support is crisis driven', *Submission 2*, p. 2.

[4] *Committee Hansard*, 30 November 2010, p. 57.

[5] *Committee Hansard*, 8 November 2010, p. 19. This was reiterated in the findings of the Productivity Commission which suggested: 'The high costs involved with crisis situations can impede funding for other support services. This is because when faced with budget constraints, systems have little choice but to give priority to families in crisis. This means that any growth in the number of crises can cause further rationing over time', Productivity Commission, Draft Report, *Disability Care and Support*, Volume 1, p. 6.

many individuals, well into middle age, who continue to live in the parental home. Professor Christine Bigby explained:

> …we do not provide the necessary support to enable people to leave home and to live independent lives with the support that is necessary. So we have this block, this brick wall, that people hit when they do have to leave home when their parents cannot care for them anymore. It has created a problem which we could easily solve in the long run by providing more supported accommodation.[6]

2.8 Scope, a disability service provider in Victoria, also suggested that managing a crisis in one part of the system only results in drawing resources from another part of the system, which in turn transfers the crisis:

> In the emergency housing area, if a crisis happens the person with the disability ends up going into respite care facility. Last year in the north-western metropolitan region 50 per cent of our respite places were blocked up—it sounds awful saying 'blocked up'—and were unable to be used because of crises that had happened in ageing carers' homes and the person with the disability had to take the place for a year or two years. That meant all the other people that wanted to use respite were not able to use it because 50 per cent of our places were taken up with crises.[7]

2.9 It is not just that resources are constantly being shifted to manage cases of crisis, but many carers only seek assistance when crisis occurs.[8] Many carers, having lost confidence in the sector, do not have any engagement with the service system and it is only when they can no longer care that they seek to re-engage the system. While this demonstrates that there are various drivers that contribute to instances of crisis, it also reinforces that there are significant levels of unmet need.

2.10 Evidence provided to the committee has made it clear that there is significant underinvestment in the sector and that there are simply not enough resources to adequately support people with disabilities. Nevertheless, the committee found it difficult to obtain specific data on levels of unmet need. While the states and territories are obliged to agree on measures to determine unmet need under the NDA, the committee heard from FaHCSIA that the department is still working with state officials on how best this can be achieved:

> We have been working with state officials on a NDA priority called better measurement of unmet need. There is a national report in draft form on that. I said there were a number of methodologies. That report takes quite a sophisticated actuarial approach to measuring unmet need. There are other approaches around and you get slightly different answers when you look at them. The unmet need report is going to go to ministers again soon—around the middle of the year—for them to consider publishing it. Actually we are quite happy with the national progress on measuring unmet need.[9]

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[6] *Committee Hansard*, 29 November 2010, pp. 12–13.

[7] *Committee Hansard*, 29 November 2010, p. 59.

[8] Mrs Joan Hughes, *Committee Hansard*, 8 November 2010, p. 26.

[9] *Committee Hansard*, 18 February 2011, p. 35.

2.11 Beyond the levels of unmet need discussed here, the committee is concerned that there is currently no sense that individuals have a *right* to support—there is no entitlement based on need. In this respect there is a significant gap between what is said, or what is aspired to, and what is being delivered on the ground. Related to the question of rights is the question of choice. For it is not simply that there is little choice in services, or service providers, but often people are reluctant to relinquish one form of care, not because that care suits them or meets their need, but because they feel that there is nothing to replace it. The notion of choice suggests corresponding options and in many instances these simply do not exist. As the submission from Mai-Wel indicates: 'Choice is only good if you have alternatives'.[10]

Navigating the disability system

2.12 In addition to the problems associated with unmet need and the lack of choice, many witnesses expressed concern about the complexity of the disability support system. There is no central or single access point for information about disability support, there is little clarity in funding arrangements and consumers suggest that the system is fragmented and difficult to navigate. Many individuals do not know where to turn for help and many more do not actually know what help is available. It represents what the Productivity Commission has referred to as the 'lottery' of access to services.[11]

2.13 In Chapter 3, the committee will examine the gaps that have developed as a result of the split of the funding and responsibilities between Commonwealth and state and territory governments and the complexity of moving between the disability and aged care sectors. It appears that, from the point of view of consumers, there is an unclear division over Commonwealth and state responsibilities, the system is complex and difficult to navigate, and there are problems with the interfaces between federal and state programs. Here the committee wishes to identify some of the major problems associated with navigating the disability system.

2.14 One of the most striking aspects of the evidence taken by the committee was that concerning the availability and accessibility of information. Common criticisms are that there is no single access point for consumers, no centralised repository of information about services, and that there are difficulties accessing information. The committee notes that under the NDA, states and territories must address the difficulties that consumers have accessing information.[12]

2.15 Other witnesses drew parallels between access to information and choice: 'Knowing what your choices are is a fundamental part of being able to make a choice'.[13] For many people with disability the information is often inaccessible:

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[10] *Submission 43*, p. 6.

[11] Productivity Commission, Draft Report, *Disability Care and Support*, Volume 1, p. 6.

[12] Council of Australian Governments, *National Disability Agreement*, Intergovernmental Agreement on Federal Financial Relations, 29 November 2008, section 26.

[13] Ms Leah Hobson, Australian Federation of Disability Organisations, *Committee Hansard*, 29 November, 2010, p. 5.

> For a lot of people with disabilities the information that is provided might be at a higher language level or it might be in English which, if you have been speaking Auslan your entire life or if you use Makaton or another form of communication, is not necessarily appropriate.[14]

2.16 Concerns were also raised with the committee about access for people from non-English speaking backgrounds and for older people not connected to the internet.[15]

2.17 Mrs Joan Hughes, CEO Carers Australia, spoke directly of the implications that poor access to information has for planning:

> Often carers are so tired and cynical in a way that they just feel they cannot go through what they need to in order to find viable options. Often carers are not aware or informed of these options or what services are available and as such they do not have the capacity to plan.
>
> Carers have consistently reported to us that searching for relevant information is very stressful to them. It is time consuming and sometimes it does not eventuate in clear options for how they will progress their future and for the people they are supporting. You can imagine how exhausting this process must be for them.
>
> Information is the key piece of the future planning puzzle, and it cannot be expected that carers have the time and resources to seek this information out on their own. Carers Australia believes that every effort must be made to simplify this process and assist carers in having sufficient information to make informed choices for their futures and the people in their families.[16]

2.18 The complexity of the service system and the availability of support arrangements act as another significant barrier to planning. Speaking about the complexity of the system Dr Ken Baker, Chief Executive of National Disability Services, observed:

> Even for someone in my position who makes a full-time job of knowing the disability service system, it is still very complicated. I cannot imagine how family carers, people with disability and even service providers find their way around the current system. The eligibility criteria are complicated, pathways between service types often end up as dead ends and the articulation between different programs and service systems and between state and federal programs is poor. This essentially generates, I think, both risk aversion and bewilderment on the part of family carers. They do not feel empowered by this system. It is too complicated. They feel risk-averse because they feel that if they, for example, encourage a son or daughter to try employment and employment does not work out then they may be left with nothing or they may be at the back of the queue. The complexity is a product of the highly rationed funding. A lot of the administrative effort

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[14] *Committee Hansard*, 29 November 2010, p. 5.

[15] See, for example, National Ethnic Disability Alliance, *Committee Hansard*, 29 November, 2010, p. 52; Vision Australia, *Submission 84*, p. 7; Ms Leah Hobson, *Committee Hansard*, 29 November, 2010, p. 2.

[16] *Committee Hansard*, 8 November 2010, pp. 23–4.

> within state and federal departments goes into refining the rationing rules and building the gateways rather than looking at ways in which pathways and access to services can be opened up.[17]

2.19 With respect to current arrangements for funding and support across disability and aged care sectors, those under 65 are currently a state responsibility whereas those over 65 are a Commonwealth responsibility. In many instances this administrative distinction is difficult for consumers to understand. This is particularly so for those people under 65 with a disability who suffer from degenerative conditions, and for those experiencing premature ageing and who require support from aged care service providers. The complexity attached to these age thresholds is covered in Chapters 3 and 4.

2.20 The sense of complexity, as stated by the CEO of a peak intellectual disability organisation, was reiterated by consumers. Ms Margaret Cooper, Women with Disabilities Australia, explained that she relies upon six organisations to provide her care package for post-polio syndrome. This involves five different programs with four different team leaders; each has its own administrative procedures and administration costs.[18] Ms Cooper added with respect to the proposed increase to the retirement age to 67:

> I understand there is some change, anticipating 2011. I am now 67 and next year I will be officially aged. Talking to my three case managers and four team leaders, I said, 'What's this going to mean for me?' The answer: I do not know. 'Am I going to be transferred to aged care and, if so, what happens to the disability part of me?' I see myself as disabled and getting older, but a lot of my friends just see themselves as disabled. We do not know what is going to happen. There is a lot of worry out there; we just do not know…
>
> I do hydrotherapy once a week to keep me flexible. As soon as I turned 66, the agency that funds that care said, 'Right, you are now in aged care; we are changing your service provider,' and they changed me to a provider that had very little experience with disability. Being able to talk better last year than this year, I yelled and carried on and asserted myself and finally got my hydrotherapy transferred back to a provider with disability experience. If I had not done that I would have been in aged care, teaching them how to look after me. I do not think that is appropriate. That was a preliminary battle, and that case manager from that agency said, 'Margaret, get ready for 2011.' Great.[19]

2.21 The complexity is then magnified when considering the way that the Disability Support Pension (DSP) interacts with aged care. For example, if a person turns 65 and chooses to remain on the DSP but then requires aged care services, or moves to the Age Pension but still requires disability services, it is unclear whether services can be accessed on either pension or whether the person must switch between

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[17] *Committee Hansard*, 8 November 2010, p. 21.

[18] *Committee Hansard*, 29 November 2010, pp. 25–6.

[19] *Committee Hansard*, 29 November 2010, p. 29.

pensions to obtain appropriate services.[20] This is an example of the lack of clarity and continuity that exists for people moving between the DSP and the aged care pension.

2.22 With respect to assessment more generally, many individuals also reported difficulties obtaining an adequate multidisciplinary assessment. Evidence indicates that there are insufficient assessment tools for people with degenerative conditions and for those experiencing premature ageing. The point was made time and again that, without adequate assessment, it is extremely difficult to create a tailor-made, or individualised, care plan. The interaction between the disability and aged care sectors and the aged care assessment process will be examined in more detail in Chapter 4.

2.23 The committee has further concerns about the interface between disability and ageing as it relates to supported employment and retirement from Australian Disability Enterprises (ADEs). Evidence suggests that people with disabilities have difficulty retiring because of a lack of support services outside of the ADE and that this also has implications for younger people with disabilities who seek employment.[21]

2.24 JacksonRyan partners suggested that part of the confusion arises as a result of national inconsistency with respect to policy and legislative settings:

> …variations in legislation underpin much of the real confusion and ignorance about policy, decision making and programs which surround people with a disability, their families and carers. These variations arise whether it is Victoria compared with the Commonwealth or Victoria compared with other states and territories. No matter how similar the acts may be or how aligned that the legislation regulations may be—and I use the word 'aligned' because that is the word that is in the National Disability Agreement—with national policy and reform direction as required by the National Disability Agreement, I cannot emphasise too strongly that, while high level agreement may be reached on the ground with the service providers, in family homes around the nation confusion and ignorance abound.[22]

2.25 It is critical that there is consistency of quality standards and portability of aids and equipment across the states and territories, as agreed to under the NDA. The committee would like to reinforce that the states and territories have not delivered on their commitment under the NDA. Matters of legislative and policy consistency will be explored more in the following chapter. The committee would like to reinforce that the states and territories have not delivered on their commitment to the NDA.

2.26 In this chapter the committee has offered a snapshot of the challenges facing the disability sector. In so doing the committee has sought to build on the evidence taken by the Productivity Commission as it is reported in its Draft Report into Disability Care and Support. In the following chapters the committee will examine many of these challenges in more detail through examining the implications they have for planning.

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[20] *Committee Hansard*, 18 February 2011, p. 49.

[21] *Committee Hansard*, 18 February 2011, p. 26.

[22] *Committee Hansard*, 29 November 2010, p. 49.

Chapter 3

Legislative and policy frameworks

3.1 For much of the 20th century, people with significant intellectual and physical disabilities were sent, at a young age, to state-run institutions established for the care of people with particular needs. People with disabilities remained in these institutions for the duration of their adult lives and were reliant on the support of formal or employed caregivers. The deinstitutionalisation of the disability sector that took place during the 1970s and 1980s was designed to shift the responsibility of care from the state to communities, but resulted in families shouldering most of this responsibility.[1] Several decades later, the first generation of people who were raised in the home is now entering middle age. Their carers, typically parent and family carers, are themselves advanced in years and many are struggling with the responsibility of care. Many now confront the uncertainty of not knowing who will care for their son or daughter when they die or when they themselves require care.

3.2 Government policy has had some role in both driving and responding to change in care provision for people with disabilities. The Australian Government's shift away from institutional care was influenced by the policy work of the United Nations in the 1970s and 1980s, in particular the United Nations Declaration on the Rights of Disabled Persons in 1974.[2]

3.3 Key Commonwealth responses during the period included the early 1980s Review of Handicapped Programs, the subsequent passing of the *Disability Services Act 1986* and the establishment of the Human Rights and Equal Opportunity Commission the same year.[3] This legislation was followed by practical measures, such as the changes to social security payments following the 1988 Social Security Review (the Cass Review).[4] The Invalid Pension (1909) was overhauled with the aim of

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[1] In some states, institutionalisation remained until much later. The Willow Court Centre in Tasmania, a residential institution for people with disabilities, was not closed until October 2000. The Tasmanian Parliament passed a tri-partite motion in October 2008 recognising that 'institutional care is no longer appropriate for people with disabilities' and requiring a Joint Standing Committee on Community Development investigation. Department of Health and Human Services (TAS), *Directions Paper, Content and Structure of New Disability Services Legislation in Tasmania*, November 2009, p. 5.

[2] See for example, Dr Sev Ozdowski, *Disability discrimination legislation in Australia from an international human rights perspective: History, achievements and prospects*, 2002, http://www.hreoc.gov.au/disability_rights/speeches/2002/history02.htm (accessed 8 June 2011).

[3] Disability Services Commission WA, *A Policy Framework is Born*, http://www.disability.wa.gov.au/aboutdisability/disabilityserviceshistory/policyframework.html (accessed 30 May 2011).

[4] Helen Browlee, *Employment and Income Security Support*, Family Matters (28), April 1991, p. 14.

encouraging rehabilitation and self-sufficiency and renamed the Disability Support Pension in 1991.[5]

3.4 The Home and Community Care (HACC) Program was introduced in 1985. HACC continues to provide services to assist people with a disability, or who are ageing, to remain at home. The *Home and Community Care Act 1985* also clearly recognised the role of carers and their needs for respite.[6] The eligibility criteria for the Handicapped Child's Allowance (later Child Disability Allowance), payable to parents of 'severely handicapped' children under the age of 16, was gradually expanded during the 1970s and 1980s. This payment was eventually replaced by the Carer Allowance in 1999, paid to people caring for either an adult or a child with a disability.[7]

3.5 During the period of reform in the 1980s, public sentiment was very supportive of the shift away from institutionalisation and towards a more inclusive social services framework that included assisted family care. However, twenty-five years have passed since the enactment of the *Disability Services Act 1986*, and evidence suggests that radical change is once again required. As outlined in the previous chapter, much of the evidence taken by the committee has suggested that existing government legislation, policy and services are inadequate in meeting the needs of people with disabilities and their carers.

3.6 This chapter begins by examining the United Nations framework on the rights of persons with a disability, before proceeding to examine Australian disability and carers legislation. It seeks to identify the roles of the Commonwealth and the states and territories in assisting people with a disability and their carers, and explore the linkages and gaps in the legislation across jurisdictions. This chapter demonstrates that while existing legislation has attempted to accommodate the needs of those with a disability and their carers, the evidence received during the inquiry from people struggling to identify, navigate and utilise government services makes a strong case for reform.

Rights based framework

3.7 In the 1970s, the UN responded to increasing international awareness of the rights of people with disabilities through the Declaration on the Rights of Mentally Retarded Persons (1971) and the Declaration on the Rights of Disabled Persons (1975). The Declaration on the Rights of Mentally Retarded Persons sought to provide a set of principles seeking to enable people with disabilities to participate and integrate in society:

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[5] Dale Daniels, Parliamentary Library *Social Security Payments for the Aged, People with Disabilities and Carers 1901 to 2010*, 21 February 2011, p. 4.

[6] *Home and Community Care Act 1985*, ss. 5(1), 7(1).

[7] Dale Daniels, Parliamentary Library *Social Security Payments for the Aged, People with Disabilities and Carers 1901 to 2010*, 21 February 2011, pp 18–23.

> ...if possible, persons with intellectual disabilities should live with their families or with foster parents and should participate in various aspects of community life.[8]

3.8 Similarly, the Declaration on the Rights of Disabled Persons promoted recognition that people with disabilities have the same civil, political and access to services rights as others.[9] This theme of participation and integration for people with disabilities culminated in the UN declaration of 1981 as the International Year of Disabled Persons, and its designation of the period 1983–1992 as the UN Decade of Disabled Persons.

3.9 The United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the CRPD Optional Protocol entered into force on 8 May 2008. Australia ratified both the treaty and the protocol in July 2008. The CRPD identified a number of principles that govern its implementation:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women; and
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.[10]

3.10 A number of non-government organisations, many of which operate according to rights-based principles themselves, told the committee that government should ensure that its commitment to the CRPD treaty is mirrored in practice, and ensure that service delivery enables these rights to be realised. Ms Sue Barnes, representing People With Disability Australia, told the committee that existing legislation does not ensure that people's rights are met:

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[8] United Nations Enable, *History of United Nations and Persons with Disabilities - A human rights approach: the 1970s*, http://www.un.org/disabilities/default.asp?id=130 (accessed 31 May 2011).

[9] United Nations Enable, *History of United Nations and Persons with Disabilities - A human rights approach: the 1970s*, http://www.un.org/disabilities/default.asp?id=130 (accessed 31 May 2011).

[10] United Nations General Assembly, *Final report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, 6 December 2006, p. 8.

> We have illustrated...the effects that the long-term failure of governments to plan for the future in the disability sector has on people with disability, which have resulted in major human rights abuses for those individuals.
>
> [T]here is absolutely no way that the system, in the way it works at the moment, can pick them up as an individual and enable them to enjoy the kinds of rights and experiences that they are entitled to under the various pieces of legislation and, as we said, under CRPD. [11]

3.11 People with Disability Australia also suggested that the CRPD should be utilised as an interpretive aid to audit and access proposed reforms to the sector.

Rights in existing Commonwealth, state and territory legislation

3.12 There are several references in Commonwealth and state and territory legislation that imply, for the most part explicitly, that people with disabilities are entitled to the same rights as other members of society. Under the National Disability Agreement (NDA), the Commonwealth is responsible for:

> ...ensuring that Commonwealth legislation is aligned with national priority, reform directions and the UN Convention on the Rights of People with Disabilities.[12]

3.13 State and territory legislation also includes references to the rights of people with disabilities. The Victorian *Disability Act 2006*, for example, lists a number of rights people with disabilities should have, and stipulates that disability services must respect these rights.[13] However, JacksonRyan Partners' submission, for example, expresses concern such rights are not comprehensive in application nor widely understood.[14]

3.14 A direct reference to rights is provided in the *Disability Services Act 2006* (QLD). This act extends on the rights declaration from the *Disability Services Act 1992* (QLD) that stated, 'All people with a disability have the same human rights as other members of society and should be empowered to exercise their rights.' The 2006 legislation expands this statement to include other references to rights of people with disabilities:

> People with a disability have the right to equal access to services available to other members of the Queensland community…
>
> These include rights when using disability services, such as the right to receive services:

- In a way that respects the confidentiality of personal information;

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[11] *Committee Hansard*, 30 November 2011, pp 55, 57.

[12] Council of Australian Governments, *National Disability Agreement*, Intergovernmental Agreement on Federal Financial Relations, 29 November 2008, section 15.

[13] Department of Human Services (VIC), *The Disability Act 2006, Information Sheet 1,*February 2011, http://www.dhs.vic.gov.au/__data/assets/pdf_file/0019/152308/disact_infosheet_1_disact06_0211.pdf (accessed 8 June 2011).

[14] JacksonRyan Partners, *Submission 15*, p. 3.

- In a safe, accessible built environment appropriate to the person's needs.

  The Act specifically recognises the right to live a life free from abuse, neglect or exploitation.[15]

3.15 However, evidence received from Queensland-based submitters indicated that the intent of the legislation above is not recognising people's rights in a practical way:

> PwDA have the same right of access to services and other supports as those enjoyed by the general ageing population, in keeping with the principle of being supported to lead an ordinary life [...]
>
> It is Endeavour's experience that these principles are markedly absent from current policies and practices impacting on the lives of PwDA.[16]

3.16 Disability services legislation in other states also includes principles that recognise the rights of people with disabilities. The *Disability Services Act 1993* (NT), for example, provides a mostly theoretical overview of the rights-based principles to be furthered with respect to people with disabilities, and the objectives that disability services should deliver.[17]

3.17 Theoretically, the recognition of these rights should ensure that people with disabilities receive appropriate care even after their family members 'can no longer care'. However, the committee heard that the complexity of the existing combination of state and Commonwealth legislation, together with an overall lack of funding, results in disjointed and ineffective service delivery that does not allow these rights to be realised. Overwhelmingly, the committee received evidence that the current system cannot meet the objectives of the legislation or safeguard the rights of people with a disability.

Commonwealth legislative framework

3.18 Many of the difficulties experienced by witnesses in relation to their attempts to identify and access satisfactory disability and carer support services were related to problems navigating Commonwealth and state and territory frameworks, legislation and services. This section seeks to identify the Commonwealth frameworks and agreements that relate to the provision of disability and aged care services, as distinct from the state and territory's responsibilities, which are discussed thereafter.

