



Productivity Commission Inquiry into Caring for Older Australians

NDS Submission

The disability service system is failing many older people with disability. It is under-resourced, inequitable, crisis-driven and difficult to navigate. It has problematic interfaces with allied service systems such as aged care, health and palliative care. It is a system in need of overhaul.

The impact of these problems is to reduce the quality of life of people who are ageing with disability and their families and carers and increase the uncertainty, anxiety and frustration they experience. The long-term solution lies in major system reform based on the principles of entitlement, sustainability, equity and choice. NDS believes this is best achieved by the establishment of a national disability insurance scheme which would guarantee long-term care and support for people with disability, an investment in early intervention, a commitment to planning and equitable access to services across Australia.

But this solution, even if agreed by governments, would not be implemented quickly and would not, therefore, be available to respond to the service difficulties currently experienced by older Australians with disability. The special needs of this group must be considered within the negotiations on the National Health and Hospitals Network Agreement and appropriate responses be implemented.

Introduction

In 2007–08, 11,845 (4.8 per cent) of the 245,746 users of CSTDA-funded services were aged 65 years or over.¹ Apart from people with sensory disabilities, this current cohort of people with disability who are ageing is the first to have survived into 'old age' in significant numbers since data have been collected. Greater longevity of people with severe disability will see this figure grow markedly over coming decades.

Generally, the prevalence of disability increases with age. The average male (in 2003) can expect to experience 18.6 years of life with a disability (5.4 of which are

¹ Australian Institute of Health and Welfare 2007, *Disability Support Services 2007-08*, Canberra: AIHW, Table 2.4, p. 17.

expected years of life with a severe or profound disability). Females can expect 20.7 years of life with a disability (8.3 years with a severe or profound disability).² Indeed, in 2010 an estimated 705,200 people aged 65 and over live with severe or profound core activity limitation and this figure will more than double over the next two decades.³ Of these, some will have lived with severe disability since their early years, others will have acquired disability as a result of ageing.

Sensory impairment is a significant contributor to age-related disability. AIHW estimates that 728,300 Australians have a sensory or speech disability. Thirty four per cent of this group have sensory or speech disability as their primary disability⁴. Much smaller numbers, however, are evident in service usage figures. In 2007–08, fewer than 1450 people with deaf-blindness, 20,300 people with vision impairment and 14,000 people with hearing impairment received services from CSTDA-funded disability support providers.

Characteristics of CSTDA-funded service users ⁵			
	Deafblind	Vision	Hearing
Primary disability	529	7,516	5,793
Other significant disability	913	12,765	8,132
Total	1442	20,281	13,925

Both vision impairment and deafness increase with ageing. This Inquiry needs to consider both those with sensory impairment who are ageing, and older Australians who acquire an age-related sensory loss. The service responses required will not be identical. Indeed, it is important to note that the support needs of people who are ageing with disability are often different from the support needs of people who acquire disability as a result of ageing. Some older people who have a disability will best be supported by disability services, some by aged and community care services, and a significant number by a combination of both disability and aged and community care services.

The correlation between ageing and disability highlights the need for the interfaces between disability services and health, allied health and aged care services to be workable for older Australians with disability. Supporting people ageing with a disability requires cooperative action across governments and across departments because administrative responsibility for aged care and disability services is split. The National Health and Hospitals Network Agreement provides the framework for negotiating these arrangements.

² AIHW 2006, *Life expectancy and disability in Australia 1988-200*.

³ AIHW 2008, *Australia's Welfare 2009*, Table A4.2.

⁴ Australian Institute of Health and Welfare (2009). *Australia's Welfare 2009*. Canberra: Commonwealth of Australia.

⁵ Australian Institute of Health and Welfare (2009) *Disability support services 2007–08: national data on services provided under the Commonwealth State/Territory Disability Agreement*. Disability series. Cat. no. DIS 56. Canberra: AIHW.