National Disability Reform Agenda

3.19 Commonwealth legislation, frameworks and funding agreements for disability are the subject of recent and current reform. On 23 July 2008, the Community and Disability Services Ministers' Advisory Council launched the National Disability Reform Agenda. Key areas identified for reform were:

- Service benchmarks;

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[15] The State of Queensland (Department of Communities) *Rights of people with a disability*, 2011, http://www.communities.qld.gov.au/disability/key-projects/disability-services-act-2006/rights-of-people-with-a-disability (accessed 31 May 2011).

[16] Endeavour Foundation, *Submission 14*, p. 2.

[17] *Disability Services Act 1993* (NT), s. 3.

- Disability services' quality standards;
- Service planning;
- Building people centred service delivery;
- Early intervention and prevention;
- Workforce capacity;
- National consistency; and
- Ageing carers.[18]

3.20 The reform agenda was envisaged to be a national measure that would improve services across jurisdictions to address the 'fragmented service system lacking in early intervention and often driven by crisis'.[19] However, evidence received by the committee suggested that while nearly three years have passed since the launch of the reform agenda, the system remains as fragmented and crisis driven as ever:

> Unfortunately, there are still some barriers within the planning and access to those programs…It is based on crisis rather than forward planning, and there are insufficient programs and services out there to meet the needs of all those who require them.[20]

National Disability Agreement

3.21 The National Disability Agreement (NDA) replaced the Commonwealth State Territory Disability Agreement (CSTDA) from 1 January 2009, as part of the wider program of reform. The NDA sets out the roles and responsibilities of the Commonwealth and the states and territories in relation to disability. In addition to joint responsibilities in the areas of policy development, research, Indigenous outcomes and data provision, the Commonwealth is responsible for:

- Employment services;
- Income support;
- Funding states and territories' programs and initiatives, where appropriate; and
- Ensuring Commonwealth legislation complies with the CRPD.[21]

3.22 The responsibilities of the states and territories under the NDA relate to the provision of specialist disability support services, and are detailed later in this chapter.

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[18] Community & Disability Services Ministers' Advisory Council, *Community and Disability Services Ministers' Conference Communiqué*, 23 July 2008, p. 1.

[19] Community & Disability Services Ministers' Advisory Council, *Community and Disability Services Ministers' Conference Communiqué*, 23 July 2008, p. 1.

[20] Mrs Lucy Crawford, Mai-Wel Ltd, *Committee Hansard*, 30 November 2010, pp 33–34.

[21] Council of Australian Governments, *National Disability Agreement*, Intergovernmental Agreement on Federal Financial Relations, 29 November 2008, section 15.

3.23 The NDA identifies ten priority areas for policy direction in the area of disability services, for example, priority (c) is 'Making Older Carers a Priority'.[22] The impact of the reforms was envisaged to:

> ...make it easier for people with disability, their families and carers to access the right support through case-based early intervention and to move through the system as their needs change. The reforms simplify funding and service delivery responsibilities to make it easier to coordinate services, close service gaps and improve access to the right services...
>
> The reforms will create an effective, efficient and equitable disability services system with a focus on timely, person-centred approaches and lifelong planning.[23]

3.24 The NDA also includes a number of performance indicators that states and territories must report against each year. These include, for example:

- The proportion of the potential population accessing disability services;
- The proportion of carers of people with disability accessing support services to assist in their caring role.[24]

3.25 The National Disability Agreement Performance Report for 2009–10 provides the most recent data on the states and territories' performance in the context of the NDA. While there are issues identified regarding the availability of data, the Report suggests that some of the performance targets have not yet been met: for example, the reported percentage of the potential population accessing disability services in 2008–09 ranged from 13.9 per cent in QLD to 32.1 per cent in the ACT. [25]

3.26 This data was reiterated in the testimony of witnesses to the inquiry, as Australian Federation of Disability Organisations (ADFO) explained in relation to accessing transition planning:

> I think the system is so fractured and so variable across Australia...you might find pockets where a disability service provider or a local Home and Community Care service might be doing better at those sorts of things and in other areas but there really is no consistent planning across Australia or

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[22] Council of Australian Governments, *National Disability Agreement*, Intergovernmental Agreement on Federal Financial Relations, 29 November 2008, section 26.

[23] Council of Australian Governments, *National Disability Agreement Factsheet*, 29 November 2008, http://www.coag.gov.au/coag_meeting_outcomes/2008-11-29/docs/20081129_national_disability_agreement_factsheet.pdf (accessed 7 June 2011).

[24] Council of Australian Governments, *National Disability Agreement*, Intergovernmental Agreement on Federal Financial Relations, 29 November 2008, section 17.

[25] However, the report identified that a lack of new data together with a lack of state and territory agreement on determining performance measures limited any assessment the report was able to make. Steering Committee for the Review of Government Service Provision, *National Agreement Performance Information 2009–10: National Disability Agreement*, Productivity Commission, Canberra, Table NDA 3.1.

> even across a jurisdiction that would allow people with disability and their families to access those kinds of gentle transitions.[26]

3.27 Most of the evidence received from families of people with a disability and advocacy organisations reflected the views and experience of AFDO. For the most part, people who use the disability support system do not consider it coordinated, effective, efficient or equitable. However, an example of a program that is partially funded through the NDA (NSW's *Stronger Together*), and has been welcomed by some service users, is provided later in this chapter.

National Disability Strategy

3.28 During 2008 and 2009, the Commonwealth Government consulted widely to assist in the formation of a National Disability Strategy. Initial consultation included the establishment of the National People with Disabilities and Carer Council, the release of a discussion paper for public comment and the opportunity for people to participate in public forums in capital cities and focus groups in regional areas.[27]

3.29 The National Disability Strategy (2010–2020) was formally endorsed by COAG on 13 February 2011. It provides an overarching policy framework for coordinated disability services across the jurisdictions, designed to be consistent with the CRPD. The strategy provides direction for the formulation of legislation and policy across six policy areas:

1. Inclusive and accessible communities;
2. Rights protection;
3. Economic security;
4. Personal and community support;
5. Learning and skills; and
6. Health and wellbeing.[28]

3.30 The strategy includes some reference to carers and long-term future planning. It acknowledges the role that families and carers play in disability support, and notes that the proportion of informal carers relative to people with a severe or profound disability is projected to decrease significantly in the next fifty years.[29] The strategy recognises the need for long-term care for people with a disability, and in this respect notes that the Commonwealth Government, as part of the strategy, has commissioned the Productivity Commission to conduct an inquiry into a long-term disability and support scheme (as discussed in Chapter 1).[30] The strategy also states that carers are

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[26] Ms Leah Hobson, Australian Federation of Disability Organisations, *Committee Hansard*, 29 November 2010, p. 6.

[27] FaHCSIA, *National Disability Strategy, Background to the Strategy*, http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/nds.aspx#4 (accessed 1 June 2011).

[28] Council of Australian Governments, *National Disability Strategy*, 2011, p. 10.

[29] Council of Australian Governments, *National Disability Strategy*, 2011, p. 19.

[30] Council of Australian Governments, *National Disability Strategy*, 2011, p. 20.

assisted by services under the NDA, and that the Commonwealth Government is committed to further acknowledgement of and assistance to carers through the development of a National Carer Recognition Framework.[31]

National Carer Recognition Framework

3.31 The National Carer Recognition Framework is comprised of carers' recognition legislation and the National Carer Strategy. The Federal Parliament passed the *Carers Recognition Act 2010* in October 2010, and the Commonwealth Government continues to develop the National Carer Strategy through FaHCSIA and DoHA.

3.32 The *Carers Recognition Act 2010* provides some recognition of the efforts made by informal support networks and carers. However, while the Act acknowledges the contribution informal carers make to society, it does not create enforceable obligations on the Commonwealth.

3.33 Schedule 1 of the Act lists ten principles relating to the recognition of carers and the opportunities they should be afforded:

> The Statement of Australia's Carers articulates principles for dealing with carers in a policy, program or service delivery setting. The Statement for Australia's Carers will not create rights, but will instead establish key principles on how public service care agencies and associated providers should treat carers when developing, implementing, providing and evaluating care supports.[32]

3.34 The *Carers Recognition Act 2010* is complemented by the development of the National Carer Strategy, which is envisaged to provide an overarching framework for future policy and service delivery for carers. Targeted national consultation was undertaken in 2010 to inform the development of the strategy, which is planned to be implemented in 2011. Dr Nick Hartland, representing FaHCSIA, explained:

> So in concept the National Carer Strategy is somewhat similar to the National Disability Strategy. It is a document that sets out the government’s vision for carers and as a mechanism for getting alignment across Commonwealth departments and with states to improve outcomes.[33]

3.35 The strategy and carers recognition legislation provide principles and a framework for carer support, while practical assistance to carers is provided via the National Respite for Carers Program (NRCP), and through it the National Carer Counselling Program (NCCP), and Commonwealth Respite and Carelink Centres (CRCCs).

3.36 Commonwealth Respite and Carelink Centres are operated by local community organisations in 54 locations throughout metropolitan and regional

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[31] Council of Australian Governments, *National Disability Strategy*, 2011, p. 51.

[32] *Explanatory Memorandum*, Carers Recognition Bill 2010, p. 7.

[33] *Committee Hansard*, 18 February 2011, p. 24.

Australia.[34] The Centres act as central points for carers wishing to arrange respite, facilitating such services as:

- In-home respite care;
- Support for carers during breaks; and
- Residential respite care.[35]

3.37 The Department of Health explained that the CRCCs provide an opportunity for carers to discuss their situation and be provided with information and referrals to respite as well as wider support services.[36] While this advice is valuable to carers, the committee heard the shortage of respite results in places only becoming available to people in crisis. This limited availability of respite, as well as the second component of the NRCP, the National Carer Counselling Program, are discussed further in Chapter 5.

Disability and aged care

3.38 The Commonwealth is responsible for providing a disability policy framework, but has a much more active role in aged care provision. While states and territories are responsible for providing specialist support services to people with a disability, the Commonwealth provides such services to people who are ageing.[37]

Aged Care Act 1997

3.39 The *Aged Care Act 1997* built on earlier legislation contained in the *National Health Act 1953* and the *Aged and Disabled Persons Care Act 1954*.[38] It provides funding for aged care services and stipulates the manner in which such services must operate. The Act details how subsidies are to be provided to facilitate residential care, community care and flexible care for ageing people.

3.40 Under the Act, the Commonwealth subsidises approved providers who then facilitate residential care to eligible people. The value of these subsidies is currently approximately $7.1 billion per annum.[39] The types of fees and maximum amounts that

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[34] Mrs Tracy Mackey, Department of Health, *Committee Hansard*, 18 February 2010, p. 53.

[35] Department of Health, *National Respite for Carers Program*, http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-nrcp.htm (accessed 30 June 2011).

[36] Mrs Tracy Mackey, *Committee Hansard*, 18 February 2010, p. 53.

[37] By contrast, the division of responsibility for disability and aged care services is the opposite: people with a disability aged 65 and under can access centralised services provided by the Ministry of Health whereas services for older people are obtained from local District Health Boards. The Allen Consulting Group, *International Review of Future Planning Options, Final Report to the Department of Families, Housing, Community Services and Indigenous Affairs*, January 2009, p. 87.

[38] Australian Law Reform Commission, *Aged Care Legislation for the Commonwealth*, 2010, http://www.alrc.gov.au/inquiries/aged-care-legislation-commonwealth (accessed 6 June 2011).

[39] Department of Health and Ageing, *What does the Australian Government Pay?* http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/content/What+does+the+government+pay (accessed 6 June 2011).

such service providers may charge residents themselves are determined by the Schedule of Resident Fees and Charges.[40] However, the Act also requires residential care service providers to keep a number of places for people who are exempt from making such payments.[41]

3.41 Particular programs that are subsidised by the Commonwealth under the community and flexible care options include:

- Extended Aged Care at Home (EACH), $206 million in 2009–10;
- Extended Aged Care at Home (EACH)—Dementia, $99.6 million in 2009–10;
- Community Aged Care Packages (CACP), $508.7 million in 2009–10.[42]

3.42 According to the Act, eligibility for care is determined by need, the identification of a particular type of care as being most appropriate, and the criteria specified in the Approval of Care Recipient Principles.[43] In practice, these determinations are made by means of an Aged Care Assessment Team (ACAT) assessment.

3.43 Earlier the committee examined the problems arising when people with a disability enter the aged care system, and cited the example of Ms Margaret Cooper, who did not experience continuity of care (paragraphs 2.20–2.21). Similarly, problems exist for people with a disability who need early access to aged care services. While ACAT assessments do not formally require a person eligible for care to have reached a certain age, the 'primary target group' of aged care services is people aged 70 years or older.[44] The Assessment and Approval Guidelines state that 'a referral to an ACAT for approval for residential care should be the absolute last resort'.[45] The guidelines indicate that younger people with disabilities can only be assessed as eligible for aged care services where 'no other [state or territory] care facilities or care services more

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[40] Department of Health and Ageing, *Fees and Charges for Residential Aged Care - An Overview*, http://www.health.gov.au/internet/main/publishing.nsf/Content/38A97C5DDFEB223ACA25744000810E58/$File/9FeesChargesResidentialAgedCare.pdf (accessed 6 June 2011).

[41] Department of Health and Ageing, *Help with Aged Care Homes*, September 2006, http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/cq-195, (accessed 6 June 2011).

[42] Department of Health and Ageing, *What does the Australian Government Pay?* http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/content/What+does+the+government+pay (accessed 6 June 2011).

[43] The *Approval of Care Recipient Principles 1997* is a legislative instrument that details the approval of people as care recipients under section 2.3 of the *Aged Care Act 1997*.

[44] Department of Health and Ageing, *Aged Care Assessment and Approval Guidelines*, 2006, http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA25774C001857CACA25721A0002E29B/$File/03part1.pdf (accessed 6 June 2011).

[45] Department of Health and Ageing, *Aged Care Assessment and Approval Guidelines*, 2006, http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA25774C001857CACA25721A0002E29B/$File/03part1.pdf (accessed 6 June 2011).

appropriate to meet the person's needs' exist. The Department of Health and Ageing told the committee that a person with advanced dementia in their forties:

> ...could end up receiving an extended aged care at home dementia package...and we already have a number of people under the age of 70 receiving those packages.[46]

3.44 However, other evidence to the inquiry suggested that even where appropriate care is not being provided by the state or territory, people with a disability cannot access aged care services:

> It becomes a particular problem for people with Down syndrome because of the very high levels of early onset dementia amongst people in their late 40s and early 50s...as high as 60 or 70 per cent...
>
> The problem is that aged-care services, which generally have the expertise and experience in dealing with dementia, do not kick in until 65 in most regions. So people have been turned away from those services because they are not old enough. It doesn't matter how they present clinically or how much they are suffering from dementia. Some people have been denied access to appropriate dementia support because they are not old enough. They might be 54 but they have to wait until they are 55. There was one man earlier this year who was 59. He was living on his own in a house that had been his mother's. He had some support that he had had for a long time, but he was not able to have an ACAT assessment until he turned 60, even though it was quite clear and he already had the diagnosis of dementia.[47]

3.45 The committee heard that the interface between the aged care system and the disability system is very difficult to navigate. While people with a disability may need specialised care that is offered by Commonwealth subsidised aged care services providers and not state or territory service providers, such as the example of dementia above, the early onset of such conditions can preclude people from being assessed as eligible to access the services they need. The committee heard that this then results in people with disabilities being referred alternatively to ill-targeted state and territory services and then to aged care services for which they are not eligible, which results in a re-referral back to the state and territory services and so on. This causes major difficulty for people with a disability who often do not receive the care they need until years after such a need emerges, or at all. For those who do not have a dedicated family advocate, navigating between the two systems is virtually impossible. This interface between the disability and aged care sectors is explored further in the following chapter.

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[46] Mrs Tracy Mackey, *Committee Hansard,* 18 February 2011, p. 46.

[47] Mrs Jill O'Connor, Down Syndrome New South Wales, *Committee Hansard*, 30 November 2010, p. 7.

Age Pension

3.46 People with a disability aged 16 or over and under the qualifying age for the Age Pension may be eligible for the Disability Support Pension.[48] The qualifying age for the Age Pension, currently 65, will increase incrementally from 1 July 2017, reaching 67 by 1 July 2023.[49] The committee heard that this change may exacerbate existing complications and difficulties navigating the divide between the disability and aged care systems:

> Raising the retirement age will mean that people with disability are on disability support pensions for a bit longer, so they are perhaps locked out of some systems that might be more appropriate for them, particularly if they are acquiring multiple disabilities that are related to their ageing. So people with disability who have had a lifelong disability, for example an intellectual disability, may begin to have a vision impairment or a hearing impairment that is ageing related or they begin to experience dementia. If we are talking about raising the retirement age for pensions then we obviously at some stage are going to start looking at the retirement age for aged care systems as well. That means that people with disability who are acquiring multiple disabilities and who may need additional support earlier on will not necessarily have access to it.[50]

3.47 The committee heard that the Department of Health and Ageing is considering the different aged care needs assessments undertaken by 108 different ACAT teams, and is seeking to consolidate them into three assessment tools over the next 12 to 18 months.[51]

Home and Community Care (HACC)

3.48 The Home and Community Care (HACC) program provides home based care and support services people with a disability, older people and their carers. The program aims to reduce admissions to residential care in cases where the provision of limited assistance can enable people to remain at home. Such services can include nursing care, respite care, transport, counselling, support and information and

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[48] As well as meeting the age criteria, eligible persons must be: 'not able to work for 15 hours or more per week at or above the relevant minimum wage or be reskilled for such work for at least the next 2 years because of your illness, injury or disability; or be working under the Supported Wage System (SWS); or be permanently blind.' Centrelink, *DSP Eligibility*, http://www.centrelink.gov.au/internet/internet.nsf/payments/dsp_eligible.htm (accessed 6 June 2011).

[49] Centrelink, *Age Pension Eligibility*, http://www.centrelink.gov.au/internet/internet.nsf/payments/age_pension.htm (accessed 6 June 2011).

[50] Ms Leah Hobson, Australian Federation of Disability Organisations, *Committee Hansard*, 29 November 2010, p. 7.

[51] Mrs Tracy Mackey, *Committee Hansard*, 18 February 2011, p. 41.

advocacy.[52] The HACC program is far reaching with significant client numbers comprising both older people (610,000 in 2009–10) and people with a disability:

> In 2009–10, 22.7 per cent of HACC clients were aged under 65 years (down from 23.2 per cent in 2007–08). Analysis of data from the HACC program in 2009-10 indicates that clients aged under 65 years were significantly over-represented in particular assistance types, including respite care (68.6 per cent)...
>
> In 2009–10, 32.4 per cent of HACC clients classified as care recipients reported that they were also receiving assistance from a relative or friend/carer (DoHA unpublished).[53]

3.49 In April 2010, COAG signed the National Health and Hospitals Network (NHHN) Agreement.[54] As part of that Agreement, the Commonwealth agreed to take full responsibility for aged care services. While most aged care services were already the responsibility of the Commonwealth before the agreement (as detailed above), the Home and Community Care program was an exception. While states and territories presently facilitate jointly-funded HACC programs for all clients, the Commonwealth will take over both funding and operational responsibility for clients aged 65 or over (and Indigenous clients aged 50 and over) from 1 July 2012. The period from 1 July 2011 to 1 July 2012 will be a transition year whereby states will still manage the operation of the services to older people but with increased Commonwealth funding.[55]

3.50 This new split between Commonwealth and state and territory responsibilities causes concern for people already struggling to navigate existing divisions between the aged care and disability care systems, and also for service providers that will be affected by the changes. Following the COAG announcement, NSW HACC service provider peak organisations formed a 'Community Care Consortium' in order to advocate collectively during the transition period. A letter from the consortium to its members reflects a lack of certainty around the upcoming changes:

> At the moment the Peaks have only the barest outline of what is proposed. As always, it is the detail which is most important and this is yet to be determined.

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[52] Department of Health and Ageing, *Home and Community Care Overview*, http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm (accessed 7 June 2011).

[53] Steering Committee for the Review of Government Service Provision, *Report on Government Services 2011*, Productivity Commission, Canberra, F 22; Productivity Commission, Draft Report, *Caring for Older Australians*, January 2011, p. 11.

[54] Western Australia was not a party to the agreement, and Victoria has not yet agreed to the changes to HACC. Council of Australian Governments, *A National Health and Hospitals Network*, 19-20 April 2010, http://www.coag.gov.au/coag_meeting_outcomes/2010-04-19/index.cfm#nathealth (accessed 7 June 2011).

[55] Ms Rachel Balmanno, Department of Health and Ageing, *Committee Hansard*, 18 February 2011, pp. 55–56.

> There will be practical difficulties for Services Providers which currently service both parts of the HACC target group, i.e. older people and younger people with disabilities.[56]

3.51 However, the Department of Health and Ageing told the committee that the changes will not affect client access to services or service provision:

> There is a misconception of the way the split is going to work that we will regularly come across. From a service provider point of view and from a client point of view HACC is not splitting. The range of services that service providers currently provide and the range of clients they currently see will in most cases continue. What is changing is how their funding flows and what contributions the state and territory governments make to the funding.[57]

3.52 Despite the Department being confident that those accessing the HACC program will receive seamless service while funding arrangements change, the committee remains unconvinced. The committee is also concerned that this new system will place a greater administrative burden on service providers.

Commonwealth planning services

3.53 Having examined the Commonwealth's role in the provision of disability services, the committee now turns to examples of specific Commonwealth programs targeted towards future planning.

Special Disability Trusts

3.54 Special Disability Trusts (SDTs) provide a vehicle for funds used to protect and support people with severe disabilities. They enable immediate family members to make private financial provision for the future care and accommodation needs of a person with a disability. Contributions to a trust have limited impact on Centrelink income or assets tests. The committee inquired into SDTs in 2008, and made a number of recommendations designed to improve the scheme.[58] The committee acknowledges that there have been a number of recent changes to SDTs, including, for example, new employment rules and expanded options for how trust money may be spent.[59] The committee also notes that the 2011–12 Federal Budget included additional measures to introduce exemptions to capital gains tax.[60] Nevertheless, in spite of these reforms, the committee is still concerned by evidence suggesting that the take-up rate remains

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[56] Community Care Consortium, *COAG Reforms to the HACC Program*, http://www.nswnassa.org.au/uploads/forms/2937_CCC_CoverLetter_HR%20(2).pdf (accessed 7 June 2011).

[57] Ms Rachel Balmanno, *Committee Hansard*, 18 February 2011, p. 43.

[58] See Senate Community Affairs Committee, *Building trust: Supporting families through Disability Trusts*, 16 October 2008.

[59] Ms Sharon Rose, FaHCSIA, *Committee Hansard*, 8 November 2010, p. 12.

[60] These changes are outlined on the FaHCSIA website: http://www.fahcsia.gov.au/sa/carers/progserv/pages/specialdisabilitytrusts.aspx (accessed 30 June 2011).

relatively low. Departmental officers informed the committee that as at 30 September 2010, there were only 119 SDTs in operation.[61]

FaHCSIA booklet: Planning for the Future: People with disability

3.55 In recognition of the need for guidance on planning, FaHCSIA released a booklet, *Planning for the Future: People with disability* in 2007. FaHCSIA described the positive feedback it had received in relation to the booklet, which has been distributed in hard copy form and is also available via the Department's website. The booklet is available in English and 13 other languages, and as at 18 November 2010, 30,600 hard copies had been distributed and 4,967 copies had been downloaded from the internet.[62]

3.56 Witnesses representing carers groups welcomed the booklet but considered that supplementary information sessions or workshops were also necessary:

> I guess the key thing for me is that a book, alone, will not do it. As I said, our training is all based on that booklet we have, but unless you have people back in little work groups working through it, parent to parent, it just does not seem to go anywhere.[63]

3.57 The committee also heard that the booklet, as well as other government publications, could be better targeted to people with a disability and their carers:

> At times information comes out from government departments and there is an expectation that it is easy to read. I am not sure if that is the case. I do not know if enough attention is given to the actual needs of the audience. It may be written up in such a way that it makes it a bit confusing and people do not take up the opportunities to look into different programs for that reason.[64]

3.58 The Commonwealth also allocates parts of the NDA funding to specific projects that provide planning assistance, such as the $60 million Supported Accommodation Innovation Fund (SAIF).[65] The committee notes that the SAIF program is an example of service planning rather than life-long planning.

Committee view

3.59 The committee acknowledges the work that Commonwealth agencies have undertaken with respect to information about planning. However, the committee is concerned that there is little evidence of any integrated or coordinated approach to planning, and while the initiatives outlined above have value, their utility is limited

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[61] Ms Sharon Rose, FaHCSIA, *Committee Hansard*, 8 November 2010, p. 12.

[62] FaHCSIA, Answer to Question on Notice 5 from public hearing 8 November 2010.

[63] Mrs Lorriane Hitt, Planned Individual Networks, *Committee Hansard*, 18 February 2010, p. 85.

[64] Mr Phillip Farrow, Bedford Group, *Committee Hansard*, 8 November 2010, p. 41.

[65] FaHCSIA, *Supported Accommodation Innovation Fund Fact Sheet*, http://www.fahcsia.gov.au/sa/disability/progserv/providers/saif/Pages/saif_factsheet.aspx (accessed 30 June 2011).

within a fragmented system that does not reach all of those who need services, much less those who need them most.

State and territory legislation

3.60 The states and territories assumed responsibility for the provision of specialist disability services in 1991 following the first Commonwealth State Territory Disability Agreement (now NDA). Under the NDA, the states and territories must provide specialist disability services in 'a manner which most effectively meets the needs of people with disability, their families and carers, consistent with local needs and priorities'.[66] The Australian Institute of Health and Welfare (AIHW) categorises specialist disability services into five service types: respite, accommodation support, community support, community access and employment (provided by the Commonwealth).[67]

3.61 The signing of the NDA coincided with a funding increase of $408 million for state and territory specialist disability services to a total $5.3 billion over five years.[68] Key reforms to be funded under the agreement were:

- Improved access to disability care including consideration of systems that provide a single point of access;
- Nationally-consistent assessment processes and a quality assurance system;
- A renewed focus on early intervention and planning to ensure that clients receive the most appropriate and timely support;
- Service providers will be better able to develop train and employ care workers;
- More consistent access to disability aids and equipment;
- A commitment by all levels of government to work together to better measure the level of unmet demand for disability services; and
- Continued work on reform of roles and responsibilities in relation to community mental health, disability services and aged care.[69]

3.62 While the state and territory legislation and policy priorities must comply with national directions, there is considerable scope under the NDA for different states and

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[66] Council of Australian Governments, *National Disability Agreement*, Intergovernmental Agreement on Federal Financial Relations, 29 November 2008, section 16.

[67] Australian Institute of Health and Welfare, *Disability Support Services 2008-09: Report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement,* 19 January 2011, Disability series, Cat. no. DIS 58. Canberra, p. vii.

[68] COAG Communique 29 November 2008, http://www.coag.gov.au/coag_meeting_outcomes/2008-11-29/index.cfm#disability (accessed 7 June 2011).

[69] COAG Communique 29 November 2008, http://www.coag.gov.au/coag_meeting_outcomes/2008-11-29/index.cfm#disability (accessed 7 June 2011).

territories to have varying systems. These differences are apparent in areas such as scope of portfolio funding, types of services available and legislation.

3.63 Some examples of state and territory variation are illustrated in recently released reports such as an AIHW report on the use of specialist disability services as well as the Productivity Commission's *Disability Care and Support* Draft Report. The AIHW report indicates the states with the highest rates of service use by people under 65 years are Victoria and South Australia, while the Northern Territory and Queensland have the lowest access rates.[70] It also notes that specialist psychiatric disability services were provided under NDA[71] funding in Victoria, Queensland and in some cases Western Australia, while in other jurisdictions such services were provided under the health portfolio.[72] In relation to funding, the PC notes that state and territory funding can fluctuate from year to year in accordance with total budget expenditure, and that the proportion of funding allocated to particular service types varies by jurisdiction, which affects the quality of services provided:

> Depending on which supports a person may require, they may find themselves better supported in one state rather than another.[73]

3.64 Differences in state and territory services provision is reflected in legislation and policy priorities. States and territories were required to pass their own disability legislation following the Commonwealth's *Disability Services Act 1986*:

- *Disability Services Act 1991* (ACT);
- *Disability Services Act 1993* (NSW);
- *Disability Services Act 1993* (NT);
- *Disability Services Act 2006* (QLD);
- *Disability Services Act 1993* (SA);
- *Disability Services Act 1992* (TAS);
- *Disability Act 2006* (VIC);
- *The Disability Services Act 1993* (WA).[74]

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[70] Australian Institute of Health and Welfare, *Disability Support Services 2008–09: Report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement*, 19 January 2011, Disability series, Cat. no. DIS 58. Canberra, p. 16.

[71] NDA was formerly Commonwealth State Territory Disability Agreement (CSTDA).

[72] Australian Institute of Health and Welfare, *Disability Support Services 2008-09: Report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement*, 19 January 2011, Disability series, Cat. no. DIS 58. Canberra, p. 45.

[73] Productivity Commission, Draft Report, *Disability Care and Support*, Volume 1, February 2011, ss 2.14, 2.20.

[74] Australian Government JobAccess, *Guide to Legislation*, http://jobaccess.gov.au/ServiceProviders/Help_available/Help_with_rights_and_responsibilities/Pages/Guide_to_legislation.aspx (accessed 8 June 2011).

3.65 The following short summary of some of the recent changes to state and territory disability policies or disability services illustrates the different approaches taken by the states and territories in disability service provision.

ACT

3.66 In September 2009 the ACT Government launched its updated disability policy framework, *Future Directions—Towards Challenge 2014*. The framework was developed by the ACT Disability Strategic Governance Group, and is structured under six policy priorities:

- I want the right support, right time, right place;
- I want to contribute to the community;
- I want to socialise and engage in the community;
- I want to know what I need to know;
- I want to tell my story once; and
- I want a quality service system.[75]

3.67 Relevant to the current inquiry, the *Futures Planning* policy document and grants program has been developed to assist people to implement personal future plans. In addition, the ACT government is developing an *ACT Government Policy Framework for People with Disability who are Ageing*. The report on the framework consultations included a section on the needs of ageing carers, reflecting many of the same planning, funding, information and respite needs that have arisen in the present inquiry.[76]

New South Wales

3.68 New South Wales' key disability reform project is entitled *Stronger Together: A new direction for disability services in NSW 2006–2016*. The ten year plan is designed to provide direction for reform and a 40 per cent increase to the capacity of the specialist service system in the state.[77]

3.69 The NSW Government's submission discussed care for people ageing with a disability in relation to wider *Stronger Together* goals:

> The AlP [Ageing in Place] initiative addresses goals outlined in *Stronger Together,* the NSW Government's 10-year plan to provide greater assistance and long-term practical solutions for people with a disability and their families, to increase assistance and options for people with a disability to live at home, as well as increase the range of specialist accommodation services, including options that promote ageing in place. Key to achieving

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[75] Community Services Directorate (ACT), *The Strategic Governance Group*, http://www.dhcs.act.gov.au/disability_act/sgg#framework (accessed 8 June 2011).

[76] Department of Human Community Services Directorate (ACT), *The Strategic Governance Group*, http://www.dhcs.act.gov.au/disability_act/sgg#framework (accessed 8 June 2011).

[77] New South Wales Government, *Stronger Together*, http://www.adhc.nsw.gov.au/about/strategies/stronger_together (accessed 8 June 2011).

> these outcomes is engaging in research on the effects of ageing on people with an intellectual disability, also an identified priority under Stronger Together. It is essential that people with a disability receive quality support, informed by good practice and research.[78]

3.70 During the first five years of the strategy, *Stronger Together* recognised the needs of carers through the creation of 4,000 new respite places, and in the second phase a large proportion of $623 million Commonwealth funding under the NDA will be directed towards older carers.[79]

Northern Territory

3.71 The Northern Territory Government engaged KPMG to undertake a review of the Disability Service System in the territory in late 2005. The report recommended that an 'integrated service model' be developed to align NT services with those in other jurisdictions as well as international developments.[80] This is explored more fully in Chapter 5 when the committee discusses the NT Government's newly established Office of Disability which offers a single access point or one-stop-shop for disability and aged care services.

Queensland

3.72 Key changes from previous legislation in the *Disability Services Act 2006* were the strong emphasis on the rights of people with a disability, and strengthened requirements for state funded service providers.[81] To ensure that people with disabilities can realise their equal right to government services, the Act requires all Queensland government departments to develop a disability service plan.[82] In addition, the *Guide, Hearing and Assistance Dogs Act 2009* legislates to allow people accompanied by guide dogs equal rights to public facilities.

3.73 *Growing Stronger: Investing in a better disability service system* is Queensland's 2007–2011 reform program that introduces a six-step service pathway:

- A single point of contact, so that clients can quickly get the information and request the support they need
- A single simplified 'Request for assistance' form

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[78] New South Wales Government, *Submission 62*, p. 10.

[79] New South Wales Government, *Stronger Together, A new direction for disability services in NSW 2006–2016*, http://www.adhc.nsw.gov.au/__data/assets/file/0014/234212/898_StrongerTogether_20102016_web_071211.pdf (accessed 8 June 2011).

[80] KPMG, *Review of Disability Services in the Northern Territory, Final Report*, 2006, http://digitallibrary.health.nt.gov.au/dspace/bitstream/10137/134/1/disability_services_overview_feb2007.pdf (accessed 8 June 2011).

[81] Department of Communities (QLD) *Key impacts of the legislation*, http://jobaccess.gov.au/ServiceProviders/Help_available/Help_with_rights_and_responsibilities/Pages/Guide_to_legislation.aspx (accessed 8 June 2011).

[82] Department of Communities (QLD) *Queensland Government Disability Service Plans*, http://www.communities.qld.gov.au/disability/key-projects/queensland-government-disability-service-plans (accessed 8 June 2011).

- A standardised assessment process to establish a person's eligibility for support and determine what support is available to them
- The ability to source assistance that will provide the most benefit to the client's needs.
- Less administrative red tape for service providers so that they can focus on what they do best—helping Queenslanders
- Improved information and reporting systems that allows the Department to better support its clients and service providers and plan for the future.[83]

South Australia

3.74 South Australia is reforming its community care provision to combine disability and aged care services via a single access point. The *Community and Home Support* division of the Department for Families and Communities is now the single access point for any enquiries about aged care, disability or caring.[84] South Australia envisages that the implementation of the single access point will be complemented by the current review of its *Disability Services Act 1993*.[85]

Tasmania

3.75 In 2008 the Tasmanian Government engaged KPMG to undertake a *Review of Disability Services in Tasmania*. Evidence received as part of the Review led to the development of several recommendations to significantly reform disability services in the state, including 'the endorsement and implementation of an entire "vision for change"'.[86] The Tasmanian Government agreed to implement the Review's recommendations over three years from 2008–09. A number of reforms have been made and the new Disability Services Bill 2011 is currently before the Tasmanian Parliament.

Victoria

3.76 The *Disability Act 2006* (VIC) replaced the previous Victorian legislation contained in the *Intellectually Disabled Persons' Services Act 1986* and the *Disability Services Act 1991*. The legislation moves towards the inclusion of a rights-based framework and more flexible service provision.[87]

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[83] Department of Communities (QLD) *Growing Stronger: Investing in a better disability service system*, http://www.communities.qld.gov.au/disability/key-projects/queensland-government-disability-service-plans (accessed 8 June 2011).

[84] Department for Families and Communities (SA), *Ageing and Disability Service Improvement*, http://www.dfc.sa.gov.au/pub/Default.aspx?tabid=908 (accessed 8 June 2011).

[85] *Carers Recognition Act 2005* (SA).

[86] Department of Health and Human Services (TAS), *Directions Paper, Content and Structure of New Disability Services Legislation in Tasmania*, November 2009, p. 6.

[87] Department of Human Services (VIC), *The Disability Act 2006*, http://www.dhs.vic.gov.au/__data/assets/pdf_file/0019/152308/disact_infosheet_1_disact06_0211.pdf (accessed 9 June 2011).

3.77 The Act aims to facilitate the participation of people with a disability in the community through: the *Victorian State Disability Plan 2002–12* (a new plan is required in January 2013); enabling people with a disability and their carers to provide policy input through the *Victorian Disability Advisory Council*; and requiring all state government public services agencies to develop and report on a Disability Action Plan to facilitate access to services for people with disabilities.[88]

Western Australia

3.78 Western Australian developed a comprehensive disability policy framework in the 1980s and 1990s including the passing of equal opportunity legislation and the establishment of the Authority for Intellectually Handicapped Persons (AIH).[89] The AIH was responsible for the Local Area Coordination program, which facilitates access to care and respite services in regional areas, reached full WA coverage in 2000. The *Disability Services Act 1993* (WA) amalgamated disability services into a single department specifically for disability services.

3.79 More recently, the 2009 *Count Me In: Disability Future Directions Strategy*, set out priorities to achieve the vision, 'all people live in welcoming communities that facilitate citizenship, friendship, mutual support and a fair go for everyone.'[90] As well as providing policy ideas and direction, the Strategy also includes initiatives such as the *Count Me In School Short Film Competition*, the *Count Me In Awards*, *Count Me In Scholarships* (to facilitate research into best practice disability services) and a media strategy.[91]

3.80 As demonstrated above, the states and territories have varying legislation, policy priorities and reform strategies. The disparity between the disability service systems across different states and territories causes particular complications with respect to the portability of services across states.

Portability Issues

3.81 The committee received evidence that existing difficulties experienced by people with a disability navigating and accessing services are compounded when they move interstate. Different eligibility requirements and entitlements between the

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[88] Department of Human Services (VIC), *About the Disability Act 2006*, p. 2, http://www.dhs.vic.gov.au/__data/assets/pdf_file/0019/152605/disability_act_web_print_version.pdf (accessed 9 June 2011).

[89] Disability WA, *A Policy Framework is Born*, April 2008, http://www.disability.wa.gov.au/aboutdisability/disabilityserviceshistory/policyframework.html (accessed 9 June 2011).

[90] Disability Services Commission (WA), *Count Me In: Disability Future Directions*, 2009, p. 4, http://www.disability.wa.gov.au/dscwr/_assets/main/guidelines/documents/pdf/count_me_in_disability_future_directions.pdf (accessed 9 June 2011).

[91] Disability Services Commission (WA), *Count Me In*, http://www.disability.wa.gov.au/countmein.html (accessed 9 June 2011).

jurisdictions can make it very difficult for people with a disability to maintain continuity of service.[92]

3.82 In recognition of this problem, the states and territories agreed to implement a National Interstate Portability Protocol following the third CSTDA in 2003.[93] Under the Protocol, people with a disability may receive disability service information and registration between the relevant jurisdictions and / or be supported by a one-off transfer of funds to facilitate a 12 month extension of their previous program.[94] People with disabilities must then reapply for funding for services beyond this period. The committee received evidence suggesting that this creates significant uncertainty and risk for people with disabilities:

> My wife and I reside in Broadbeach on the Gold Coast and our son resides in South Tweed Head, NSW. We went through the process of trying to move him into QLD to be close to us and his sister...but it all fell apart when QLD disabilities informed us that when the portability funding from NSW ran out in 12 months, they would not be able to promise any further funding and also that no suitable accommodation was available.[95]

3.83 The committee heard that such problems navigating interstate transfers were recognised by FaHCSIA five years ago, and that the issue has been regularly considered by the Disability Policy and Research Working Group (DPRWG):

> Part of that working group has been making sure the right processes are in place to simplify possible approaches to the move from states and territories to other states and territories. There is now a network of those contact points so that they talk to each other frequently and they know what people want to do and how they want to move. [96]

Committee view

3.84 The committee recognises that FaCHSIA is aware of the issues surrounding portability. However, given these issues were identified in 2006, the committee considers that the progress of the DPRWG on issues of portability to be extremely slow. The committee is also concerned that the Protocol may present circumstances where support is not available to a person 12 months after settling in a different state.

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[92] The Productivity Commission has recognised this issue, and has suggested that assessments of need and support packages as part of its proposed National Disability Insurance Scheme would need to be portable across states and territories. Productivity Commission, Draft Report, *Disability Care and Support*, Volume 1, February 2011, p. 2.

[93] FaHCSIA, *Funding and Operation of the Commonwealth State Territory Disability Agreement (CSTDA)*, http://www.fahcsia.gov.au/sa/disability/pubs/general/cstda_agreement/Pages/rec_1_5.aspx (accessed 10 June 2011).

[94] Community and Home Support SA, *Disability Services Information Sheet: Moving Interstate*, http://www.sa.gov.au/upload/franchise/Community%20Support/Disability/Information%20sheets%20-%20Disability%20SA/moving-interstate.pdf (accessed 9 June 2011).

[95] Name Withheld, *Submission 87*, p. 1.

[96] Ms Helen Bedford, Department of Families, Housing, Community Services and Indigenous Affairs, *Committee Hansard*, 18 February 2011, p. 24, p. 26.

Recommendation 1

The committee considers that there is a need for a clear transition process to facilitate uninterrupted funding when people with a disability move between states, and recommends the Department of Families, Housing, Community Services and Indigenous Affairs work with the states and territories to seek to resolve issues related to portability as a matter of urgency.

3.85 Having provided an overview of the legislative and policy frameworks, the committee now turns to examine the need for lifelong and sustainable planning. In the following chapter the committee begins by examining population ageing and documents many of the challenges faced by parent-carers. In so doing, the committee is interested in exploring the current life path for people with a disability and the challenges for those with physical and intellectual disabilities who may experience premature ageing.

Chapter 4

Need for lifelong and sustainable planning

4.1 As noted in its terms of reference, the committee seeks to assist carers find an appropriate answer to the question: 'What happens when I / we can no longer care?' or the attendant question: what happens when there is nobody to continue in a planning or quality monitoring role? In responding to these questions the committee proposes to examine future planning options that involve ongoing, sustainable, 'big picture' planning. Critical to such planning is the involvement of people who care, including friends, relatives and other members of the community, who can do what one disability support organisation in New South Wales referred to as: the caring *about*, and not just the caring *for*.[1] In this chapter the committee will examine the challenges faced by carers, the current life path of people with a disability and the need to establish planning cultures. This will be followed by a chapter which provides an overview of different planning models and which explores the types of assistance that could be provided to families to promote 'big picture' planning.

4.2 The committee notes that as people with disability are a large and extremely diverse group their planning needs are likely to be equally varied. For example, the planning support required for a person with a decision making impairment, be it an intellectual disability or a mental health disability, will be very different from that required by a person with a physical disability, who may be experiencing premature ageing. There will also be significant variation in the needs of different people within these groups. The planning challenges will also vary for Aboriginal and Torres Strait Islanders; for people from non-English speaking backgrounds; or for people living in rural and remote areas where there are inadequate formal support services.

Population ageing

4.3 As briefly discussed in Chapter 1, Australia is experiencing significant population ageing and it is anticipated that within the next decade there will be a considerable reduction in the levels of informal care and support available to people with disabilities.[2] The Australian Bureau of Statistics (ABS) recently released updated data on Disability, Ageing and Carers. This builds on data published by the ABS in 2003. It suggests that in 2009 there were 2.6 million carers who provided assistance to a person with a disability, or to a person aged over 60 years. This represented 12.2 per cent of the population. Just under one third of these (29 per cent) were primary carers;

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[1] Family Advocacy, *Submission 2*, p. 7.