Within employment, the ageing of supported employees poses new challenges. The 2007 Disability Services Census⁶ showed that of supported employees, 47 per cent are aged 40 or older (38 per cent in open employment). Two hundred and seventy-seven were aged over 65 years. Figures from yet-to-be-released research⁷ indicate that the proportion of supported employees aged over 50 will increase from 21 per cent to almost 50 per cent in just 15 years⁸. Of particular concern are the growing numbers of people with disability whose productivity is diminishing and who would like to retire from work, but cannot do so because they are unable to access appropriate non-vocational support services.

While this submission will focus primarily on the needs of people who have acquired a long-term disability at a younger age, there are a growing number of people acquiring a disability after the age of 65 years who would benefit from the services provided by the specialist disability sector. People should be able to access the most appropriate support from the most appropriate provider, regardless of whether that provider is part of the aged care sector or the disability sector. At present, that is often not the case.

Background

The problems that arise for people with disability who are ageing are not new and over the past decade have been discussed in numerous reports. In 2000, the AIHW report, *Disability and Ageing*⁹, identified the following groups as being at risk of not being able to access appropriate services:

- people with an early onset disability who have fewer basic living skills and so need higher levels of assistance in these areas as they age;
- people ageing with disability acquired during adulthood and have increasing support needs as they age;
- some people ageing with an intellectual disability may acquire dementia and/or may become frail and need increasing health and medical care;
- people retiring from Commonwealth-funded employment services; and
- people accessing CSTDA accommodation support who desire more flexible 'retirement' services.

Since this report was published, little progress has been made. CSTDA¹⁰ bilateral agreements specifically identified the need to improve linkages between aged care and disability services, yet these linkages remain poor. A 2005 Senate Inquiry into aged care recommended:

that, in supporting the approach in *The Way Forward* for implementing a more streamlined and coordinated community care system, the Commonwealth

⁶ FaHCSIA *Australian Government Disability Services Census 2007*, Table 2A, p120.

⁷ Research undertaken by the Social Policy Research Centre, University of Sydney; preliminary findings presented at the 2009 NDS Employment Forum.

⁸ FaHCSIA, figures provided to SPRC for the Retirement Research Study, from FOFMS 2009.

⁹ Australian Institute of Health and Welfare (AIHW) 2000. *Disability and ageing: Australian population patterns and implications*. AIHW cat. no. DIS 19. Canberra: AIHW, p. xxi.

¹⁰ The CSTDA has now been replaced by the National Disability Agreement

address the need for improved service linkages between aged care and disability services.¹¹

This need for improved service linkages was echoed in the research on ageing and disability commissioned by the National Disability Administrators¹², and again in the 2007 AIHW report, *Current and future demand for specialist disability services*:

The interface between the disability and aged care sectors is of particular pertinence for people ageing with early onset disability. For these people the ageing process often begins at earlier ages than for the general population, and they are likely to have both ageing-related and disability-related needs.

...

There are also interface issues for younger people with disabilities, both in terms of their ability to appropriately access services funded under the aged care sector, and their possible inappropriate placement in residential aged care in the absence of more age-appropriate accommodation and support.¹³

Although both the aged care and disability service sectors provide some similar services, there are important differences. Nursing and allied health services are more commonly part of the aged care sector and tend to become increasingly important as people age; disability services tend to have a greater focus on community access and participation. As people with disability age, they are increasingly likely to require services from both sectors.

An important aspect of this Inquiry is that it can consider the needs of unpaid carers—in particular the parents—on whom many people with lifelong disabilities rely. These carers are also growing old, with their capacity to provide care for their sons and daughters diminishing as a consequence.

Many families want to continue providing support to their adult son or daughter with disability but need assistance. Between 2000 and 2002, the Australian Government allocated funds to address the ‘unmet need’ for disability services. An AIHW report¹⁴ indicated that the funding had a broadly positive effect on meeting some of the known service gaps, particularly in accommodation support and respite assistance. It, however, identified a number of concerns for older carers:

- the need for ‘handing over’ options—substantial care packages and a range of accommodation and support options are required to assist older carers withdraw from the primary care role;
- their guilt about abandonment and their concern about ‘when can I retire’ and ‘what will happen if I die?’; and
- the need for flexible consumer and carer driven services and supports.