[2] The formal sector constitutes paid care workers who have the benefit of legal employment protection and rights at work. The informal sector constitutes carers, and family caregivers, who provide unpaid care to people with disabilities and who are offered no workplace protections.

that is, they were people who provided the majority of the informal support. Over two-thirds of them, or 68 per cent, were women.[3]

Age of carers in Australia 2009—Numbers ('000)

Age Group	Primary carer	Not primary/ Other carer	Total carers
Less than 18 years	4.4	148.1	152.5
18–24	18.5	133.8	152.3
25–34	65.5	193.3	258.8
35–44	140.0	295.5	435.5
45–54	167.9	408.0	575.8
55–64	179.3	357.4	536.7
65–74	121.3	207.5	328.8
75 years and over	74.6	117.1	191.7
Total	**771.4**	**1860.7**	**2632.1**

Source: ABS 2009 Survey of Disability, Ageing and Carers[4]

4.4 These figures suggest that a significant number of the 2.6 million carers in Australia are over the age of 60—328,800 are aged over 65 and 191,700 are aged over 75 years. A further 536,700 are aged between 55 and 64. In examining the numbers of *primary* carers aged 65 or more we find the number at close to 200,000. While it should be noted that these figures relate to the number of total carers—people who provide assistance to older people and people with disabilities—these statistics reinforce the urgency of the planning challenge. They reinforce that in the next decade

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[3] 2009 Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers: Summary of Findings*, 2010, p. 10. In 2003, 3.9 million Australians were living with disability (20 per cent of the population), of which around 1.2 million were living with a severe or profound limitation (6.3 per cent of the population). People over 65 accounted for 18 per cent of all carers and 24 per cent of primary carers. By comparison in 2009, 4.0 million people were reported as having a disability (18.5 per cent of the population). The rate of profound or severe limitation in the core activities of communication, mobility and self-care declined, from 6.3 per cent in 2003 to 5.8 per cent in 2009. 2009 Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers: Summary of Findings*, 2010, p. 3.

[4] 2009 Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers: Summary of Findings*, 2010, p. 10. The committee notes that it received evidence suggesting that the SDAC data is inadequate both in terms of its sampling size. It also received evidence suggesting bias towards English speaking populations. The National Ethnic Disability Alliance (NEDA) estimates are that there are around one million people from non-English speaking backgrounds with disability in Australia. That makes one in four of the general population of people with disability, *Committee Hansard*, 29 November 2010, p. 45. Numerous witnesses expressed concern about data. Carers Victoria, for example, emphasised that there has been 'little systematic research in Australia about the needs of ageing people with a psychiatric disability and their families', *Committee Hansard*, 29 November 2010, p. 37.

many carers will either die or find themselves unable to care. Therefore, as the size and capability of the informal care sector declines, it is essential that the community finds alternative ways to ensure the quality of support for people with disabilities.[5] Given that Australia is anticipating significant population ageing and there is expected to be a significant reduction in the amount of informal care support available, the committee is deeply concerned about the outlook for people with disabilities.

4.5 In October 2008, the ABS published *A Profile of Carers in Australia*. The report provides an overview of the characteristics of people who provide informal assistance to someone with a disability, or long-term health condition, or to a person aged 60 years and over. The report suggests that primary carers were often related to the person they were caring for: 42 per cent were partners; 26 per cent were children (caring for a parent); and 23 per cent were parents (caring for a child). The report also suggests that the most common reported reason for why primary carers take on a carer role was: family responsibility (58 per cent), carers feeling that they could provide better care than others (39 per cent) and emotional obligation (34 per cent). In addition, carers are reported to have, as a consequence of their caring role, lower incomes, lower labour force participation and lower levels of educational attainment than non-carers.[6]

4.6 In the above statistics, 23 per cent of all carers were identified as being parents who cared for a child. It is this 23 per cent, many of whom are aged over 65, who represent the most urgent planning challenge.[7]

4.7 In the consideration of one particular cohort of carers, mental health carers, the statistics are even more concerning. In referring to the Mental Health Carers Report 2010, the Mental Health Council of Australia provided the following data to the committee:

> We had 765 responses to the carers report 2010, and I will give you a little bit of background of who these people were. They were all mental health carers. Eighty-two per cent of them were women, sixty per cent of them cared for an adult son or daughter and the average age of the carers was 58—that is the average. Thirty per cent of the carers were actually over the retirement age of 65, and 88 per cent of them were over the age of 45. We are talking about seriously ageing people. Sixty-one per cent of them said that the consumers had lived with them during the last 12 months. So we have a picture here of adult sons and daughters living at home with ageing

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[5] In 2003, the Australian Bureau of Statistics identified 28,000 older carers, over 65 years of age who were caring for an adult child, Carers Australia, *Submission 39*, p. 2. Bedford Group suggested that in South Australia, for example, Carers SA, have predicted that 56 per cent of carers will be over 65 by the year 2031, *Submission 29*, p. 2.

[6] 2008 Australian Bureau of Statistics, *Profile of Carers in Australia*, 4448.0, p. 8. According to Carers Australia, the two most common family situations involving older carers are: older carers caring for a son or daughter with disabilities, including psychiatric disabilities; older carers caring for spouse or partner with dementia, chronic conditions, terminal illness or disabilities resulting from ageing, Carers Australia, *Submission 39*, p. 2.

[7] Carers SA have predicted that by 2031, 56 percent of carers will be over the age of 65, Bedford Group, *Submission 29*, p. 2.

> parents or carers or a single carer. One of the most staggering figures was that 77 per cent of the respondents said that they were responsible for the day-to-day integration of any sorts of support systems for the person they cared for, whether they lived at home or lived out of home—not social services, not PHaMs [Personal Helpers and Mentors Program] workers but the carers themselves.[8]

4.8 The Mental Health Council of Australia also explained that these carers are seriously concerned about the lack of options to assist with accommodation and care and, by and large, remain unprepared for the time when they can no longer care.[9]

Challenges faced by carers

4.9 While the ageing demographic and the anticipated reduction in the number of informal carers suggests the need for planning services, evidence taken by the committee indicates that many people are so consumed by their day-to-day caring role that they have not even begun to start thinking about planning.

4.10 There may be other reasons why planning is not taking place. Some carers may even deliberately avoid planning as they are unable to come to terms with the prospect of living without a dependent child. Some are concerned about their capacity to cope emotionally while others are concerned about their capacity to cope financially. Other carers find it difficult to acknowledge their own mortality and therefore struggle with the gravity of the question: 'What happens when I can no longer care'? [10]

4.11 Further, a large portion of the disability community is not currently involved in any type of formal planning process.[11] In referring to the reach of disability service organisations involved in planning, Dr Ken Baker, National Disability Services, suggested:

> Many disability service organisations are involved in planning with clients and their families, but there is a significant population of people with disability and carers who are only marginally involved with services, or not at all involved.
>
> In 2007–08, 245,000 people received some form of support from specialist disability service funded under the CSTDA (now National Disability Agreement). Many of these people—particularly those receiving accommodation support and community access services—are engaged in regular (usually yearly) planning. When done thoroughly, this planning involves families and informal carers as well as the person with disability and it considers longer-term future needs as well as developing a plan for the coming year or so. Families with ageing carers often need additional

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[8] *Committee Hansard*, 18 February 2011, p. 2.

[9] *Committee Hansard*, 18 February 2011, p. 1.

[10] For more explanation of why planning is not taking place see, Carers Victoria, *Submission 54*, p. 7. Carers Victoria also suggested that often carers are reluctant to discuss their concerns about the future with other family members, *Submission 54*, p. 7.

[11] For example, in its assessment, Carers Victoria suggested, 'few ageing parents are believed to have plans for the future in place', *Submission 54*, p. 7.

> assistance to start putting in place arrangements in preparation for changed circumstances into the future.
>
> About two-thirds of the potential population (people with severe or profound disability aged under 65 years) do not currently receive any form of specialist support services. While they may receive some services, such as HACC or respite, they will typically miss out on regular and detailed planning processes that identify future as well as current needs.
>
> Of particular concern are the people with disability who first come into contact with the service system at a time of crisis. They are not connected with any services and may find the sudden engagement with unfamiliar people and places very disconcerting. Carers of these people, if they can be identified, will often need significant support and encouragement to have in place emergency plans as well as plans for the future.[12]

4.12 Dr Baker's evidence offers some explanation as to why planning is not taking place. It suggests that the large number of people who operate outside the specialist support network—two thirds of the population of people with severe or profound disability—are only coming to the attention of the disability support organisations when they reach the point of crisis. They are therefore not being encouraged to undertake planning until it is too late.

4.13 Yet it is not simply that people with disabilities and their carers frequently operate outside the formal service system, but many carers have lost confidence in the capacity of the system; others have disengaged as a result of the lack of formal planning mechanisms. These people need information and support to understand and manage what is a complex process, and to be reassured that there is value in planning.

4.14 In Melbourne the committee received evidence from Ms Lesley Baker. Ms Baker's evidence is compelling for it offers a snapshot of the day-to-day challenges faced by the carer of a child with complex care needs. It is useful to quote Ms Baker's evidence at length because it demonstrates that many parent-carers do not have the time to plan; it illustrates the social isolation that is often experienced by parent-carers, while also articulating the concerns that parent-carers have for the future:

> In January I will be 67 years old. I am the sole carer of my 33-year-old intellectually and physically disabled son, Benjamin. I have been his sole carer since his father left when he was 18 months old…[Ben] does not speak and he displays some autistic tendencies. He can walk but not for distances, so he requires a wheelchair outside home. He also suffers from chronic sleep apnoea and he is one of the worst recorded cases worldwide. He requires 24-hour supervision and care which means virtually I toilet him, bathe him, feed him, dress him, teach him, entertain him and do everything else. He cannot be left alone in the house at any time and I have to sit next to him at night when he is going to sleep to watch for obstructions with the sleep apnoea. With all of that he is the most delightful young man with a whimsical sense of humour and he adores people.

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[12] Answers to questions taken on notice, No. 2, 9 November 2010. FaHCSIA suggested that 25 per cent of carers do not have any contact with the Centrelink system, *Committee Hansard*, 8 November 2010, p. 8.

> He attends a day training centre five days a week. He leaves around 8.15 and gets home at four. He enjoys his life. He is very happy at the centre with his peers and his special workers and he enjoys coming home for tea, activities and bed…The rest of the time I am on my own. I have the eight hours a day that he is away to do everything else, household chores, household maintenance, gardening, banking, cooking, shopping, maintaining his accounts in accordance with VCAP [Victorian Carers Action Plan] requirements, meeting with support workers and agencies, constantly updating the endless paperwork…
>
> I do get one night a week to possibly go to the movies and, if I do go, I go alone. Older friends have drifted away because they now have their retirement and their grandchildren to look forward to. My parent friends are equally confined to barracks. Most of my social interaction is with the carers who come in to look after Ben. I have had a rotating workforce of literally almost hundreds of carers over the years, so it is hardly surprising I live basically in social isolation. Caring for Ben has also taken a physical toll. I am currently on the waiting list for a complete shoulder reconstruction but I am on the list behind a lot of people who can afford private health insurance and who have no-one waiting for caring. However, I will not be able to have that operation unless I can find the funding for care for Ben during my rehabilitation.[13]
>
> Certainly, for those of us who are caring for adult children still at home there is no retirement date, there is no superannuation. We gave away our careers and money many years ago. Our reward for years of care really is the agony of wondering what the hell is going to happen to them when we are no longer around…I am the only one who can interpret what Ben wants, what he needs or is comfortable with, and what he is afraid of…
>
> The future for both of us really cannot be taken any further than the fact that I will be at home this afternoon to get him off the bus. Despite being 12 years on the urgent needs for housing list, he has never had an offer and there is no reason to suppose he will get an offer within the next 12 years because of a massive shortfall in housing. When the call does come from an impersonal voice we will be given an address and a contact phone number for a house that we will not be familiar with nor with any of its occupants. We will just be given a date and have to take it from there…
>
> Intellectual disability does not mean stupidity. It does not mean anywhere will do. He has got the same hopes, likes and fears as any other young man. He just cannot express them clearly. But one thing he does not have is a concept of the future. He has no concept of death or loss or that some day

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[13] It appears that Ms Baker may herself be struggling with health issues and may require assistance to continue to care. In the 2004–05 Budget, the Commonwealth government announced $72.5 million over four years from 2004–05 to 2007–08, to increase access to respite care for older parents caring for their sons and daughters with a disability. Under this measure, parents aged 70 years and over who provide primary care for a son or daughter with a disability are entitled to up to four weeks respite care a year. Parent carers aged between 65 and 69 who themselves need to be hospitalised are entitled to up to two weeks respite care a year: http://www.fahcsia.gov.au/sa/disability/progserv/govtint/policy-cstda/Pages/default.aspx (accessed: 31 May 2011).

> he will be without me. It is impossible to inform him that one day he will live with other people and that on another day I simply will not be there.[14]

4.15 Ms Baker, like many contributors to the inquiry, have suggested that parent-carers are so consumed by their caring responsibilities that they have little opportunity to start thinking meaningfully about the future.[15] This combined with the fact that it is extremely difficult for carers to access respite, means that many carers have not had the opportunity to begin to think about planning. The lack of future planning by parent-carers, their lack of energy and resources, is poignantly represented by Ms Baker's statement that the sense of the future is confined to being available to get Ben off the bus.

4.16 Parent-carers such as Ms Baker often see support workers come and go but feel that it is the parent alone that understands and advocates for the needs of the child with a disability. The parent-carer therefore becomes both the primary advocate and the repository of all the information about the needs of the person with a disability. Other submitters to the inquiry have explained how this may further detract from the establishment of a planning culture. Down Syndrome New South Wales referred to problems associated with a parent retaining all the knowledge of an individual's care needs:

> As parents, we are not very good at keeping records of what we have done. As the mother of a person with a disability, you are the boss of the game, you keep it all in your head and you keep it going. When you are not there, who knows what you have even tapped into, what has been explored before and what has not? That is something else that we should perhaps be talking to parents and families about—keeping better records, in whatever format, of what the person's needs are and how they are actually being met on a day-to-day basis rather than just letting mum take care of it so that, when mum is not there, nobody knows where to start and it all has to start over again.[16]

4.17 Evidence about the social isolation Ms Baker experiences as a result of her care commitments was also reinforced by other witnesses. Life Without Barriers expressed concern about the mental health of both socially isolated care providers and older people with disability living with parent-carers:

> There is a great deal of depression and mental health issues in the population of older people with disability who reside at home with their parents. And, more broadly, older people with a disability do experience greater issues around mental health. Often parents are suffering mental

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[14] *Committee Hansard*, 29 November 2010, pp. 37–38.

[15] This was clearly expressed by carers who attended a 'Community Forum' in Toowoomba, *Committee Hansard*, 1 December 2010, pp. 32–44. It has also been expressed in the Anglicare publication, *Care to live or live to care?*, this study was undertaken with 289 carers 39 per cent of whom were aged 75 or over, see Chapter 2: 'Ageing Parent Carer Well Being': http://www.daisi.asn.au/index.php?option=com_content&view=article&id=168:care-to-live-or-live-to-care-anglicare-report&catid=14:latest-news-a-updates&Itemid=15 (accessed 30 May 2011).

[16] Down Syndrome NSW, *Committee Hansard*, 30 November 2011, p. 13.

> health problems as well. Often this is due to isolation experienced by these family units.[17]

4.18 Against this backdrop of social isolation and depression, it can be difficult for carers who have spent decades caring for a person with a disability to begin to consider future planning options. To do so requires carers to contemplate a situation whereby they are no longer the primary carer for their son or daughter, and further, that at some point they will die and there will be no choice in the matter—the person with a disability will need someone else to care for them. Issues around personal mortality are particularly difficult for carers who have spent their own lives keeping someone else alive and well. As Dr Ken Baker explained:

> What has been striking not just from the Anglicare Sydney study but from an earlier study of maybe five years ago by Scope Victoria is the extent to which people overestimated their capacity to continue a caring role long into the future. People well into their 70s are anticipating in the Scope study that they can continue to care for another 20 years.[18]

4.19 Other concerns carers may have with respect to future planning relate to feelings of guilt relinquishing the care of a person with a disability and loneliness following the departure of a family member from the family home.[19] In some cases, carers of people with an episodic mental illness might find future care planning particularly confronting when what they actually hope for the future is that the person will recover.[20]

4.20 Ms Baker's account reveals the complexity involved in planning for someone with a decision making impairment. For while it is clear that people with intellectual disabilities remain heavily reliant upon the parent-advocate, they may well be capable of participating in decision making about their ongoing support and representation. However, in Ben's case, his involvement in the planning process may be limited by the fact that he has no concept of the future.

Life path for people with a disability

4.21 The current life path for a person with a disability is, in most instances, very different from a person without a disability. People with disabilities rely heavily on parental support; spend more years in the family home; may not participate in the workforce or, if they do, may require additional support; and they may retire from employment earlier than others.

4.22 As documented above, many people with disability continue to live with their parents or family until the family no longer has the ability to care. Life Without Barriers expressed concern about the way that this affects the independence, and

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[17] *Committee Hansard*, 30 November 2010, p. 15.

[18] Dr Ken Baker, National Disability Services, *Committee Hansard*, 8 November 2010, p. 18.

[19] Mrs Joyce Bellchambers, Dare to Care, *Committee Hansard*, 1 December 2010, p. 36.

[20] Ms Linda Rosie, Mental Health Council of Australia, *Committee Hansard*, 18 February 2011, p. 11.

decision making capacity, of the person with a disability in ways which may ultimately affect their capacity to plan:

> In many ways people remain essentially stuck in a childlike or adolescent life stage instead of developing the emotional, psychological, financial and functional skills to be as independent as they can be to make their way in the world without their parents and vice versa, for their parents to make their way in the world without their children.[21]

4.23 While this comment suggests relationships of co-dependency it also suggests that future planning options need to emphasise transition planning to assist people with disability effectively negotiate the various life stages—moving out from the family home, finding employment, and retirement from employment.

4.24 While it would be useful to be able to normalise the moving out of home experience for people with disability, any current attempt to engender independence is undermined by a lack of services, accommodation and employment prospects. For those able to work, employment provides the financial independence necessary to assist people plan for the future and potentially move out of the family home. Without it, people with disability are reliant on either informal support or the housing support system which, as we have seen, has very long waiting lists. Additionally, people with disabilities who are employed may find it easier to access other supports like aids and equipment. Nevertheless, in spite of the obvious benefits of employment, evidence provided to the committee suggests people with disability may find themselves unable to find work, not as a result of any inability to participate in the workforce, but because of the limited opportunity.[22]

4.25 For those who do participate in the workforce, transitional life planning also needs to be undertaken for people seeking to retire, particularly those retiring from Australian Disability Enterprises (ADEs). Clearly people ageing with a lifelong disability have distinctive needs in relation to retirement. Mai-Wel, a disability service providers in the Lower Hunter region, outlined what is involved in retirement placing for people with disabilities:

> Obviously retirement planning is very important for an organisation that has over 100 supported employees. We acknowledge that for all employees, as for all other employees in the community, there needs to be some planning process in place. We also acknowledge that for people with a disability this may well be a staged process, beginning with the development of a retirement plan and then having a number of steps until retirement finally takes place and there is an exit from the workplace. There are things like sampling of retirement options. If you have been in an ADE or an Australian business enterprise for 40-odd years, you really do not know what options are out there, so there is sampling of those. There is also reducing their work hours so that they can access a generic or disability-specific day program. We believe that the federal government has some role in this. At the moment they do not give us funds to be able to assist

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[21] *Committee Hansard*, 30 November 2010, p. 14.

[22] It is equally important that those unable to find or maintain employment have the supported option of living outside of the family home.

> supported employees down the retirement process, and I think that is something that they could do by way of releasing the older supported employees to be able to access some of those options.[23]

4.26 The committee heard that it is currently very difficult for people with disabilities to retire because there appears to be a complete lack of post-retirement support. Suggesting that almost 50 per cent of the people in supported employment are going to be aged over 50 in the next five or six years, Professor Christine Bigby suggested:

> It is also going to affect the quality of life of those people who want to have less of a stressful life and may want to retire. At the moment, it is very hard to retire. People see it as an enormous risk because they may be left at home with no support to swap work for more meaningful activity of their choice.[24]

4.27 Even more concerning was evidence provided by the Mai-Wel, which explained that they have 12 supported employees who are depending on fundraising for their retirement.[25]

4.28 Beyond the difficulty of managing the transition for each of these life stages there is no sense that there is any effective planning system enabling a person to feel, with any confidence, that he or she can negotiate moving through the traditional life stages. People with Disability Australia pointed to the lack of cohesion:

> We have had a number of governments working very hard over a number of years to set up responses to people with disability, but there is no cohesion to those responses. There is no sense that I would imagine, beginning life as a person with disability, that I could see my way forward all the way through to old age, knowing how things are going to be laid out for me, how I am going to have opportunities for education and employment, where I am going to live when I choose where I want to live, those kinds of things.[26]

4.29 In short, there is too little support available at each transitional life stage let alone any support that resembles an integrated and cohesive life plan. The committee would like to stress that managed transitions are particularly important for people who may find unpredicted change difficult, such as people with intellectual disabilities.[27]

Recommendation 2

The committee considers it critical that effective planning support be available for people with disabilities transitioning from education to employment and from employment into retirement. The committee recommends that the Department of

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[23] *Committee Hansard*, 30 November 2010, p. 45.

[24] *Committee Hansard*, 29 November 2010, p. 13.

[25] Mai-Wel added: 'I would like know what the Australian population at large would think if we decided that their retirement would be funded through fundraising', *Committee Hansard*, 30 November 2010, p. 45.

[26] *Committee Hansard*, 30 November 2010, p. 58.

[27] See Down Syndrome NSW, *Committee Hansard*, 30 November 2010, p. 2.

Families, Housing, Community Services and Indigenous Affairs provide retirement planning support options for people employed in Australian Disability Enterprises.