¹¹ Senate Community Affairs Committee, June 2005, *Quality and Equity in Aged Care*, Canberra.

¹² Fyffe C, Bigby C & McCubbery J, 2006, *Exploration of the population of people with disabilities who are ageing, their changing needs and the capacity of the disability and aged care sectors to support them to age positively*, National Disability Administrators.

¹³ AIHW 2007, *Current and future demand for specialist disability services*, pp 96 & 99.

¹⁴ AIHW 2002, *Unmet needs for disability services; effectiveness of funding and remaining shortfall*, AIHW, Canberra.

The report noted that the funds were primarily used to respond to crisis situations; future planning was a low priority. This suggests that targeted initiatives are required to encourage and support carers to undertake planning for the future accommodation and support needs of their adult son or daughter.

Of concern is the fact that we have only limited information about the size of this future need for more intensive support services. It's likely that official waiting lists significantly under-estimate the future need for services. In 2004, the multi-service provider Scope Victoria surveyed 257 carers whose sons and daughters received support from Scope. The carers were typical of carers more broadly, except that an unusually high proportion was caring for sons or daughters with very high support needs. The average age of the Scope sample was 58 years and most experienced 'fair' to 'low' health. Half, moreover, were sole carers.

Given these factors, it is unsurprising that the carers anticipated a substantial increase in their need for support services over the next five years. Their anticipated need for in-home respite, for example, was double their present allocation. The anticipated need for their son or daughter to have accommodation support away from home (36 per cent) was almost nine times greater than their current need. Anticipated demand for holiday support was seven times higher than the proportion receiving that form of support now. Only 14 per cent of primary carers reported receiving therapy now, but 21 per cent believed it would be needed in five years.

Yet, although the survey respondents had been caring for a son or daughter with a disability for typically more than 20 years, only half had even heard of the Services Needs Register, Victoria's then official waiting list for disability services, and fewer had registered their needs on the Register. Most over-estimated their capacity to care far into the future.

For many carers of people with disability, the most important recognition of their role and contribution will come from acknowledgement that the care role is not theirs alone—they want to be informed about options and assured that access to formal support services for the person they care for will be available when required. They need information and assistance to plan for the future, including access to financial planning, guardianship and legal advice services. They also need access to the levels and types of support services that are sufficient to meet their needs, including easy access to respite services. And they need assurance that should there come a time when they require additional assistance, or find themselves unable to continue to provide everyday care, additional supports will be available for them and their son or daughter.

National Health and Hospitals Network Agreement

The National Health and Hospitals Network Agreement, signed in April 2010, has implications for people ageing with disability as it gives the Commonwealth full funding and policy responsibility for aged care (with the exception of Victoria and with negotiations still continuing with Western Australia).

The reform will involve a transfer to the Commonwealth of current resourcing for aged care services from the HACC program. These changes will be implemented from 30 June 2011.

The Agreement states that the Commonwealth will assume:

- funding and program responsibility for basic community care services for people 65 years and over (50 years and over for Indigenous Australians); and
- funding responsibility for specialist disability services delivered under the NDA [National Disability Agreement] for people aged 65 years and over.

And that the states and territories will assume:

- funding and program responsibility for basic community care services for people under the age of 65 years; and
- funding responsibility for packaged community care and residential aged care delivered through the Commonwealth aged care program to people under the age of 65 years.

The NDA will be amended to include coverage of these former HACC services for people under the age of 65 years. Current arrangements for access to disability services under the NDA for people 65 years and over will remain unchanged. Current arrangements for access to Commonwealth aged care services for people under 65 will also remain unchanged.

The Commonwealth and state and territory governments will share program responsibility for community care and residential care services for Indigenous Australians aged 50 to 64 years (they will be able to receive services from an appropriate provider under programs of either level of government). The Commonwealth will, however, meet the cost of service.

Implementation of this reform will need to be carefully managed. Appropriate arrangements for existing HACC service users aged under 65 years need to be agreed and responses developed for new users (under 65) seeking supports currently available through the HACC program (such as domestic assistance and meals) but not generally available through disability services.

Also required is a commitment from all jurisdictions to support ageing in place for all older people with disability who wish to remain living in their home, including a group home. This will require developing processes to provide additional supports for ageing people with disability who require them. Admission to residential aged care should only occur when it is the most appropriate response; it must never be a means to reduce the costs of care or to 'free up' a place in a disability group home.

NDS is also keen that consideration be given to identifying the opportunities the new arrangements may offer to improve the supports available to this 'special needs group' of older Australians.

Victoria has so far elected to remain outside the reforms to the provision of aged care. Specific issues that exist within that State - particularly with the provision of HACC services to older people with disability - are not addressed in this submission, but clearly need attention.

Barriers to appropriate support for people ageing with disability

The barriers that hinder or prevent people ageing with disability receiving good support services are multiple, diverse and complex. The Commonwealth-funded aged care system and state-funded disability systems have different philosophies, assessment tools and service planning mechanisms which lead to difficulties for clients or service providers trying to navigate the systems. Obtaining the assistive technology to maximise mobility, communication and independence is restricted, sometimes expensive, and long waiting lists generally exist. Access to health, health screening and promotion activities is often less than optimal (invitations to participate in health screening programs are frequently linked to the electoral roll but some people with disability do not vote); obtaining greater assistance when ageing increases support needs is difficult to obtain; and seeking the state-funded support required to enable retirement from work is elusive.

In 2008, research undertaken by Verso Consulting (for NDS Victoria)¹⁵ identified a range of barriers that operate to reduce the likelihood that people with disability will be well supported as they age. These were grouped into categories:

- policy (e.g. community aged care packages not being available to group home residents);
- program (how things work on the ground as a result of program guidelines and management);
- practice (e.g. gaining access to an aged care assessment services particularly if aged less than 65 years);
- personnel (e.g. staff skills and levels of staffing);
- personal (e.g. the availability of informal supports or income level); and
- place (e.g. variable access to services for people living in different accommodation types).

This submission focuses primarily on the policy barriers that prevent older people with disability from receiving the supports they need. But these barriers are not the only reason people receive variable responses to similar needs. Problems also exist at the level of service delivery which results in older people with disability not receiving the support they require. Responding to these is important and challenging.

¹⁵ NDS Victoria 2009, *Interface barriers: Impediments to 'ageing in place' for Victorians with a disability Stage 1 report*, p. 45-6.

Barriers to older carers receiving good support

Carers and carers' experiences are diverse—in cultural and language backgrounds; current engagement with services and supports; health status; levels of interdependence; and available informal support. Some are well connected with carer services and/or the disability services sector but others are not. Research undertaken for England's *Valuing People*¹⁶ initiative, a program aimed at supporting older carers of people with learning disabilities, found that about 25 per cent of people with learning difficulties only become known to agencies when their older family carer was unable to continue to care.

Reaching carers of people ageing with disability who could benefit from information and assistance is, therefore, a challenge. In Australia, Indigenous families and families from CALD backgrounds are likely to be over-represented in this group.

A key challenge is the provision of support that is flexible and that respects the needs and interests of both carers and people with disability. Carers Australia, in a submission to the Australian Government stated:

It comes down to the capacity of our society to provide real choices about how the caring is best shared by families, formal services and other informal community support networks. It requires policy makers to think through the full spectrum of supports needed—income support, taxation incentives, superannuation, health and community care services, disability services, mental health services, carer specific support services, housing and accommodation and so on. The policy choices we make in one area can inadvertently devalue caring. Equally, other policy choices can value caring but limit people's access to work, education and leisure.¹⁷

Over recent years, the growth in the provision of respite services - designed primarily to support carers in their role - has been very substantial. It's time to clarify respite's role in the lives of adults with disability, particularly how it integrates with broader community and disability services, and how it is delivered.