Premature ageing for people with physical and intellectual disabilities

4.30 In considering the current life path for a person with a disability it is also important to recognise that some people with physical and intellectual disabilities age prematurely. Evidence suggests that the use of chronological age for determining eligibility for access to specialist aged care services has proved a significant barrier for people with physical or intellectual disabilities.[28] The committee heard from several witnesses affected by either cerebral palsy or post-polio syndrome who experience early-onset ageing. The stress on muscles and bones that people with these conditions experience often results in osteoporosis. Further, those confined to wheelchairs often experience poor circulation and reduced muscle tone in the legs which can result in other muscular-skeletal problems. Other disability groups also have degenerative conditions that require them to access specialist aged services, among them, people with intellectual disabilities, and in particular, people who experience early-onset dementia. People with intellectual disabilities are one of the largest groups of people who will have early-onset dementia because of the connection between Down syndrome and dementia. Professor Christine Bigby offered the following comment:

> I think that one of the issues is that this is a unique group of people who are ageing with a lifelong disability. They have very different characteristics from a lot of older people, they are a very small minority potentially within the aged-care system, and at the moment there is a policy vacuum because nobody wants to take the responsibility for this group of people.[29]

4.31 The committee raised concerns about access to aged care services for people affected by cerebral palsy or post-polio syndrome with the Department of Health and Ageing. The department explained that they were not aware of access problems for those who had acquired a disability as a result of polio or for those with cerebral palsy.[30] However, the department suggested that if people are experiencing need to access aged care services they would be able to undergo an assessment processes:

> The agreement that was established back in the late 1990s with the states and territories around people under the age of 70 accessing community care or residential care will remain in place. If it is agreed there are no other facilities or care services more appropriate to meet the person's needs then that is when an ACAT [Aged Care Assessment Team] assessment is the most appropriate assessment and that is the pathway to community care or residential care.[31]

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[28] For example, Professor Christine Bigby, *Committee Hansard*, 29 November 2010, p. 15.

[29] *Committee Hansard*, 29 November 2010, p. 12.

[30] *Committee Hansard*, 18 February 2011, p. 50.

[31] *Committee Hansard*, 18 February 2011, pp. 45–46.

4.32 Despite the reassurance of the department the committee received evidence suggesting the assessment process is not operating as seamlessly in the community and that people with premature ageing were experiencing difficulty at the disability and aged care interface:

> It is also very hard for people who have intellectual disabilities—who have, for example, Down syndrome and are ageing prematurely and have dementia—to get access to high-quality aged-care assessments, aged-care clinics and geriatric medicine. Because of the age barriers to those services, they are stuck at the interface. There are protocols that say you should not use aged care unless it is the last resort, so people get batted backwards and forwards between the disability system and the aged-care system. As a result, some people die prematurely. They do not get the type of treatment that they should have.[32]

4.33 The Department went on to explain that someone in their forties with advanced dementia, for example, may receive an Extended Aged Care at Home (EACH) dementia package or may be admitted to a residential facility. The Department also assured the committee that they are aware of the difficulties that people with premature ageing experience navigating the interface between the disability and aged care systems:

> We acknowledge that it is a complex system. The feedback you have received to your inquiry is consistent with what people have said to the Productivity Commission and elsewhere. This is a complex and difficult system to navigate at times. We have significant effort under way to actually improve the way people get information around how they are assessed, how they are referred. We also did a big round of consultations with people around the country prior to Christmas in terms of the work we are doing on one-stop-shops. It is also consistent with the feedback that has been provided in those sessions. People are comfortable that the initiatives we have under way are the ones they think are needed.[33]

4.34 Numerous submitters suggested that assessment of need should be based on new criteria. The Victorian disability services organisation Scope suggested:

> [Scope] would call for criteria that are based on functional changes for that individual but also on the perceptions of that individual and the people who care for that individual in terms of how they are ageing and what impact ageing is having on them. So there should be a combination—functional criteria and criteria based on perceptions.[34]

4.35 Others solutions included identifying this group of people as a unique group who are likely to need aged care services at an earlier age, such as age of 50 or 55 (Mai-Wel suggested that for people with Down syndrome, a more appropriate age would be 40).[35] This would prove an appropriate way of setting the aged care

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[32] Professor Christine Bigby, *Committee Hansard*, 29 November 2010, p. 14.

[33] *Committee Hansard*, 18 February 2011, p. 50.

[34] *Committee Hansard*, 29 November 2010, p. 61.

[35] See, Scope, *Committee Hansard*, 29 November 2011, p. 60; *Committee Hansard*, 30 November 2010, p. 49.

threshold or interface for people with disability, making sure appropriate services are accessible to them when they have the need. Professor Christine Bigby suggested that, from an administrative point of view, this was relatively easy to do if you do it on a fee-for-service basis that allows the disability system to purchase into the aged-care system when it is absolutely necessary.[36] For these disability groups the policy frameworks should provide additional flexibility to enable providers to categorise people according to need rather than age.

Committee view

4.36 This evidence suggests that there are problems associated with using chronological age to determine eligibility for access to specialist aged services. This has significant implications for people with physical and intellectual disabilities. The committee notes that Aboriginal and Torres Strait Islanders have been identified as a category of people who age more quickly than other members of the population. It therefore considers that there would be benefit in also identifying people with disabilities as a group who age earlier.

Recommendation 3

The committee recommends that the government look to identify people with disabilities as a special group who may age earlier than other members of the population and should therefore have access to a range of aged care services at an earlier age.

Recommendation 4

The committee recommends that the Department of Health and Ageing review the assessment tools used by the network of Aged Care Assessment Teams (ACAT) to take into account the needs of people with a disability who are ageing prematurely.

Establishing planning cultures

4.37 Planning is a complex and multifaceted task that requires knowledge and expertise. It requires a comprehensive understanding of the disability service sector, funding arrangements and housing and support options. Above all, individuals involved in planning need to know where the relevant information is available and how this information can be accessed. Planning is also a consultative process and involves discussion with the person with a disability and other significant people. Numerous other witnesses referred to planning as a long process that develops over time. Family Advocacy suggested that 'Planning is not a one off event—it occurs slowly over time'. Moreover, that while it is never too late to plan, 'everyone's quality of life is enhanced the earlier they are helped to develop a vision and put plans in place to realise that vision'.[37] It is also imperative that planning cultures are predicated on understanding the distinction between life-long planning and service planning.

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[36] *Committee Hansard*, 29 November 2010, p. 21.

[37] Family Advocacy, *Submission 2*, p. 6.

4.38 There are also aspects of planning that require an understanding of legal and financial planning. Carers Victoria referred to the challenges that carers face trying to understand legal and financial issues:

> For financial planning you need to understand families need to know about rules in estate planning, about distributing your property and your assets and how you might record future wishes within those. You need an understanding of formal guardianship and financial administration, what they offer, what the weaknesses are. You need to know about the pros and cons of various forms of trust arrangements for your son or daughter. You need an understanding of the operation and implications of Centrelink's income and assets test and gifting rule. You need the opportunity for family discussion about roles in succession plans, family plans, support networks in the future for the person with a disability and you need to develop and share with significant others emergency care plans, what happens when you are ill; when you are carted off to hospital, how the care of your son or daughter can be maintained.[38]

4.39 While service provision is critical to planning, and services contribute to the wellbeing of the individual, Professor Christine Bigby spoke to the committee of differentiating between life planning and service planning. In so doing she reemphasised the distinction between caring for and caring about:

> The sense is, I think, that we need to think about what we are planning for, and I think it is useful to think about planning to care about a person and planning to care for a person. You can replace some of the roles that parents have done by planning to have other people to be involved in somebody’s life—other people who care about them, who are committed to them, who are not part of the service system, who can act in an advocacy role, who can negotiate with services and who can negotiate flexibly for change as a person's situation changes. Where somebody lives and the type of support they get will change over time and cannot be locked in at one point in time, so planning has to be flexible, and the way to achieve that is to have people involved your life.
>
> There are issues, too, around preparing for that separation, helping people to develop skills, to develop independence, so that they can easily separate from their parents while still maintaining, clearly, a relationship with them and other family members. The planning has to think about preparation for that separation as well as where somebody might live in the future.[39]

4.40 Pave the Way reinforced the importance of planning outside the service context through drawing on the distinction between family and external services:

> Pave the Way strongly believes that planning in the context of parents or other important family members aging is vastly different from service planning. This is planning for a safe, secure and meaningful life in which services may or may not play a role. This is planning that families must

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[38] *Committee Hansard*, 29 November 2010, p. 36.

[39] Professor Christine Bigby, *Committee Hansard*, 29 November 2010, p. 13.

> drive and control. This is 'whole-of-life' planning and is in the realm of family business, not service business.
>
> Direct support services can play a role in assisting individuals to achieve some goals, for example, those concerning home, work, recreation, communication and education, but are unlikely to play a role in many other aspects of the individual's life, such as personal security, financial security, decision-making, relationships and friendships, health, spirituality and developing individual passions. Even where services do play a role, they are unlikely to be the only factor in assisting an individual to achieve a particular goal. For example, supporting a young person with disability to live in their own home might involve a mix of paid support, unpaid support and financial contributions by the individual and/or their family. Services can assist people to have a good life; they do not constitute a life.
>
> All services do some sort of planning with the people they support, such as 'individual education plans', or 'individual program plans', or 'family support plans', but that service planning is limited to what the service can do within its purview as a service provider. Service planning is very different from the whole-of-life planning relevant to planning for the future.[40]

4.41 Numerous submitters to the inquiry have offered suggestions as to how whole-of-life planning may be done. These have included:

- The development of wills and estate plans to define how property and assets should be distributed;
- Appointing Powers of Attorney and Guardianship or developing an Advanced Care Directive;
- Considering the establishment of trusts such as a Discretionary Trust or a Special Disability Trust;
- The development of emergency care plans in case of sudden parent illness or death and sharing these with the person with a disability and other key people;
- The development of succession plans or arrangements for medical, financial and lifestyle representation. This will ensure that a trusted person can oversee the ongoing care and support needs of the person with a disability, and advocate for housing and support services consistent with family wishes. Such plans will also be interpreted to the person with a disability;
- Creative use of respite and recreation programs to explore and practice eventual separation;
- Transition planning to housing and support outside the family home will also be required. To this the committee would add the importance of assistance with transition planning to assist families manage different life stages.[41]

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[40] Pave the Way Mamre Association, *Submission 18*, p. 5.

[41] See, for example, Carers Victoria, *Submission 54*, p. 7.

4.42 In the following chapter the committee will offer an overview of the major impediments or barriers to planning before then examining some mechanisms for formal succession planning. It will examine the way that the involvement of significant people in the life of a person with a disability, who have ongoing responsibility in supporting and assisting them, can be an important mechanism for families whose sons and daughters no longer live in the family home. In so doing, the committee stresses that that there is a need for a cultural change acknowledging that it is the responsibility of the community—not just the family—to provide support for people with disabilities. Or to restate a comment provided by Ms Melissa Young, Perth Home Care Services: '...this is not a disability issue, an ageing issue or a carers' issue. This is a personal and community issue for us all'.[42]

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[42] *Committee Hansard*, 8 November 2010, p. 44.

Chapter 5

Barriers to planning

5.1 In the last chapter the committee considered some of the challenges faced by carers and some of the reasons why planning may not take place. It was identified that many carers are not receiving planning assistance from specialist support networks until it is too late. Further, in examining the profile of the parent-carer, it was suggested that many parent-carers are so consumed by their caring role they do not have the time, energy or resources to plan. In this chapter the committee examines barriers to planning in more detail. It provides a summary of recent studies on barriers to planning, and then draws upon evidence obtained during the inquiry to identify three major impediments to planning: access and availability of information; access to services (including: accommodation, respite, legal and financial advice and counselling); and a lack of confidence in the system. Following this the committee will briefly consider barriers to planning for specific groups: people with a mental illness, people with an intellectual disability, Aboriginal and Torres Strait Islander people and people living in regional and remote areas.

Studies on barriers to planning

5.2 In October 2010, Anglicare Sydney released a study of carers of people with disability, *Care to live or live to care?* The study was undertaken with 289 carers, 87.5 per cent of whom cared for an adult son or daughter. Of those surveyed, 39 per cent were aged 75 or over and 20 per cent were aged 80 or over.[1] Despite their age, only one in four had a plan for the future care of their disabled son or daughter. Eight out of ten were anxious about the future of the son or daughter for whom they cared and more than half said that they needed time out from their caring role.[2] The study also provided a gap analysis which compared the support considered to be important and the support carers actually receive. Revealingly, four out of five carers ranked the development of a transition plan as important but only one in ten had been supported to develop such a plan.[3]

5.3 The results of the Anglicare study were reinforced by an Australian Government Discussion Paper on Succession Planning for Carers, released in early 2007. The Discussion Paper was the product of a series of national consultations with carers that sought to identify the needs of families in relation to future planning. The key barriers outlined in the report included:

- Families do not know where to start; who to go to; where to find information or what to do;

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[1] Anglicare, *Care to live or live to care?* p. 5, http://www.anglicare.org.au/news-research-events/latest-research/care-to-live-or-live-to-care (accessed 30 May 2011).

[2] Anglicare, *Care to live or live to care?* p. 9.

[3] Anglicare, *Care to live or live to care?* p. 13.

- The costs of disability and caring are such that many parents may not have accumulated many assets in their lifetime and may not be able to financially provide for their child's future, without significant government assistance;
- Future planning is a sensitive issue, challenging family assumptions and requiring people to face their own mortality and discuss personal issues and information;
- A planned transition is not considered feasible while services and governments continue to place only those people with disabilities in crisis or emergency situations;
- Many carers are too busy or tired from day-to-day responsibilities to be able to find the energy to undertake the complex and time-consuming task of planning for the future;
- Many ageing carers may not have expected their son or daughter to outlive them and may have unrealistic expectations around what governments, services and family members can provide when they need to relinquish care;
- Future planning is an extremely complex issue, across state, territory and Commonwealth law and regulations covering financial, legal, property, taxation and government support issues. Circumstances will change between any plan and its implementation, and establishing support networks is hard work.[4]

Availability and access to information

5.4 The committee received strong evidence demonstrating that there are significant problems with the availability and accessibility of information about disability services and planning support. The major concerns with availability relate to the fact that there is no single access point for information, and that information about options is hard to find. Further, that searching for relevant information is stressful and time consuming, and carers do not have the time and resources to seek this information out on their own. The committee identified that there were at least three concerns related to the availability of information: information about services; information about entitlements; and information about planning.

5.5 Carers need information about available services in order to plan for the future, and primary carers in particular can only contemplate the future with an awareness of alternative care arrangements. However, the committee heard that carers are often not aware about available service options, and that it is unclear what services are provided and funded by different tiers of government.

5.6 In Chapter 2 the committee cited evidence from Ms Joan Hughes, Chief Executive Officer, Carers Australia, in which she suggested that 'Information is the key piece of the future planning puzzle'. She continued:

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[4] *Succession planning for carers:* Report on consultations—January 2007, prepared by N-Carta Group for the Australian Government, http://www.fahcsia.gov.au/sa/carers/pubs/Documents/SuccessionPlanningReport/exe_summary.htm (accessed 30 May 2011).

> Even with improved services, a lack of information when carers need to plan for the future is a significant issue. We still have levels of service provided and funded by tiers of governments and through different programs even at the federal level for carers...
>
> Often carers are not aware or informed of these options or what services are available and as such they do not have the capacity to plan...
>
> Carers Australia believes that every effort must be made to simplify this process and assist carers in having sufficient information to make informed choices for their futures and the people in their families.[5]

5.7 Down Syndrome NSW suggested that carers usually find out about services through 'word of mouth and informal networks'.[6] This shortcoming in the availability of information extends in some cases to a lack of information about entitlements.

5.8 Future planning is difficult for carers who face immediate challenges accessing services and entitlements. Contemplating future plans in itself is complex for carers; any problem accessing information to assist with such planning adds an unnecessary layer of complexity. However, the committee heard that in many cases, difficulties planning are amplified by difficulties accessing information about planning, as Carers Victoria explained:

> There is poor access for older people and older people with a disability to get assistance with what are essentially complex and multifaceted tasks in planning for the future. I think the advice families get is piecemeal rather than comprehensive and the planning tasks involved require a whole lot of knowledge and expertise. For example, to have access to discussion about housing and support options and models in collaboration with the person with a disability and other significant people, you need to know about financial planning for the future. You need to know about rules in estate planning, about distributing your property and your assets and how you might record future wishes within those. You need an understanding of formal guardianship and financial administration, what they offer, what the weaknesses are. You need to know about the pros and cons of various forms of trust arrangements for your son or daughter. You need an understanding of the operation and implications of Centrelink's income and assets test and gifting rule. You need the opportunity for family discussion about roles in succession plans, family plans, support networks in the future for the person with a disability and you need to develop and share with significant others emergency care plans, what happens when you are ill; when you are carted off to hospital, how the care of your son or daughter can be maintained.[7]

5.9 Like information about services, information about planning is often gained informally or as a consequence of carers coming into contact with service providers in relation to another matter, as Perth Home Care Services explained: 'People might

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[5] *Committee Hansard*, 8 November 2010, p. 24.

[6] Mr Stephen Clarke, *Committee Hansard*, 30 November 2010, p. 10.

[7] Ms Gill Pierce, *Committee Hansard*, 29 November 2010, p. 36.

come to the agency for some specific respite...and we will use that opportunity to talk to them about their plans for the future'.[8]

Centrelink payments

5.10 People with a disability who cannot work are likely to be eligible for entitlements such as the Disability Support Pension, and their carers are likely to be eligible for the Carer Allowance (see Chapter 3). These payments are designed to assist people with a disability and their carers, but as with services, cannot be of benefit if carers are unaware of their eligibility.

5.11 Some form of payment has been available to parent-carers of children with a disability since 1974. The current payment, Carers Allowance, was introduced in 1999.[9] The FaHCSIA Statistical Paper No. 9, Income support customers, indicates that the uptake of Carers Allowance increased dramatically from supporting 37,746 carers in 1990 to supporting 495,733 carers in 2010.[10] However, the committee heard that there are still carers who are not aware of either the payment or their eligibility to receive it. Mrs Jill O'Connor, Down Syndrome NSW, explained:

> We still come across people—it is almost unbelievable; we are nearly in 2011—who do not know that they are entitled to a carers allowance.[11]

5.12 When this was put to FaHCSIA, Ms Helen Bedford conceded that she was aware that there is a significant proportion of carers not supported by Centrelink payments:

> When we did the consultations for the supported accommodation, carers turned up who were not part of the Centrelink system. I have seen figures in some reports from community groups that say that 25 per cent of carers are not in the system at all.[12]

5.13 While some carers may be aware of Centrelink entitlements but choose not to avail themselves of payments, Down Syndrome NSW's evidence suggests that there are carers who would access payments if they realised they were eligible.

5.14 In Chapter 1, the committee noted the 2009 House of Representatives Standing Committee on Family, Community, Housing and Youth report, *Who Cares...?: Report on the inquiry into Better Support for Carers*, and in particular, Recommendation 22. This recommendation was that Centrelink establish a dedicated Carer/Disability Unit to assist care givers and receivers. The government responded

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[8] Mrs Marita Walker, *Committee Hansard*, 8 November 2010, p. 47.

[9] Payments to parents of children with disabilities have evolved from the Handicapped Child's Allowance (1974) which was subsequently replaced by the Child Disability Allowance (1987), and most recently, the Carers Allowance (1999).

[10] FaHCSIA, *Income support customers: A statistical overview 2010*, Statistical Paper No. 9, Table 20, http://www.fahcsia.gov.au/about/publicationsarticles/research/statistical/Documents/stps9/default.htm (accessed 5 July 2011).

[11] *Committee Hansard*, 30 November 2010, p. 10.

[12] *Committee Hansard*, 8 November 2010, p. 8.

by noting the existing Centrelink mechanisms that address carers' needs for advice and information. The evidence received by the committee suggests that such mechanisms are still not benefiting all carers who need advice.

Limitations of web-based information

5.15 Whether it relates to information about services or planning, witnesses agreed that searching for relevant information is time consuming, stressful and frequently did not deliver a result. The committee heard that many older carers are unlikely to have high computer literacy, and need information in alternative formats:

> In our client group we have people in their 40s and 50s, which naturally means that some of the family members and carers are in their 60s, 70s or thereabouts and have not really grown up in a technological age. They find that quite confronting...
>
> There is a presumption made at times, I think, that once it has gone out on the net it is there and everyone has access to it. It is not necessarily the case.[13]

5.16 As the internet has become the primary medium for information distribution, well-developed technological skills are required to navigate the information picked up by search engines and contained on websites. While internet-based information may effectively reach some audiences, it is unlikely to fulfil the needs of all older parent-carers. It is unreasonable to expect that a carer of person with a disability could successfully navigate complex information online during a couple of hours of respite.

5.17 Problems with the provision or availability of information becomes more acute in cases where carers experience difficulty reading, either due to ailing vision or a lack of familiarity with the English language. Mr Ah Tong-Pereira, Vision Australia, suggested that only three to five per cent of all published information is available to people who are blind or have low vision, and emphasised the need for information about planning to be provided in formats accessible to vision impaired people:

> We have looked at future information around planning services. For example, if I want to find out about aged care services, about what the options are for nursing homes or about options for volunteering, the information that is provided generally to the public needs to be made available in a format that can be accessed—electronically, braille, audio, large print and those sorts of areas.[14]

5.18 People who speak a language other than English as their first language may also experience additional difficulties reading available information on disability and planning assistance:

> It takes 10 years to be eligible to get the disability support pension once you have arrived in Australia if you have disability. So that, combined with the

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[13] Mr Phillip Farrow, Bedford Group, *Committee Hansard,* 8 November 2010, p. 40.

[14] Mr Ah Tong-Pereira also suggested that Vision Australia would support a central portal or one-stop-shop to allow people to access government information about disability services, programs and funding. *Committee Hansard,* 18 February 2010, pp. 16–17.

> additional language barriers and perhaps cultural perceptions around disability, might mean that those people have a much more limited access to information.[15]

5.19 The Australian Federation of Disability Organisations explained that people from low socioeconomic backgrounds, including a significant proportion of people from Culturally and Linguistically Diverse (CaLD) backgrounds, are less likely to have internet access. The committee heard that clear, accessible information for carers and people with a disability that is currently not delivered, and cannot be delivered, via the internet.