Primarily, respite services should be widely available to meet the irregular, unplanned, intermittent, short-term and emergency needs of carers. The services should be flexible and responsive to meet the needs of carers. The nature of the respite service (the activities involved) should meet the needs and interests of the person with disability.

Respite services perform a key role in the support system but rarely stand alone. They should be underpinned by adequate levels of regular and planned support services. These services enable the person with disability to have the support they require when they require it, and provide carers with regular times when they are not actively engaged in their caring role.

¹⁶ Department of Health 2001, *Valuing People*, Department of Health, London. Available at www.valuingpeople.gov.uk

¹⁷ Carers Australia 2008, *Submission to the House of Representatives Inquiry into Better Support for Carers*, Carers Australia, Canberra, p. 31.

NDS believes that support for carers would be improved by simplifying access to information and planning services, by increasing the availability of disability support services for their adult son or daughter with disability, and streamlining access to respite services.

Informing the National Health and Hospitals Network Agreement

While using an arbitrary age (65 years) to divide responsibilities between disability and ageing in the National Health and Hospitals Network Agreement concerns some providers of disability services, it does provide an opportunity to re-negotiate the frequently ad hoc and unsatisfactory arrangements that have existed for supporting people ageing with disability. To inform these negotiations, NDS makes the following recommendations:

- **In the design of new arrangements for the funding and program responsibilities for aged care services, support older people with disability to ‘age in place’**

‘Ageing in place’, with its emphasis on keeping elderly and frail people in their home or family setting as long as they desire, has become a central tenet of successive Australian and State/Territory Governments’ aged care (and healthy ageing) policies. This principle is supported by the growing proportion of aged care funding that is directed to community-based care services.

In recent years, numerous reports have identified barriers to ageing in place as a problem for older people with disability. The 2005 Senate report into aged care recommended improved ‘access by people ageing with disability to appropriate aged care, including provision in supported accommodation’. This sentiment was echoed in the 2007 Senate report on the ‘Funding and operation of the Commonwealth State/Territory Disability Agreement’:

As a growing number of people with disability are living longer, the principle of ‘ageing in place’ should apply to the disability community, just as it does to the general community, so that people with disability are encouraged to age in place and, where they choose to do so, are able to access appropriate support services.¹⁸

The regular references to the need to extend the concept of ageing in place to include people ageing with a disability indicate that it is time to act. People with disability should have the right to age in place, with appropriate supports, wherever they live. Being in receipt of disability support services must not exclude them from access to appropriate aged care services.

¹⁸ Senate of Australia 2007, *Funding and operation of the Commonwealth State/Territory Disability Agreement*, Canberra, p. 117.

This issue becomes particularly pertinent when the costs of supporting a person with disability in their everyday life are considered. The cost of supporting a person with severe disability is frequently much higher than the cost of supporting an older person to remain living at home or in residential aged care. And that is before there is any escalation in costs associated with increased support needs as the result of ageing. New program arrangements to implement the National Health and Hospitals Network Agreement must be designed in such a way that cost pressures are not an impetus to move older people with disability from community living arrangements to residential aged care.

The 2007 election commitment (subsequently incorporated into the national Disability Agreement) to make available Community Aged Care Packages to people living in group homes, while not yet implemented, establishes an important principle for people ageing with disability: it acknowledges that aged care programs should be available to people with disability who find their support needs increasing as they age. The focus should not be on their living arrangements but on their support needs.

Ageing in place should be a real option for all older Australians, including for people with disability. Personal choice about where a person lives should be respected.

- **Provide supported accommodation residents with improved access to Commonwealth-funded community care services, such as community nursing, health promotions and screening, palliative care, dementia support and allied services, to enable them to age in place**

Unfortunately, many of the services available to support ageing in place are denied to people ageing with a disability who receive a State-funded disability service. At present, some group home (supported accommodation) residents are denied community nursing, palliative care, dementia support and allied services, because these services are administered by different levels of government. Effectively these people are denied the right to 'age in place', a right that the broader community expects.

- **Implement appropriate responses to changing support needs**

As people with disability age their support needs often increase. Current responses by state and territory governments to these changing needs are inadequate. All governments (including the Commonwealth when it takes responsibility for funding services provided to people with disability aged over 65 years) must put in place processes that allow the support arrangements for people with disability to be re-assessed and adjusted as required (regardless of the person's age).

For older people with disability—particularly those living in supported accommodation—this will mean providing a mechanism to allow for an increase in support beyond the levels provided by current disability-funded services. Where an individual is under 65 years this would be funded by state or territory governments, and when 65 and over by the Commonwealth.

Currently, Aged Care Assessment Teams are the gateway to aged care services but extensive anecdotal evidence suggests these teams frequently struggle with

providing adequate assessment of the needs of older people with disability. Indeed, it is not infrequent that NDS hears reports that older people with disability are refused assessment.

Improved assessment protocols for people aging with disability need to be negotiated as a component of the implementation of the National Health and Hospitals Network Agreement reforms.

➤ **Recognise people with disability as a ‘special needs’ group in aged and community care policies**

The Aged Care Act 1997 states that it aims “to facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstance or geographic location’ and ‘to promote ageing in place through the linking of care and support services to the places where older people prefer to live.”¹⁹

To assist in achieving this, the Act (Section 11-3) defines some groups within the population as ‘people with special needs’, namely, people from Aboriginal and Torres Strait Islander communities; people from non-English speaking backgrounds; people in rural and remote locations; people who are financially or socially disadvantaged; and people of a kind (if any) specified in the Allocation Principles.

The Minister for Ageing is required to take account of ‘people with special needs’ in making decisions about planning and the allocation of aged care places.

NDS proposes that the Australian Government amend the Act to include people with disability on the list of ‘people with special needs’. This would facilitate access to appropriate aged care services for people with disability while providing the Government with a mechanism to manage the allocation of places to this group.

The needs of people with disability who are ageing are generally different and more complex than those of the general ageing population. These need to be addressed, either through adding ‘people with disability’ to the list of ‘people with special needs’ in the Aged Care Act 1997 or through the explicit articulation of the special characteristics of this group in the policies and guidelines developed to support the implementation of the National Health and Hospital Network Agreement.

➤ **Provide older Australians with improved access to specialist disability services where appropriate**

The skills best suited to supporting an older person with disability may be sourced from the aged care sector, the disability sector or possibly from both. New service arrangements must recognise this fact and allow services to be sourced from the organisation/s best placed to provide them.

¹⁹ Commonwealth of Australia 2004, *Aged Care Act 1997*, Canberra, pp. 3–4.

- **Expand the Council of Australian Governments' initiative to reduce the number of young people in residential aged care to include people under 65 years**

The COAG initiative to reduce the number of younger people living in residential aged care is targeted at people aged under 50 years. This should be extended, with increased funding, to cover all people under 65 years (bringing it in line with the National Health and Hospitals Network Agreement).

Additional recommendations for Improving services for older people with disability

- **Address the unmet need for disability support services by implementing a national disability insurance scheme**

The current inadequate provision of support for people with disability is unwarranted in a developed nation; significant additional investment into disability support services is urgently needed. An increase in the availability of planned and regular community participation services, leisure and recreation services and employment support would reduce the participation barriers that both adults with disability and carers face.

NDS is pleased the Productivity Commission has been given the task of undertaking an inquiry into a national long-term care and support scheme for people with disability. A no-fault social insurance scheme is needed to replace the current lottery in which many Australians with disability cannot get the support services they need. This problem will intensify as demand for services rises, unless there is systemic reform and increased investment in service provision.