Centralised information

5.20 It is clear that shortcomings in the way information is currently made available is a significant barrier to carers seeking to plan for when they 'can no longer care'. As discussed in Chapter 3, while Commonwealth Respite and Carelink Centres do provide information to carers, some witnesses made suggestions for reform. Carers Australia noted that the government is already taking steps to facilitate education and training for carers, and suggests that a module or workshop on planning options would fit well into this training.[16] Carers Australia, alongside a number of other groups, also suggested that there needs to be more centralised information provision, such as via a national information line or resource guide.[17] Mr Heckendorf suggested that centres of disability excellence be established to provide information and research to specialists and others working or participating in the disability system.[18]

5.21 Other witnesses expressed their support for a one-stop-shop for disability services. The states and territories are working to consider this option as part of their obligations under the National Disability Agreement (see Chapter 3). The NDA prescribes a number of conditions that states must comply with in order to receive disability funding, including the requirement to consider a single access point (also called a one-stop-shop) for disability services. One example of progress on the establishment of one-stop-shops is the Northern Territory Office of Disability.

5.22 The Office of Disability was established in Darwin in May 2010 in response to recommendations from a KPMG Review of Disability Services in the Northern Territory calling for a new integrated model of service delivery. The Office provides integrated aged care and disability service functions which include: a general information and inquiries service; first point of intake for entry into the aged and disability service sector in Darwin; and space for consumers and the sector to hold meetings and client consultation rooms. The office also has a shopfront in Alice Springs to meet service needs in Central Australia. The Northern Territory Minister of Health informed the committee:

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[15] Ms Leah Hobson, Australian Federation of Disability Organisations, *Committee Hansard*, 29 November 2010, p. 2.

[16] Mrs Joan Hughes, *Committee Hansard*, 8 November 2010, p. 27.

[17] Mrs Joan Hughes, *Committee Hansard*, 8 November 2010, p. 24.

[18] *Submission 65*, p. 3. See also, Bedford Group, answers to questions on notice from public hearing 8 November 2010, p. 2.

> The Office of Disability have been successful in establishing networks across both general and specialised disability areas in order to incorporate information from a range of organisations and to support information and referral services. This has occurred at the regional level and has been supported by dedicated resources, namely staff who have worked to establish an identity and regional presence and build relationships across priority service areas accessed by people with disabilities.[19]

5.23 While acknowledging the benefits that a centralised system could have in enabling carers to access appropriate services and information, the committee is also aware that it is local service providers which are most likely to be of assistance to carers. It would therefore be imperative that a centralised service was able to refer people locally, and that local service providers were adequately funded and equipped to provide assistance to people with a disability and their carers.

Committee view

5.24 While the committee acknowledges the role undertaken by Commonwealth Respite and Carelink Centres, it is concerned that information about disability services and planning options is not reaching its target audience. The committee urges all government agencies involved in disability services provision to consider alternative methods of information communication, in consultation with local disability service providers which have first-hand awareness of the needs of the target audience.

Recommendation 5

The committee notes the National Disability Agreement requirement for states and territories to consider one-stop-shops for disability services. The committee recommends that the Commonwealth, in consultation with the states and territories, establish its own presence and representation at one-stop-shops. The committee considers that one-stop-shops must be capable of directing enquiries towards whichever service is most appropriate, whether that service is provided at a state, territory or Commonwealth level. Further, the committee endorses Recommendation 22 of the *Who Cares...? Report on the inquiry into better support for carers*, calling for the establishment of a dedicated Carer / Disability Unit at Centrelink. This dedicated Unit should be accessible via disability services one-stop-shops.

Recommendation 6

The Committee recommends that the Department of Families, Housing, Community Services and Indigenous Affairs improve its website to make information about disability services and planning support more up-to-date, comprehensive and navigable. In so doing, the Department should establish a working group, which includes carers, people with disabilities and disability services organisations, to seek feedback on matters of design, utility and accessibility.

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[19] The Hon Kon Vatskalis MLA, Northern Territory, Minister for Health, additional information, 4 April 2011.

Recommendation 7

While the committee would like to see improvement in the quality and accessibility of information on government websites for people with disabilities and their carers, it also mindful of the limited reach of new technologies. In acknowledgement of this, the committee recommends that all levels of government should consider effective non-web-based tools for the communication of critical information on disability and planning services. The working group suggested in Recommendation 5 should also be engaged for this purpose.

Recommendation 8

The committee is seriously concerned by evidence suggesting that as many as 25 per cent of carers are not linked in with Centrelink and therefore are not receiving payment to which they are entitled. The committee therefore recommends that Centrelink review its communication strategy with respect to carers and engage local disability service providers more directly.

Availability of services

5.25 Parent-carers of people with a disability provide enormous unpaid assistance to their sons and daughters, which can include help with everyday tasks, managing finances and navigating the disability service system. In considering planning options for people with a disability, carers must be confident both that appropriate services are available and that the person with a disability will be able to obtain these services. The committee heard that services are not available to all those who need them, and that this failure of the disability system prevents ageing carers from planning for the future:

> Unfortunately, there are still some barriers within the planning and access to those programs. I think only 10 people over our entire organisation were able to get places in those programs. It has been Mai-Wel’s experience that accessing services for people with a disability who are ageing is inequitable. It is based on crisis rather than forward planning, and there are insufficient programs and services out there to meet the needs of all those who require them…[20]

5.26 As well as the range of specialist disability services people with a disability require, there are some services that have particular relevance to planning. These include: accommodation, respite care, financial and legal advice and counselling.

Accommodation and respite places

5.27 In Chapter 1 the committee considered the how unmet need, lack of choice and underinvestment in housing across the disability sector has affected the capacity of families to plan. The committee acknowledges the additional accommodation places are being provided, such as via programs such as NSW's *Stronger Together* program, but heard from witnesses that such places are not sufficient to meet demand:

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[20] Mrs Lucy Crawford, Mai-Wel, *Committee Hansard*, 30 November 2010, pp. 43–44.

> The issues around transition are inextricably linked to the lack of services and provision of accommodation. If there were sufficient disability supported accommodation available to people with disabilities when they chose to leave their parents' home—whether that be in young adulthood or in middle age—we would not have such a major problem. So the problem is created by the lack of accommodation within the system.[21]

5.28 The committee heard that there is demand for a range of long-term, supported accommodation options for people with disabilities. People have different needs and wishes and therefore require availability and choice of accommodation. Options referred to during the inquiry included: group homes, congregate care or small group living, key-ring accommodation, village-style accommodation, international communities, shared care and aged care facilities.[22] Regardless of the preferred option, witnesses felt that it was important that accommodation also supported people's 'wellbeing, social inclusion [and] health needs'.[23]

5.29 Respite care also has an important role in future planning because the everyday demands on carers' time does not leave any space to think about the future. Carers of people with a disability are often involved in around-the-clock care and do not have time to think about the future. The committee heard that, 'for many people, just coping day-to-day and week-to-week is really all they can manage.'[24] The committee heard that it is usually during periods of respite that carers are able to begin to think beyond the immediate needs of their relative with a disability. As Perth Home Care Services explained:

> The general barrier is mostly about people being able to feel that it is something they can even start to think about…
>
> So the time-off and planning went together because if you could give people time off, then they were able to move their headspace into thinking about planning.[25]

5.30 However, the committee received overwhelming evidence that there are insufficient respite places available. Due to under-provision and the 'crisis-driven' nature of the disability system, normal respite needs are not being met because respite places must be prioritised to support people in crisis:

> Last year in the north-western metropolitan region 50 per cent of our respite places were blocked up—it sounds awful saying 'blocked up'—and were unable to be used because of crises that had happened in ageing carers' homes and the person with the disability had to take the place for a year or two years. That meant all the other people that wanted to use respite were

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[21] Professor Christine Bigby, *Committee Hansard*, 29 November 2010, p. 12.

[22] Discussions about the various options for accommodation are found, for example, in *Committee Hansard*, 29 November 2010, pp 13–18, 32, 39–40, 60, and 75.

[23] Ms Diana Heggie, Scope, *Committee Hansard*, 29 November 2010, p. 59.

[24] Mrs Marita Walker, Perth Home Care Services, *Committee Hansard*, 8 November 2010, p. 36.

[25] Mrs Marita Walker, *Committee Hansard*, 8 November 2010, p. 46.

> not able to use it because 50 per cent of our places were taken up with crises.[26]

5.31 Problems accessing government funded respite has provided impetus for carers to look to other means to access respite services, such as via local service providers such as Mai-Wel:

> We have a four-bedroom unfunded respite facility that was set up again through fundraising—it was set up through our women's auxiliary—and we have been able to get some small blocks of funding here and there...[27]

Committee view

5.32 The committee believes that inadequate investment in accommodation places is significantly affecting families' ability to plan. For people with a disability who currently live with a parent-carer, confidence in accommodation options is integral to future planning. The committee considers that increased accommodation places would enable families to plan for the future, secure in the knowledge that there will be somewhere appropriate for their son or daughter to live.

5.33 Further, the committee considers that the opportunity for respite is key to enabling carers to move into a planning headspace. The committee recognises and commends the respite options offered by organisations such as Perth Home Care Services, and the efforts of other non-government service providers such as Mai-Wel, to assist people to access respite. The committee believes that greater provision of respite places is an essential part of enabling the disability sector to move away from the current 'crisis-driven' approach, and towards encouraging a planning culture that addresses the long-term needs of people with a disability.

Access to financial and legal advice

5.34 People with a disability and their carers need access to financial resources in order to plan for the future. However, as discussed in Chapter 4, carers are often completely preoccupied with caring and have little opportunity for participation in the wider workforce. In addition, people with a disability who work in supported employment, or are not employed at all, are similarly unlikely to have access to significant financial resources.[28]

5.35 This has repercussions for future planning because while home care is generally provided on an unpaid basis, or supported only by the Carers Allowance, future care options are likely to include utilising fee-based services. This requires carers to have an understanding of financial management and the legal system.

5.36 The committee heard that existing planning and financial difficulties are often exacerbated by a lack of technical knowledge about these issues:

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[26] Ms Diana Heggie, Scope Victoria, *Committee Hansard*, 29 November 2010, p. 59.

[27] The role of local disability service providers is discussed in more detail in Chapter 6. Mrs Lucy Crawford, *Committee Hansard*, 30 November 2010, p. 52.

[28] Ms Margaret Cooper, Women with Disabilities Australia, *Committee Hansard*, 29 November 2010, p. 25.

> [People with severe and profound lifelong disabilities] have very little opportunity to build wealth in their own right. I think it is very unfair to penalise these people by having income and asset tests. Furthermore, if my parents are thinking about making a will and leaving the house to me or leaving it to my siblings, a common mistake is to think: if I leave it to David he will lose his pension.[29]

5.37 The committee heard that carers may need advice in order to navigate existing financial and legal frameworks such as Centrelink payments and rules, Special Disability Trusts and legal guardians and wills. While information is available on government websites, these websites often include a disclaimer advising carers to access specialist financial and legal advice, for example, 'Centrelink recommends consulting with a financial advisor and/or a solicitor for advice before establishing a Special Disability Trust'.[30]

5.38 Dr Baker, National Disability Services, explained that carers need specialist advice in order to plan effectively:

> People need an advice service because the range of things family carers need to consider are quite complex and do include financial and legal considerations, as well as trying to work out an appropriate sustainable service response. I would have thought that special disability trusts alone are very difficult for ordinary people to understand.[31]

5.39 The committee also heard that in some states, the legal system can act as an impediment to planning. Carers Victoria explained that carers and people with a disability cannot make anticipatory decisions to appoint enduring guardians or attorneys, and legal mechanisms operate as a crisis-driven 'last resort', which is 'not a suitable arrangement for helping people with a disability with their legal and financial matters.'[32] However, the legal expertise required to navigate issues related to disability is complex and expensive:

> Consideration might also be given to funded independent legal services for parents so that the cost of making wills and drawing up Trust documentation is negated. Legal advice in the area of disability is specialised so a list of experienced lawyers specialising in this area and operating in conjunction with groups like the Future Living Trust would greatly assist parents.[33]

5.40 It is clear that carers and people with a disability need access to specialist advice to navigate the complicated financial and legal issues involved in planning. Current services and payments arrangements are difficult to navigate, especially in a

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[29] Mr David Heckendorf, *Committee Hansard*, 8 November 2010, p. 35.

[30] Centrelink, Special Disability Trusts,June 2011, http://www.centrelink.gov.au/internet/internet.nsf/publications/fis034.htm (accessed 27 June 2011).

[31] *Committee Hansard*, 8 November 2010, p. 21.

[32] Ms Gill Pierce, *Committee Hansard*, 29 November 2010, p. 35.

[33] Future Living Trust, *Submission 83*, p. 3.

planning context. The committee considers that there is a disconnect between the government services and payment systems offered and the expertise necessary to navigate these systems. People with a disability and their carers need financial and legal advice to inform their planning decisions. As Family Advocacy expressed, 'I think probably the financial intermediary will be the key for many people in going forwards'.[34]

Recommendation 9

Within the framework of life-long planning, the committee recommends that the government facilitate the provision of specialist financial and legal advice to people with a disability and their carers to assist them with planning decisions, including the decision to utilise a Special Disability Trust. This advice could be made available via:

- **Commonwealth funded financial and legal planning workshops specifically targeted to address the issues that arise in disability planning;**
- **The provision of specialist advice through an established Disability / Carers' Unit at Centrelink; and / or**
- **Commonwealth funded independent legal services specialising in disability services, potentially operating in conjunction with non-government service organisations, and nationally registered on a list accessible to people with a disability and their carers.**

Information and counselling

5.41 While access to counselling may be perceived as less vital than access to financial and legal advice, for many carers, planning for the future is a confronting process. Counselling can assist carers to contemplate difficult decisions, and take first steps to seek out practical assistance measures. The committee heard that the National Carer Counselling Program, in operation since 2003 and delivered via state-based carers' associations, is a useful initiative and has been well-received by carers. The program assists 6,000 carers Australia-wide, representing 0.3 per cent of the national carer population.[35] As Carers Australia explained, 'many [carers] may need significant assistance, information or even counselling before they even begin to think long-term and plan for the future.'[36]

5.42 The committee suggests that the National Carer Counselling Program be expanded to reach a greater proportion of the carer population. The provision of counselling services also has the potential to overcome some of the personal sensitivities raised by the prospect of future planning.

Confidence in the system

5.43 A carer who feels as though they have been battling with the disability service system over the entire life of their adult son or daughter with a disability is unlikely to

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[34] Ms Belinda Epstein-Frisch, *Committee Hansard*, 30 November 2010, p. 76.

[35] Mrs Joan Hughes, Carers Australia, *Committee Hansard*, 8 November 2010, p. 25.

[36] Mrs Joan Hughes, *Committee Hansard*, 8 November 2010, p. 24.

be inclined to turn to the system for help with planning. Submissions were almost unanimous in reporting that carers experience significant challenges accessing services and information, and in the process many lose confidence in the disability system. A carer who has experienced difficulty navigating the system to access a relatively immediate or short-term service will not be able to contemplate the potential complexity of resolving long-term planning questions:

> I could not tell you how many assessments I have had to do for every single person who has come into the house from different services. Even though it is for the same thing you have to go through the same assessment all over again. It is a pain in the neck.[37]

5.44 In this respect, it is clear that for ageing carers to have confidence in considering options for future care, the wider disability system needs to deliver better services across the whole life of a person with a disability. As Dr Baker explained:

> …I think society has an obligation to provide these people with greater certainty and greater peace of mind about the future care and support of their son or daughter. We cannot do that in any systematic way without overhauling the basis on which we fund and provide disability services.[38]

5.45 In addition to issues with the disability system, carers also have the same concerns as parents of children without a disability relating to their adult son or daughter becoming more independent. These concerns are even more worrying for parents of children with a disability as they consider the difficulties their adult children might experience navigating the outside world. In the same way, some people with a disability are keen to leave home and others would prefer to continue living with their parents.[39] As suggested in Chapter 4, it can be difficult for carers to come to terms with the prospect of living without a dependent child:

> ...sometimes the adult child with disability is really keen to take off in a particular direction, but it is their ageing parents who have a hard time imagining what it would be like for that child to be out in the world…just like you and I, sometimes a parent is ready to let go and sometimes not.[40]

5.46 While this chapter has outlined the significant barriers to planning faced by most carers, there are particular groups for whom planning presents specific difficulties.

Barriers to planning for certain groups

Barriers to planning for people with a mental illness

5.47 The committee heard that it can be particularly difficult for carers of people with a mental illness to plan for the future. The episodic nature of some mental illnesses has implications for service delivery. When people are well they are less

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[37] Mrs Joyce Bellchambers, Dare to Care, *Committee Hansard*, 30 November 2010, p. 81.

[38] *Committee Hansard*, 8 November 2010, p. 17.

[39] Mrs Del Woodcock, Disability Services, *Committee Hansard*, 1 December 2010, p. 36.

[40] Mrs Melissa Young, Perth Home Care Services, *Committee Hansard*, 8 November 2010, p. 48.

reliant on care and support but episodes of illness can have significant flow-on effects such as the loss of accommodation.[41] In addition, people with a mental illness and their carers may experience difficulties accessing payments, services or planning arrangements such as the Special Disability Trust because the definition of 'severe disability' can result in the non-eligibility of people with episodic illnesses. While representatives from FaHCSIA did not eliminate the possibility that people with episodic illness could be considered eligible for SDTs, Dr Nick Hartland suggested:

> I think it is true to say that when we established special disability trusts we did have, if you like, an image of a permanent, ongoing disability, so it was about a lifetime provision. I think also it is true to say that we did not anticipate that they would be a vehicle for people caring for someone with an episodic illness.[42]

5.48 The committee expresses concern that people with episodic mental illness may be excluded from entitlements and schemes such as Special Disability Trusts.

5.49 The Mental Health Council of Australia explained that caring for a person with an episodic mental illness can also be difficult because that person may consider the carer to be part of the problem and that this has implications for planning. The Council further noted that privacy restrictions on carers knowing about their son or daughter's medication presents a practical impediment to even short-term planning.[43]

5.50 The Council emphasised that high staff turnover within a fragmented system contributes to poor case management and poor service coordination.[44] In this respect, the Council welcomed the Personal Helpers and Mentors Program, which is operated by FaHCSIA. This program provides a support worker to help a person with a disability to access community services and social opportunities, as well as assisting with building confidence and everyday practical needs.[45]

5.51 The committee acknowledges the additional planning challenges faced by parent-carers of people with a mental illness. It stresses the importance of a coordinated approach to care that includes continuity in case management, support via the Personal Helpers and Mentors Program, and the involvement of parent-carers.

Barriers to planning for people with intellectual disabilities

5.52 The committee recognises that the abilities of people with an intellectual disability varies widely, and does not seek to classify people into groups. However, some people with an intellectual disability may be unable to contemplate the future as an abstract concept, while others may be capable of expressing their preference for one planning option over another but not be capable of putting their preference into

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[41] Mental Health Council of Australia, *Committee Hansard*, 18 February 2010, p. 9.

[42] *Committee Hansard*, 18 February 2010, p. 32.

[43] *Committee Hansard*, 18 February 2010, pp. 12–13.

[44] *Committee Hansard*, 18 February 2010, p. 10.

[45] FaHCSIA, *Personal Helpers and Mentors Brochure*, February 2010, http://www.fahcsia.gov.au/sa/mentalhealth/pubs/Pages/phams_brochure.aspx (accessed 1 July 2011).

practice. The committee heard evidence of non-government sector involvement in planning for people with an intellectual disability. Organisations such as *Pave the Way* provide family-centred planning assistance to people with an intellectual disability 'who do not have the capacity to make decisions for their own life.'[46] Other organisations involve people who can participate in decision making to do so, such as the recent decision by People with Disabilities Australia to allow people with a cognitive impairment to participate on their board.[47]

5.53 It should also be noted that many people with intellectual disabilities have difficulty adjusting to change, and that this will have implications for future planning. Integrated forward planning that takes the person with an intellectual disabilities' needs and wishes into account is particularly important in minimising dislocation, as Ms Baker explained:

> I want the right to choose with him the type of housing he would be most suited to, long before he has to go in so that he can become familiar with the people, the surroundings and the philosophy so that when the time comes it will be as easy for him as possible. The separation for him is going to be frightening and for me it is going to be equally bad, but it will be less so if he is familiar with where he is going.[48]

5.54 While some parent-carers may consider there is no other option apart from aged care future planning, the committee also heard that aged care facilities are not ideal for younger people with intellectual disabilities:

> Those people's health needs are met very well in residential aged care, but their social integration needs are not. They are isolated. They are a very unique group within those residential aged-care facilities. There are only two or three in each facility, and the staff have no idea about how to deal with them. Other residents do not like them being there particularly, and other residents’ families do not like them there either...[49]

5.55 The committee recognises that it can be particularly difficult for parent-carers of people with an intellectual disability to identify viable future planning options. The committee recognises the need for planning services that assist people from the point of diagnosis. The committee considers that the current crisis-driven approach to disability services is particularly inappropriate for people with an intellectual disability. Plans need to be in place early for people with an intellectual disability so they have time to adapt to new circumstances and to develop the necessary skills and independence needed to live away from the parent-carer.[50] In particular, parent-carers and family carers need assistance and time to develop ways to replace their own roles in supervising the quality of their loved one's life.

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[46] Mrs Cathrine Raju, Mamre Association, *Committee Hansard*, 1 December 2010, p. 17.

[47] Mr Michael Bleasdale, People with Disability Australia, 30 November 2010, p. 56.

[48] Carers Victoria, *Committee Hansard*, 29 November 2010, pp. 38-39.

[49] Professor Christine Bigby, *Committee Hansard*, 29 November 2010, p. 13.

[50] See for example, Professor Chistine Bigby, *Committee Hansard*, 29 November 2010, p. 13.