It is imperative that governments—Commonwealth, State and Territory—agree on a funding mechanism that guarantees lifetime support and care for people with disability who require it. That would also go a long way towards providing family carers with the assurance and support they deserve.

- **Promote universal design principles and expand the availability of assistive technology**

Despite decades of discussions about the need to improve access to the built environment for people with disability, progress has been limited. Poor access to and around many public buildings and spaces continues to be a barrier to community participation, as is the restricted availability of accessible public transport and affordable specialised transport. As the prevalence of disability will increase with the ageing of Australia's population, reducing these barriers must be a priority.

Physical restrictions to accessing or moving around venues, however, are only part of the problem. The absence of adaptive practices or technologies—such as hearing loops, captioning, audio description, Braille and large print signage—limits participation by many older people with sensory loss.

The promotion of universal design principles for private housing, equipment and goods has received limited attention by governments, architects and designers. Improvements in these areas would be of enormous benefit to millions of older Australians.

Improving access to specialised equipment or assistive technology is also long overdue. At least two million Australians with disability rely on assistive technology (specialist equipment or aids) to help them manage with their daily life; this number will dramatically increase. In many cases, access to appropriate equipment and technology reduces the need for more expensive personal support services. All people with disability, regardless of age, should be provided with the assistive technology they require.

➤ **Provide retirement options for people supported by disability employment services**

Unmet demand for disability services exists at both ends of the working life. Most supported employees who are ageing have nowhere to go if they retire; and not enough school-leavers and young adults in post-school programs have access to disability employment services. Providing retirement options (in cooperation with state and territory governments) would not only assist ageing employees, it would create employment places for young people with disability who wish to enter the workforce.

Case management services will be required to assist retirement planning for many supported employees.

➤ **Improve access to adequate levels of irregular and flexible support services (often provided through respite services)**

Respite is regularly identified as an important support service for carers; its availability to meet the irregular, unplanned, intermittent or emergency needs of carers should be strengthened. Increasing the provision of regular disability support services will assist, as respite will be less likely to be used to meet gaps in disability service provision and will be more available to be used for the 'short-term and time-limited break' for which it was primarily designed.

Access to respite services should, however, be streamlined and simplified. Carers should have clear information about how to access a simple process that will quickly enable them to receive the flexible and responsive support they need.

➤ **Ensure respite services are delivered in a manner that supports the needs and interests of the adult with disability**

While respite services are primarily provided as a support for carers, they should also be delivered in a manner which supports the interests and wishes of the person with disability. This approach is supported by Carers Australia:

In arguing the rights and opportunities that should be available to carers, it is critical to recognise that people with disabilities, older people and people with mental health conditions have a right to equal opportunities and choice in their

lives. While this is not necessarily at odds with family care, the goals that people needing support have for independence, integration and inclusion need to stand alongside the goals of extending choice and opportunities to carers.²⁰

Respite services must have a dual focus; the needs of the carer and the person with disability are equally important. Future tenders and service agreements for the provision of respite services for carers of people with disability should be explicit about this expectation.

➤ **Strengthen common training elements between the aged care and disability service workforces**

The growing number of people with disability who are ageing will increase pressures on the community services workforce. Disability sector workers will need to become more skilled at supporting people who are ageing; aged care workers will need to become more skilled at supporting people with significant disabilities (particularly those disabilities of a long-term nature). Greater sharing of knowledge and skills across the sectors should be facilitated.

Improving support for older carers of people with disability

➤ **Improve access to future planning services**

Major barriers to planning are the lack of entitlement to services, the complexity of the service system and the poorly articulated pathways between allied service systems. People with disability are living longer, creating a pressing need for families to consider future support arrangements for their family member with disability. Older carers, in particular, need support to undertake this future planning task—involving legal, financial, housing and support, and guardianship decisions—which can be emotionally difficult and administratively complex.