Barriers to planning for Aboriginal and Torres Strait Islander people and people living in regional and remote areas

5.56 The need for better disability service provision is particularly acute in Aboriginal and Torres Strait Islander communities. While family networks in Indigenous society are highly valued and people with a disability are likely to be cared for at home by their extended family members, this means that younger carers may miss significant parts of their education.[51] In addition, a 2006 report by the Disability Services Commission WA raised a number of other challenges facing many Aboriginal people with disabilities and their carers, including: housing, poverty and high living costs in remote areas, lack of advocacy, reluctance to access government systems, problems with transport, lack of coordination between disability, Aboriginal and other support agencies, and lack of advice about employment opportunities.[52] Together these challenges are likely to make future planning extremely difficult.

5.57 The committee did not receive detailed evidence about Aboriginal access to disability / planning services during the inquiry. However, the committee did hear that Indigenous carers living in remote areas are unlikely to find appropriate services close to where they live. Mr Stephen Albert gave the example of carers in north Western Australia who need to travel to Broome to access good respite services, because the local services that do exist are only offered sporadically:

> ...carers who are out in the bush, if they are lucky and know the information, are able to try to go to this place of respite. I know that once a year in the Kimberley they try to get carers together and they might go to Kununurra for a big workshop where they can relax and work out how they can be better carers, or they might do one in the West Kimberley or somewhere in Fitzroy. Those things are happening but they are only once a year, sort of thing. The everyday thing about carers is that they do it themselves.[53]

5.58 While the need for better targeted service provision has been a common theme throughout the inquiry, Mr Albert, who described the system as a 'maze', suggested that it was critical that consultation with Indigenous families take place.[54]

Recommendation 10

As Aboriginal and Torres Strait Islander people with a disability face particular barriers accessing planning services, the committee recommends that the Office for Aboriginal and Torres Strait Islander Health undertake research to identify how planning support can best be provided to them.

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[51] Mr Stephen Albert, Western Australian Aboriginal Education and Training Council, *Committee Hansard*, 18 February 2010, p. 64.

[52] Disability Services Commission WA, *Aboriginal People with Disabilities: Getting services right*, April 2006, West Perth, pp. 19–25.

[53] *Committee Hansard*, 18 February 2010, p. 64.

[54] *Committee Hansard*, 18 February 2010, p. 65.

5.59 Disability services are extremely difficult to access in regional and remote areas.[55] This affects both Aboriginal and non-Aboriginal people living outside metropolitan centres. The Australian Federation of Disability Organisations suggested that the support available in a given regional or remote area is unlikely to be appropriate for all the people with a disability in that area.[56] Therefore people with a disability and their carers must make an uncomfortable choice—either to access proximate care, which might be inappropriate, or move away from their social network to areas where they can seek appropriate care.

5.60 As well as facing limited options accessing specialist disability services, people in regional areas experience difficulties with transport to attend medical appointments and social events some distance away. The committee received evidence in Toowoomba that the expense of long-distance travel in taxis, combined with excessive waiting times and issues such as wheelchair accessibility, makes travel very difficult:

> You have carers who no longer have licences and who are expected to take the person they are caring for to medical appointments and to all sorts of other things. They have to use taxis. Oftentimes they are 30 or 40 kilometres out of town. It is very, very expensive. It is not only that but also the distance from where they live to the support or service they are going to get. This came up, and it is really high on our priority list. It is one of the things that we will be putting in our recommendations—that it has to be addressed—because the carers just cannot keep footing the bill for this out of their allowances.[57]

5.61 The scarcity of transport has implications for access to appropriate services and for social and community engagement. The committee heard that bus travel is not an option for people with restricted mobility or for people who wish to attend events at times when bus services are not available:

> Now if he wants to go out to Down syndrome disco at night or he wants to go to a movie or a concert or something special for the disabled that is on at night, he cannot go out. It would cost him at least $20 to get there and $20 to get home, which is $40 for an outing, so he cannot do it unless he relies on parents to go out there at night to do it for him...At 70 there is no guarantee I am going to continue to drive...That is a disadvantage to people who can catch a bus in the daytime but they cannot do anything at night because they cannot afford to do it on a disability pension. There are no buses at night here in Toowoomba, or on a Sunday.[58]

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[55] This can be due to transport and other additional costs. Mrs Margaret Haskal, Mai-Wel, *Committee Hansard*, 30 November 2010, p. 51.

[56] Ms Leah Hobson, *Committee Hansard*, 29 November 2010, p. 2.

[57] Mrs Del Woodcock, Disability Services, *Committee Hansard*, 1 December 2010, p. 42.

[58] Mrs Annette Gerrard, *Committee Hansard*, 1 December 2010, p. 43.

5.62 The committee heard an instance of a parent-carer who addressed this lack of services themselves through privately purchasing a maxi-taxi.[59] Parent and community driven initiatives are discussed further in Chapter 6.

Recommendation 11

As people with disabilities living in regional and remote areas face particular barriers accessing planning support, the committee recommends that the Department of Families, Housing, Community Services and Indigenous Affairs provide additional funding and resources to develop planning services in these areas. The committee also recommends that the Department establish a working group of people with disabilities, their carers and regional disability service organisations, to provide advice on how additional funding should be utilised.

5.63 The committee has identified the major barriers to future planning and made recommendations on information provision and access to financial and legal advice. In the following chapter, the committee examines ways in which community based, non-government organisations have responded to the demand for planning services.

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[59] Miss Carol Coombes, *Committee Hansard*, 1 December 2010, p. 43.

Chapter 6

Current lifelong planning and support schemes

6.1 In Chapter 4 the committee outlined the urgency of the planning challenge. It suggested that as a result of population ageing it was essential that planning be developed to support ageing parent-carers and people with disabilities. Effective planning, the committee argued, would minimise crisis responses, provide reassurance for family and friends, and would assist people with disabilities transition through the different life stages. The committee also discussed the fact that planning is a complex and multifaceted task that involves families marshalling a wide variety of information related to funding arrangements and the disability service system, housing and support options and guardianship and financial matters. In this chapter the committee turns to consider some of the innovative planning work that is currently being undertaken by non-government organisations and makes recommendations on what the government can do to assist these organisations continue with this important work. In making these recommendations the committee considers that while it is important that government provide the frameworks to underpin or facilitate planning, it is the community-based organisations, people with disabilities and their carers, operating at the local level, that are best positioned to develop and deliver lifelong planning support.

6.2 Earlier in the report the committee sought to differentiate between individual service planning and whole-of-life planning. Professor Christine Bigby suggested that while support services can play a role in assisting individuals achieve work, recreational or educational goals, these services are unlikely to assist with matters such as personal or financial security, decision making, relationships or goal setting.[1] In order to make this distinction clear, it is worth citing Pave the Way's description of the whole-of-life planning work that exists independently of service planning:

> People may put plans in place thinking that that is the final solution for their son or daughter, because a place has been found, a roof over their head has been found but we all know that circumstances may well change in that regard with a change in services or a change in legislation. So people need to have in place some thinking in their planning that lies beyond or beneath service planning. That is where the work of Pave the Way comes in, which is not to say that the funding and services are not very important. But there is a question about planning that lies beyond that, which is: who are the people involved in knowing my son or daughter and being there to bear them in mind in the future?[2]

6.3 Ms Belinda Epstein-Frisch, Family Advocacy, New South Wales, offered another rationale for planning. This relates to the limited social capital established by families who care for a person with a disability. Ms Epstein-Frisch suggested that many people with disabilities have fewer opportunities to build the types of

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[1] Pave the Way Mamre Association, *Submission 18*, p. 5.

[2] Pave the Way Mamre Association, *Committee Hansard*, 1 December 2010, p. 16.

connections that assist people negotiate 'life steps', such as leaving school, finding a first job or moving out of the family home. As discussed earlier, this is exacerbated by the fact that carers of a person with a disability are frequently socially isolated and may also have limited social or community connectedness:

> When you think about it, for the vast majority of us, as we have taken our life steps—our first job, finding a place to live and who you live with—it is about our connections. It is about the people you know—your mother's sister's best friend who helped you to get that job.
>
> People with disability, because of the restricted opportunities that many face, have had far fewer opportunities to build those connections. So the first step—and it is a step in planning—is helping the family to bring other people into their intimate circle. It is about saying, 'I'd like you to help me think about Robert. I'm worried.'[3]

6.4 The committee has heard many inspiring stories, frequently told by parent-carers, documenting the work taking place in the community to support people with disabilities and their carers. Across Australia there are pockets of people doing extraordinary work, often voluntarily, because they see the need. The committee heard of disability advocacy groups who have established 'supported living funds' or 'circles of support' to assist with the future care of their disabled adult child; parents in Sydney who are setting up an 'intentional community'; a group in Gunnedah who established a rehabilitation day program for mental health consumers; a group of parents in Toowoomba who organised a letter campaign, successfully advocating for funding to establish a house for shared accommodation—the Anden; and an individual in Hervey Bay who has organised the council to provide accommodation where she can support mental health consumers in living independently.[4] While it should be acknowledged that some of these initiatives have received some government funding, many are established by parent-carers and are taking place independently of government.

6.5 Many of these grass-roots level, non-government initiatives have emerged in response to the lack of government support, or from the cumulative frustration of dealing, over many years, with complex and confusing government bureaucracies. Others have emerged in response to service support which is often piecemeal or where there is an absence of ongoing case management. Above all, these initiatives, frequently parent-run, have emerged in response to the frustration of dealing with bureaucracies that are simply not responsive enough, inventive enough or flexible enough to meet people's complex needs.

6.6 Individuals involved in establishing these organisations suggested that one of the challenges they confronted was rejecting the culture of dependency that has developed among families reliant on the disability service sector. Ms Epstein-Frisch

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[3] *Committee Hansard*, 30 November 2010, p. 67.

[4] These examples are taken from evidence provided by Ms Epstein-Frisch, *Committee Hansard*, 30 November 2011; Futures Alliance, *Committee Hansard*, 30 November 2011; Mrs Lorraine Hitt, Planned Individual Networks, *Committee Hansard*, 18 February 2011; Mrs Fay McKenzie, *Committee Hansard*, 1 December 2010, p. 25; Mental Health Council of Australia, *Committee Hansard*, 18 February 2011.

suggested that families needed to regain their 'family authority' or decision making power:

> The way in which our system has worked is that people have been rewarded and encouraged to go into crisis. People who are, say, my generation—families in their forties and older—were taught that the service system will provide you with the answers and that you should wait and get services et cetera. They have been taught to give up important family authority and decision making to a service system. That has immobilised them in their capacity to plan. How can you plan when so many of the answers seem to be completely and absolutely outside of your control?[5]

6.7 Others spoke to the committee about dispensing with the culture of learned helplessness, and looking beyond government:

> We are aware that the government cannot and will not provide all and that sometimes doing things yourself brings about really good outcomes for the person with the disability and their family. So I guess it is about changing attitudes as well as the work that we do.[6]

6.8 In what follows the committee offers a profile of some of the non-government organisations involved in planning. Thereafter, it seeks to consider some of the critical planning concepts that emerge out of the work of some of these organisations.

Organisations involved in long-term planning

Planned Individual Networks

6.9 Planned Individual Networks (PIN) is a Perth-based organisation modelled on the Canadian Planned Lifetime Advocacy Network (PLAN). It was formed after a group of parents did PLAN training and then established their organisation on the PLAN model. PIN is 'a family leadership initiative' whose goal is to develop individual networks to offer long-term planning support to a family member with disability. Chairperson of PIN, Mrs Lorraine Hitt, described the network that families look to establish as a 'bike wheel':

> The easiest way of explaining the network is if you think of a bike wheel. The person at the centre is the person with a disability. That is the hub of the wheel. The spokes are the people who freely form a relationship with the person at the centre. It may be family, it may be friends, it may be neighbours or it may be somebody that one of the family members has a connection with but who has shown an interest or has similar goals and interests. The areas that people can look at particularly are friendship and social contact because people are quite isolated when they have a significant disability. The other areas families are quite concerned about are financial advocacy, medical advocacy and planning. Often a family member—and most often the mother—will take this on. If you have got a

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[5] *Committee Hansard*, 29 November 2010, pp. 66–67.

[6] Mrs Lorraine Hitt, Planned Individual Networks, *Committee Hansard*, 18 February 2011, p. 84.

> number of people in the network then the role is shared and supported, so the challenge is not so great.[7]

6.10 The networks provide a holistic approach to social, financial, planning and medical care and could be described as also being engaged in a coordination and quality monitoring role. To date, PIN has established 25 networks.[8]

6.11 PIN also runs Safe and Secure Workshops for Families which introduce families to planning for the future. These cover subjects such as: building relationships, home and lifestyle options, estate planning, wills and trusts, and supporting participants to become informed about life insurance, income protection, and trauma and accidents. In addition to the workshops, PIN holds quarterly orientations for which it does not charge.[9]

6.12 PIN was established with grants from Lotterywest. It has received two grants from the Disabilities Services Commission, Western Australia. Currently it has no recurrent funding and operates as a fee-for-service provider or survives on donations, membership fees and fundraising. Mrs Hitt described one of the challenges facing the organisation is that it does not have the funds to support a chief executive officer who could potentially assist the organisation grow.[10]

Pave the Way

6.13 Pave the Way is a team within Mamre Association in Queensland. The Mamre Association is a family support service based in Brisbane. Pave the Way began in September 2002 as a small project funded by Mamre Association, before receiving funding from Disability and Community Care Services in the Queensland Department of Community Services. Pave the Way is funded to provide succession planning resources and support to families throughout Queensland who have a family member with a disability. The aim of Pave the Way is 'to assist families with a family member with a disability to develop a vision for now and the future, to plan to implement that vision and to safeguard that vision…in the long-term'.[11] Pave the Way stresses that it works with families, not for them. It focuses on vision building and future planning issues, not case work, advocacy or service development.[12]

6.14 Pave the Way is the only project in Queensland which focuses on whole-of-life planning on a state-wide basis.[13] Pave the Way operates on the following principles:

- It is never too early or too late to plan;

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[7] *Committee Hansard*, 18 February 2011, p. 82.

[8] *Committee Hansard*, 18 February 2011, p. 92.

[9] *Committee Hansard*, 18 February 2011, p. 83.

[10] *Committee Hansard*, 18 February 2011, p. 83.

[11] *Submission 18*, p. 2.

[12] Pave the Way, Marme Association website: http://www.pavetheway.org.au/ (accessed 27 June).

[13] *Submission 18*, p. 3.

- Future planning begins with developing a clear vision for the best possible life we can imagine;
- There is no template or recipe—every family will create their own vision and plan, at their own pace;
- People keep other people safe—inviting others to share our vision and our planning is one way to help secure our hopes for the future.

6.15 In keeping with the perspective that people keep people safe, Pave the Way encourages families to develop networks of support, including support circles, around their family members. Pave the Way assists families to establish these networks or circles and acts as a resource for families who want to come back for further assistance when they need it.

6.16 Beyond supporting the development of networks, Pave the Way offer one day workshops and two day and six day live-in workshops which provide in-depth opportunities for families to focus on future planning.[14] Pave the Way also provides information and guidance in relation to legal issues relevant to planning and preparing for the future, including Special Disability Trusts. Pave the Way refers families to a panel of solicitors in Brisbane and throughout Queensland who are experienced in wills and trusts and with working with families who have a family member with a disability.[15]

Future Living Trust

6.17 The Future Living Trust provides services to people with developmental disabilities and their families. Based in Perth, the Trust is an incorporated body founded in 1989. Future Living Trust's mission is to provide a means for families to make reliable plans for the future and assist in the implementation of those plans. Future Living Trust does not provide whole-of-life planning but offers specialised, boutique planning services to assist parents with wills, trusts and estate planning and has formulated specific policies to deal with the legal complexities involved in these matters. It also engages in planning and advocacy work to assist ageing carers access funding, respite and support services and to develop individualised care plans.[16]

6.18 The Future Living Trust is a not for profit, non-government funded charity. In its submission, Future Living Trust explained that as a charitable Trust, it is restricted in the number of parents it can assist as the types of advice services it provides are not funded by state disability services organisations or FaHCSIA in any way.[17]

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[14] *Submission 18*, p. 1.

[15] See Pave the Way's planning booklet, 'Planning for Now, Tomorrow and the Future': http://www.pavetheway.org.au/pdf/planning.pdf and *Submission 18*, p. 1.

[16] *Submission 83*, p. 1.

[17] *Submission 83*, p. 3.

Perth Home Care Services and Vela Microboards

6.19 Perth Home Care Services (PHCS) is a not-for-profit organisation established in 1967. With an annual turnover of $36 million, and 850 staff, they are developing individualised care and planning solutions. PHCS supports 1,200 people per fortnight, including over 300 people with individualised disability support.[18] PHCS provides assessment, case management, crisis care, domestic assistance, nursing consultancy, respite, social support and personal care. These services are provided to people with disability, those who are aged or those who have mental health issues across the Perth metropolitan area, as well as the Midwest and Wheatbelt regions of Western Australia.[19]

6.20 Since 2007 PHCS has been funded by the Disability Services Commission, Western Australia, to promote the use of Vela Microboards. Vela Mircoboards Australia (VMA) describe a microboard as a:

> …small (micro) group of committed family and friends (board) who join with a person who has life challenges to create a non-profit community board. The Microboard supports the person to plan for a good life and to achieve their goals, dreams and wishes.[20]

6.21 As with a PIN network, membership of a microboard is voluntary and people freely give their time and support. VMA is modelled on Vela Microboards British Columbia where it has been operating for approximately 16 years and there are now 1,600 boards established.[21]

6.22 Sharing similarities with the notion of the 'bike wheel' network, described by Mrs Lorraine Hitt of PIN, each microboard supports one person, the person is the centre of their microboard, and every decision reflects the person's goals, dreams, needs and desires. Importantly, like the PIN network model, these are 'self-organising' groups committed to planning, advocacy and support. The important feature of these networks is their inbuilt sustainability for in order for a member to leave the board a replacement has to be found.

6.23 Mircoboards may be established as companies or as incorporated associations and may manage funding or individualised supports and services for a person who needs them.[22] They also include arrangements for governance, accountability and quality of service.[23] PHCS explained to the committee that in late 2010 they had two,

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[18] *Committee Hansard*, 8 November 2010, p. 44.

[19] *Submission 47*, p. 1.

[20] Vela Microboards Australia, http://www.microboard.org.au/ (accessed 27 June 2011).

[21] *Committee Hansard*, 8 November 2010, p. 47. VMA is predominantly made up of people with disabilities, their families and microboard members who are working to establish individual microboards. Mircoboards also look for ways that the wider community can have a relationship with the person with a disability. Vela Microboards Australia, http://www.microboard.org.au/page/what_is_vela_microboard_australia (accessed 27 June 2011).

[22] Vela Microboards Australia, http://www.microboard.org.au/ (accessed 27 June 2011).

[23] *Committee Hansard*, 18 February 2011, p. 74.

almost three, microboards that had been formally constituted and that they anticipated that there will be more over the next few years.[24]

6.24 Importantly, for those people who may not have anyone to form a circle of support and may not know anyone particularly well other than their service providers, the network or mircoboard models are able to connect them to people to help support them at vulnerable stages of their lives.

Other organisations involved in planning

6.25 The committee heard from other disability advocacy groups that have created other types of planning models. For a number of years Family Advocacy (NSW) has been holding workshops, information sessions and teleconferences to promote 'supported living funds'. Ms Epstein-Frisch compared the supported living fund to the networks established by PIN, explaining, 'there should be a network of people who care about the person…rather than care for the person'.[25]

6.26 Ms Epstein-Frisch also referred to some examples of the important planning work that is taking place within the Jewish community:

> …there is little project that we have had going there for about four to five years, a circles project. It is tiny. It has grown. We got funding from within the Jewish community, so it is not funded from government. There are eight families who are assisted to plan. Last year we spent $8,000 on eight families over a full year. That provides for a coordinator and some very part-time sessional facilitators. It gives us the opportunity to select different facilitators. It is nobody's job but there are a lot of people who have that kind of knowledge, skill and empathy who are very happy to be involved.
>
> So what that does is provide someone external to the family who works with the family to facilitate—to perhaps get it started, to do that initial ask and to facilitate the meetings. Sometimes the meetings are once a month and sometimes they are once a quarter…[26]

6.27 Witnesses representing Futures Alliance (NSW) also introduced the committee to the work they were doing to establish an 'intentional community'. Drawing on the example of Deohaeko in Canada, they explained how this was based on the creation of informal and formal supports: formal support from a disability provider and informal support from residents within the 'intentional community' and from brothers, sisters, cousins and family friends who form circles of support.[27] The committee also received evidence from peak bodies like Carers Victoria who have developed planning programs and support services and who have advocated for the appointment of guardians or administrators to oversee the affairs of people with disability.[28] Life Without Barriers, a not-for-profit organisation providing care and

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[24] *Committee Hansard*, 8 November 2010, p. 47.

[25] *Committee Hansard*, 30 November 2010, p. 67.

[26] *Committee Hansard*, 30 November 2010, p. 68.

[27] *Committee Hansard*, 30 November 2010, p. 39.

[28] *Committee Hansard*, 29 November 2010, p. 34.

support services in urban, rural and remote locations, also informed the committee about the person-centred planning they offer, through which specialised coordinators develop individual plans.[29]

Establishing sustainable networks

6.28 There are a number of planning concepts that are common to each of these planning initiatives. While there may be some variation in emphasis between the different models, be it the network, the microboard or the circle of friends, each gives emphasis to the same planning concepts. These include:

- Respite and readiness;
- Individualised or person-centred care;
- Relationship building and family involvement;
- Establishing sustainable networks;
- Role of paid facilitators.