While the booklet developed by the Department of Families, Housing, Community Services and Indigenous Affairs, *Planning for the future: people with disability*, provides useful advice to assist families make arrangements, some require additional informed support and have difficulty in identifying such assistance.

The historical practice of primarily directing government funds in response to crisis situations fails to give due recognition to the need for future planning. Older carers need:

- encouragement and support to undertake future planning;
- handing-over options: that is, substantial care packages and a range of accommodation and support options to assist them to withdraw from their primary care role;
- flexible consumer and carer-driven services and supports; and
- access to (episodic) case management services when necessary.

²⁰ Carers Australia 2008, op. cit., p. 28.

The key elements of any future planning initiatives ought to include:

- a dual focus that ensures the needs and desires of the person with disability, as well as those of the carers and other family members, are included in planning processes;
- engagement with the service system; and
- both future and emergency planning.

As the key aim of future planning is often to facilitate transition to alternative accommodation and support arrangements when the person with disability is no longer able to live with the family, it is important to encourage early engagement with the disability service system that will ultimately have a role in providing support.

Some carers, particularly those who have not used the service system, will need to establish confidence in the ability of services to provide quality support for their family members. They may require time to build this trust. Consideration should be given gradually to building the range of services accessed by the person with disability, including:

- in-home support;
- community access and participation (which may include transport assistance);
- day programs;
- leisure and holiday services; and
- respite.

Planning should also consider options that would be available for the provision of emergency care, whether it is for a temporary period until the family can return to usual support arrangements or an interim period while alternative arrangements are sought.

Affordable access to financial, legal and guardianship advice must be part of the future planning services. Case management, particularly to assist during times of transition, should also be available.

➤ **Increase the availability of specialised planning services for older people with disability**

Individualised or person-centred planning has gained acceptance as an important service in the lives of some people with disability, but warrants further expansion and development. Sanderson describes person-centred planning as:

a process of continual listening, and learning; focused on what is important to someone now, and for the future; the acting upon this in alliance with their family and friends...the person will be at the center, working in partnership with family and friends, the plan will clearly identify what the person's capacities are, what is important to her, and what support she requires; there

will be actions that have a bias towards inclusion, and the learning and reflecting are ongoing.²¹

Such an approach ensures that individuality takes precedence and encourages support arrangements to be tailored to fit the individual, rather than trying to fit a person into pre-defined compartments. It is a critical component of assisting a supported employee to retire from work.

Individualised planning, with its requirement for continual review, also provides a mechanism for identifying the changing support needs and interests of the adult with disability. This process—done well—also identifies the supports which are available from disability and community services, and from carers. It can identify flexible partnership arrangements for supporting the person with disability to live within the community and help deliver good outcomes for all partners.

➤ **Improve the structure of special disability trusts to increase their uptake**

While NDS acknowledges the efforts that have been made to assist families make future provision for their son or daughter through the establishment of special disability trusts (SDTs), design flaws have limited their take-up.

NDS is pleased that some changes to the structure of these trusts are to be implemented—including the expansion of the definition of a beneficiary to include people with disability who can work up to seven hours a week, and a broadening of allowable uses to include medical expenses, including membership of private health funds, property maintenance and discretionary spending of up to \$10,000 per year.

The Senate Community Affairs Committee Inquiry into Special Disability Trusts was conducted to examine why so few SDTs had been established. The Committee made 13 recommendations; NDS believes implementing more of these recommendations will make SDTs more attractive to people wanting to make private provision for their family member with disability.

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²¹ Sanderson H. 2000, *Person Centred Planning: Key Features and Approaches*, York: Joseph Rowntree Foundation, p. 11 cited in Bigby C. 2004, *Ageing with a Lifelong Disability*, London: Jessica Kingsley Publishers, p. 55.

About National Disability Services

National Disability Services is the peak industry body for non-government disability services. Its purpose is to promote and advance services for people with disability. Its Australia-wide membership includes around 700 non-government organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.