6.29 In addition, each of these models acknowledges the challenges associated with any planning process. In the previous chapter the committee identified carers need for respite and the lack of respite service was identified as a barrier to planning. In acknowledgement of the need for respite, Perth Home Care Services have created the 'Time Off and Planning' (TOP) initiative to enable families to start to think about planning. The target group for the service is family carers of people with permanent disabilities and priority is give to carers who are aged 65 years or over. Previously funded by both the Commonwealth government and the Disability Services Commission Western Australia, it provides carers with access to a coordinator who discusses with the family their care needs in relation to time off, planning, emotional support, information and advocacy. Carers are then encouraged and supported to plan for the future.[30]

6.30 The committee believes that the provision of respite services is integral to planning and suggests that organisations involved in planning make special provision for respite within their planning models. However, given the committee's previous discussion on the availability of respite, it acknowledges that until opportunities for respite improve, this will continue to be extremely difficult.

6.31 Another critical aspect of the planning journey is taking into account the concept of readiness. Several planning organisations emphasised to the committee that it is not uncommon for a family to attend a series of preliminary planning workshops, but still not be ready to embark on the planning journey:

> It is not an uncommon experience for us to have a family say after they attended a workshop, for example, two years ago: 'I know that stuff is really important. Now I am ready and now I am here to have that conversation.'[31]

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[29] *Committee Hansard*, 30 November 2010, p. 23.

[30] Ms Melissa Young, Perth Home Care Services, Answers to Questions on Notice, received: 25 November 2010, p. 2.

[31] Pave the Way, *Committee Hansard*, 1 December 2010, p. 16.

6.32 This was reiterated by PIN who suggested that it often it takes families a long time to grasp the need to plan and prepare.[32] Another factor affecting readiness is that planning can often be personally confronting because it requires parent-carers to give consideration to their own mortality. Ms Epstein-Frisch, Family Advocacy, added:

> …it takes quite a long time for parents to come to it and say, 'Yes, I'll give it a go,' because it is a scary idea to invite other people into your life. Then you need a whole lot of time and talking and what have you before you get into the big issues.[33]

6.33 Life Without Barriers added that because some older carers are often distrustful of outside support it is critical that time is invested in developing ongoing relationships.[34] In trying to develop planning cultures within disability communities across Australia, it is absolutely critical that planning not be seen as a one-off or short-term project.

6.34 In much of the evidence received by the committee witnesses emphasised the importance of putting the person at the centre of policy and practice through enhancing mechanisms which promote individualised funding and self-directed supports. It was argued that these mechanisms should also emphasise flexibility and recognition of the culture, values and preferences of each person and, where appropriate, their family.[35] Mr Edward Birt, Life Without Barriers, explained person-centred planning in the following way:

> If you think about a system like person-centred planning, which is something that is talked about a lot at the moment in disability services, where the person's goals and aspirations are at the centre of what you are doing, their vision for what their life might look like is the driving force behind what we do, and every disability service standard around the country would say that is absolutely right: individual needs, decision making and choice, service access, valued status—the list goes on. They are all wonderful things. The legislation has it absolutely right, but I think that lack of funding and service options is a big problem.[36]

6.35 It is this approach that underscores the approach to establishing networks, mircoboards and circles of support.

6.36 Another critical aspect involved in establishing sustainable networks or circles of support is relationship building and family involvement. Various organisations spoke to the committee about the different ways in which they establish networks. PIN offered the following description of the process:

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[32] *Committee Hansard*, 18 February 2011, p. 83.

[33] *Committee Hansard*, 30 November 2010, p. 69.

[34] *Committee Hansard*, 30 November 2010, pp. 15–16.

[35] See, for example, People with Disability Australia, *Committee Hansard*, 30 November 2010, p. 55.

[36] *Committee Hansard*, 30 November 2010, p. 19.

> Yes, we usually encourage people to come along for the orientation and the workshop so they get an understanding of what PIN is and what we do. Primarily, the people that we support at the moment are 18-plus, although we have realised that it would be very good to start with children who are transitioning from high school, because often they lose their friends, who could become very good parts of the network. We have a network and membership coordinator. A family member will go and talk to the person and listen to what their expectations and hopes are. Sometimes they do not fit well with PIN—they want funding—and we talk to them about funding and where they can go for that, but we also say to them that funding alone is not the answer. We tell them that what you need is a very strong plan and you need to focus on who the person is, what their gifts and passions are, what contributions they can make and who they have been connected with in past years. We get them to think about and write down all of the people that have passed through their life that really had an impact on them. From there we encourage them to invite them to a social function. We talk about sharing the stories, sharing the history and through hospitality.[37]

6.37 Within each model outlined above a third party, a coordinator or facilitator, is utilised to help families plan. The PIN model is particularly interesting as it reveals the way that small community-based organisations can sustain networks. It also provides an example where people can build and sustain circles of support if they do not already have them. Under the PIN network model, each network has a facilitator and the facilitator is the only person who is paid. They are employed by PIN but they are selected by the person/ family.[38] Mrs Hitt impressed that while all the networks are different they attempt to progress through similar planning stages:

> In the early stages it is important to have at least once-a-month meetings. It might take 10 hours or maybe a little longer with the coordinator to work through the early exploration stage and how they process that. I have got quite an extensive background in human services so I hurried my son along quite quickly because I knew what to expect. But if you have a family that does not have that background you would need a good 10 hours minimum, and then you have the network happening once a month for the first year. We found, because we have been going for a long time that we have one meeting with the facilitator and one meeting where there is a social gathering for people—we have a meal or go out somewhere.[39]

6.38 The other critical role undertaken by the facilitator is that if somebody moves out of the network for some reason the facilitator will work with the group to bring in a replacement. If the facilitator leaves for some reason, the coordinator—who trains and supports the facilitators—is reintroduced and goes through the process of recruitment, matching and getting the new facilitator sorted.[40] So long as there is

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[37] *Committee Hansard*, 18 February 2011, p. 85.

[38] With respect to the cost of facilitation services families pay a $1,100 lifetime membership and they pay $35 an hour for the facilitator's time, *Committee Hansard*, 18 February 2011, p. 86.

[39] *Committee Hansard*, 18 February 2011, p. 86.

[40] *Committee Hansard*, 18 February 2011, p. 87.

funding for the coordinator and the facilitators, both of whom are essential, sustainability of the network is guaranteed. For larger organisations, such as Perth Home Care Services, they have a larger pool of human and financial resources to ensure their sustainability.

6.39 In order to ensure governance standards are met PIN has a board of management. The board includes: a businessman, a retired businessman, a physiotherapist; a local area coordinator with an extensive human service background; a financial planner, and a person who works in the disability field.[41]

Committee view

6.40 The committee acknowledges the important work that is taking place in the non-government sector to facilitate planning for people with disabilities and their families. Organisations providing planning support, many of which have been founded by parent-carers, have identified substantial community need. In responding to this need, these organisations have proved themselves to be flexible, innovative and consumer focused.

6.41 Community-based organisations have knowledge of local amenities and local service providers and a detailed understanding of state legislation. They also have a connection to the community that underpins their success. It is the community-based organisation who can build and maintain informal local networks. The committee therefore sees substantial benefit in this planning work continuing at the community level and considers that it is the size of these organisations, and their connection to the community, that is critical to their success.

6.42 However, while the committee acknowledges the efforts of these organisations and commends them for their initiative, it is clear that they are too few in number; their reach is limited and they do not reflect any type of integrated or coordinated national approach to managing disability planning. There are areas of the country, such as Perth, where government-funded and non-government-funded planning services are more available than in other areas of the country where there is little evidence that planning is taking place.

6.43 The committee also notes that there is growing demand for planning services and that many organisations offering planning services are under resourced and cannot meet demand. The committee therefore considers that it is critical that government increase its support for these organisations. Further, that while government provide the framework or architecture to facilitate the development of planning cultures, lifelong planning will continue to be implemented through community-based organisations.

6.44 Increased government funding, from both the Commonwealth and state and territory governments, would ensure the creation of new organisations to assist families with planning. The committee is concerned however that existing service or accommodation providers not be in a conflict of interest if they also choose to provide planning support services.

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[41] *Committee Hansard*, 18 February 2011, p. 84.

6.45 The committee also consider it essential that organisations responsible for planning are accountable for any monies they may receive. It is important that these organisations are properly constituted, have clear governance arrangements, and are transparent in their management of funds.

Recommendation 12

The committee recommends that the government, through the Department of Families, Housing, Community Services and Indigenous Affairs, work with the states and territories to establish a succession planning framework. The framework should:

- **Make clear the importance of long-term planning;**
- **Provide guidance on the critical aspects of long-term planning;**
- **Take into account the individual differences of families;**
- **Support a range of approaches to planning.**

Recommendation 13

The committee recommends that as part of the succession planning framework the government establish nationally consistent guidelines on lifelong planning. It is recommended that these guidelines consider matters such as: registration, constitution of boards, management of funds, governance arrangements, transparency, reporting requirements, and the role of paid facilitators.

Recommendation 14

The committee recommends that the succession planning framework be the first step in the development of an integrated and coordinated national approach to planning. In making this recommendation, the committee stresses that the framework should balance the need for individualised or tailored planning support with clear standards of governance and accountability.

Recommendation 15

The committee recommends that in its next Budget the government allocate funds to assist with the development of disability planning. It is suggested that this funding be made available to:

- **Organisations currently involved in planning;**
- **Individual families seeking to purchase planning services from providers;**
- **Other disability service organisations that intend to develop lifelong planning services for families.**

The committee recommends that this funding be made available on a recurrent basis.

Senator Rachel Siewert

Chair

APPENDIX 1

LIST OF PUBLIC SUBMISSIONS, TABLED DOCUMENTS AND ADDITIONAL INFORMATION AUTHORISED FOR PUBLICATION BY THE COMMITTEE

Submissions Received by the Committee during the 42nd Parliament

1. Riverland Respite and Recreation Service Inc
2. Family Advocacy
3. The Centre for Cerebral Palsy
4. Hon Dr Bob Such MP
5. The Partners of Veterans Association of Australia Inc.
6. Motor Neurone Disease (MND) Australia
7. Bigby, Professor Christine
8. Alzheimer's Australia
9. Toowoomba Intellectual Support Association Inc. (TIDSA)
10. Office of the Public Advocate (Victoria)
11. Disability Services Commission
12. Siblings Australia
13. Council on the Ageing (COTA) Australia
14. Endeavour Foundation
15. JacksonRyan Partners
    - Supplementary Submission
16. Futures Alliance
17. Scope
18. Pave The Way Mamre Association Inc
19. Dare to Care
20. Department of Families, Housing, Community Services and Indigenous Affairs
21. Gay Lesbian, Bisexual, Trans and Intersex Retirement Association Inc
22. Down Syndrome NSW
23. The Mai Wel Group
24. Women With Disabilities Australia (WWDA)
25. National Association of Extremely Disabled War Veterans
26. National Ethnic Disability Alliance

27 Mercy Aged Care Services

28 Polio Australia Inc

29 Bedford Group

30 Victorian Deaf Society

31 Attendant Care Industry Association of NSW Inc. (ACiA)

32 Julia Farr Association

33 Joint submission by the Disability Council of NSW and the Council on the Ageing (COTA) NSW

34 Aged & Community Care, Victoria

35 Catholic Health Australia

36 Latrobe Community Health Service

37 Aged and Community Services Australia

38 Trustee Corporations Association of Australia

39 Carers Australia

40 Life Without Barriers

41 Royal District Nursing Service of SA Inc

42 The Royal Society for the Blind of South Australia

43 Ethnic Disability Advocacy Centre

44 South Australian Council of Social Services Inc (SACOSS)

45 National Disability Services

46 NSW Council for Intellectual Disability

47 Perth Home Care Services

48 Australian Federation of Disability Organisations

49 UnitingCare Australia

50 National Council on Intellectual Disability

51 Australian Blindness Forum

52 People with Disability Australia

53 Parkinson's Australia

54 Carers Victoria

55 Community Living Project Inc

56 Multicultural Disability Advocacy Association of NSW

57 Joint Submission by the Australian Federation of AIDS Organisations and the National Association of People Living with HIV/AIDS

58 Physical Disability Australia

59 Ability Options Australia

60 Western Australian Aboriginal Education and Training Council

61 Villa Maria Society

62 NSW Government

63 Pawagi, Ms Val

64 Whitelock, Mr Rod & Ms Ann

65 Heckendorf, Mr David

66 Dainton, Mr John & Ms Rae

67 Gurr, Mr Robert

68 Tasmanian Government

69 Roberts, Ms Lois

70 McCall Gardens Community Ltd, facilitated by NSW Council for Intellectual Disability *plus* Attachments

71 Antioch, Dr Kathryn

72 Law Institute of Victoria

73 Carers WA (Inc)

74 Rigoni, Ms Maria

75 Warren, Mr Geoff

76 Name Withheld

Submissions Received by the Committee during the 43rd Parliament

77 McKenzie, Mr and Mrs Peter and Fay

78 Lifestyle in Supported Accommodation (LISA) Inc

79 Warwick and District Disability Support Group Inc

80 Self Help Workplace

81 Blind Citizens Australia

82 AHURI Ltd

83 Future Living Trust

84 Vision Australia

85 ARAFEMI Victoria Inc.

86 Carers NSW

87 Name Withheld

Additional Information

National Ethnic Disability Alliance

- Migrants with Disability and the 10 Year qualifying Residence period for the Disability Support Pension, received 1 December 2010.

Lifestyle in Supported Accommodation (LISA)

- Document, received 29 November 2010.

Breakaway Toowoomba

- Letter to the Committee, received 10 January 2011.

Carers Victoria

- Letter to the Committee, received 15 December 2010.

Mental Health Council of Australia

- Adversity to Advocacy – Report Card.
- Adversity to Advocacy, The Lives and Hopes of Mental Health Carers, October 2009.
- Mental Health Carers Report – November 2010.

NSW Department of Human Services

- Letter to the Committee, received 4 April 2011.

PATH – Penrith Association for People with Disabilities, their Carers, Families and Friends

- Final report, ASAP Project.

Answers to Questions on Notice

National Ethnic Disability Alliance

- Migrants with Disability and the 10 Year qualifying Residence period for the Disability Support Pension, received 1 December 2010.

Dr Ken Baker

- Received 9 November 2010.

Mr Phil Farrow

- Received 25 November 2010.

- Supplementary Answers to Questions on Notice and Additional Information, received 02 December 2010.

Melissa Young, Perth Home Care Services

- Received 25 November 2010.

Margaret Cooper, Women With Disabilities Australia (WWDA)

- Received 2 December 2010.

Futures Alliance

- Received 04 December 2010.

JacksonRyan Partners

- Received 17 December 2010.

Tony Tregale, LISA Inc.

- Following a public hearing on 29 November 2010.

FaHCSIA (following public hearing 8 November 2010)

- Question 1.
- Question 2.
- Question 3.
- Question 4.
- Question 5.
- Question 6.
- Question 7.
- Question 8.

Carers Victoria

- Following public hearing 29 November 2010.

FaHCSIA (following public hearing 18 February 2011)

- Question 1 - Portability Issues.
- Question 2 - Funding of ADEs: long term or the vision process.
- Question 3 - Special Disability Trust forms.
- Question 4 - Special Disability Trusts.
- Question 5 - Eligibility criteria on aged care.

APPENDIX 2

WITNESSES WHO APPEARED BEFORE THE COMMITTEE AT PUBLIC HEARINGS

Monday, 8 November 2010
Parliament House, Canberra

Committee Members in attendance

Senator Rachel Siewert (Chair)
Senator Sue Boyce
Senator Mark Furner

Witnesses

National Disability Services

BAKER, Dr Ken, Chief Executive

Department of Families, Housing, Community Services and Indigenous Affairs

BEDFORD, Ms Helen, Branch Manager, Disability and Carers Policy,
ROSE, Ms Sharon, Acting Group Manager, Disability and Carers
WALSH, Ms Donna, Assistant Section Manager, Disability and Carers Payments
WINKLER, Ms Deborah, Mental Health and Autism Branch Manager

DAINTON, Miss Amelia, Private capacity

DAINTON, Mr Ben, Private capacity

DAINTON, Mr Bruce James, Private capacity

DAINTON, Mr Edgar John (John), Private capacity

DAINTON, Mr Mark, Private capacity

DAINTON, Mrs Rae, Private capacity

Government and Sector Relations, Bedford Group

FARROW, Mr Phillip John, General Manager

HECKENDORF, Mr David, Private capacity

Carers Australia

HUGHES, Mrs Joan, Chief Executive Officer
WALKER, Mrs Marita, Chief Executive Officer, Perth Home Care Services Inc

Perth Home Care Services Inc.

YOUNG, Mrs Melissa, Manager, Systems and Business Development

Monday, 29 November 2010
St James Court Conference Centre, Melbourne

Committee Members in attendance

Senator Rachel Siewert (Chair)
Senator Sue Boyce
Senator Carol Brown
Senator Mark Furner

Witnesses

Australian Federation of Disability Organisations

HOBSON, Ms Leah, National Policy Officer

BIGBY, Professor Christine, Private capacity

Women with Disabilities Australia

COOPER, Ms Margaret, Member

Carers Victoria

BAKER, Ms Lesley Joy, Parent Representative
COLLIN, Ms Emma, Executive Manager, Marketing, Strategy and Policy, Education and Research

PIERCE, Ms Gill, Program Manager, Policy and Research

National Ethnic Disability Alliance

KACZOREK, Ms Sibylle, Executive Officer
WILLIAMS, Mrs Christine Anna, Consumer Representative

Scope

HAGILIASSIS, Dr Nick, Acting Head of Research
HEGGIE, Ms Diana, Chief Executive Officer
WILSON, Ms Jacqui, Project Adviser, People and Culture

JacksonRyan Partners

JACKSON, Mr Maxwell John, Partner
RYAN, Ms Margaret Anne, Partner

Life in Supported Accommodation

TREGALE, Mr Anthony David (Tony), Coordinator, Secretary and Public Officer

Tuesday, 30 November 2010
Christie Conference Centres, Sydney

Committee Members in attendance

Senator Rachel Siewert (Chair)
Senator Sue Boyce
Senator Carol Brown

Witnesses

Down Syndrome NSW

CLARKE, Mr Stephen George, Chief Executive Officer
O'CONNOR, Mrs Jill, Information Officer

Life without Barriers

BIRT, Mr Edward Oliver Ross, National Disability Practitioner

Futures Alliance

HAGGETT, Ms Rachael Mary, Parent Advocate
HAYHOE, Ms Nicola, Research Officer
HEWITT, Ms Jo-Anne, Chairperson

Mai-Wel Group

CRAWFORD, Mrs Lucy, Executive Manager
HASKAL, Mrs Margaret, Executive Manager

McCall Gardens Community Ltd

BLASZCZYK, Mr Michael John, Chief Executive Officer

People with a Disability Australia

BARNES, Ms Sue, Manager, Individual Advocacy
BLEASDALE, Mr Michael Peter, Executive Director, Leadership Team

Family Advocacy

EPSTEIN-FRISCH, Ms Belinda Ruth, Systemic Advocate

Dare to Care

BELLCHAMBERS, Mrs Joyce, Secretary

NSW Department of Human Services

McALPINE, Ms Ethel, Deputy Director-General, Ageing, Disability and Home Care Agency

PATH – Penrith Association for People with Disabilities, their Carers, Families and Friends

CRADDOCK, Mrs Marie, Manager
NOLAN, Ms Joan Estelle, Member, Management Committee

UnitingCare Ageing NSW ACT

McNAMARA, Mr Edward, Manager, Planning and Government Relations

Wednesday, 1 December 2010
Burke and Wills Hotel, Toowoomba

Committee Members in attendance

Senator Rachel Siewert (Chair)
Senator Clare Moore (Deputy Chair)
Senator Sue Boyce

Witnesses

Endeavour Foundation

ROWE, Mr Geoffrey Francis, General Manager, Policy Research, Planning and Strategy

Mr Mike Horan MP, Member for Toowoomba South, Queensland Parliament

Pave the Way, Mamre Association

RAJU, Mrs Catherine Patricia, Manager
WARD, Mr Jeremy, Consultant

Mrs Fay and Mr Peter Mckenzie, Private Capacity

Toowoomba Intellectual Disability Support Association

LANIGAN, Mr Anthony John, President

Breakaway Toowoomba

DEVINE, Mr Paul, Chairperson

Alzheimer's Association

SLOMAN, Mrs Rosemary Joan, Volunteer and Carer

Warwick and District Disability Support Group

STACY, Mr Peter Brian, Chairman

BEAZLEY, Mrs Anita, Private capacity

COOMBES, Miss Carol, Private capacity

COOMBES, Mrs Darcy, Private capacity

DIETZ, Mrs Pattie, Private capacity

GERRARD, Mrs Annette, Private capacity

MORRIS, Ms Karin, Private capacity

PESCH, Mrs Donatella, Private capacity

WALLACE, Ms Veronica, Private capacity

WEIR, Mr Robert Arthur, Private capacity

WILSON, Mrs Pamela Jean, Private capacity

Friday, 18 February 2011
Parliament House, Canberra

Committee Members in attendance

Senator Rachel Siewert (Chair)
Senator Sue Boyce

Witnesses

Mental Health Council of Australia

ROSIE, Ms Linda, Manager, Carer Engagement Project
TATZ, Mr Simon, Director of Communications and Marketing

Vision Australia

AH TONG-PEREIRA, Mr Brandon, Policy Officer

Department of Families, Housing, Community Services and Indigenous Affairs

BEDFORD, Ms Helen, Branch Head, Disability and Carers Policy
HARTLAND, Dr Nick, Group Manager, Disability and Carers Group
HARTLAND, Dr Nick, Group Manager, Disability and Carers Group

Department of Health and Ageing

BALMANNO, Ms Rachel Ann, Assistant Secretary, Home and Community Care Reform Branch
MACKEY, Mrs Tracy, Assistant Secretary, Community Programs and Carers Branch
SMITH, Mrs Carolyn, First Assistant Secretary, Ageing and Aged Care Division

Western Australian Aboriginal Educational and Training Council

ALBERT, Mr Stephen Michael, West Kimberley Member

Disability Services Commission, Western Australia

CHALMERS, Dr Ron, Director General

Planned Individual Networks

HITT, Mrs Lorraine Margaret, Chairperson