



**Australian Federation of Disability Organisations (AFDO)
Submission to the Senate Community Affairs Inquiry into
Aged Care Reform**

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Introduction

People with disability who are ageing have the same fundamental aspiration as people without disability who are ageing: the desire to remain in their homes and participate in their communities for as long as possible. At present, the system of supports available to older people with disability does not allow for a genuine choice to maintain that autonomy of choice and participation, a fundamental human right protected in a number of United Nations Conventions. In particular, the UN Convention on the Rights of People with Disability (UN CRPD) recognises that people with disability may require different measures to ensure that these fundamental rights to choose where you live, who you live with and how you participate in the community are protected.

There are two key groups of older people with disability who must be considered in the context of aged care reforms. Firstly, there are people who have had a disability prior to ageing and who may need assistance to maintain consistent supports which allow them to age in place and have choice about the time and manner in which they access the aged care system. This group may have specific needs which are not being addressed by the aged care system as it currently exists, such as a requirement for Auslan interpreters for older people who are Deaf, or assistance with managing the effects of a psychosocial disability.

In the future, it is anticipated that this group will be coming from the relatively well funded, consumer focused and entitlement based National Disability Insurance Scheme (NDIS) to the aged care system. The NDIS Bill 2012 says that participants in the NDIS will enter the aged care system from the NDIS when they are permanently using home care or permanently living in an aged care facility. In general, this group will be familiar with what their disability related needs are and how to articulate them, and will increasingly have some experience of control and choice over their supports.

The other cohort is older people who acquire a disability as they age. This group may not identify as 'disabled' and often has limited experience of disability support systems. There are higher rates of a number of disabilities as people age, including physical disabilities and sensory disabilities (SDAC 2009).

Both groups of older people with disability will need a range of supports to access the full spectrum of choice which should be available to all older people, including the right to remain in their own home for as long as possible, and to accept home based care and other ageing specific supports at a time of their choosing.

To maintain and prolong the time an older person is able to remain in their own home requires a consistency of disability supports, so that a change in age or level of disability does not arbitrarily mean less choice. Sometimes providing consistency of outcomes may mean that supports need to be provided by people who have a specialist understanding of the ageing experience of people with disability. For example, a support worker should be able to identify the need to check for dementia signs in an older person with intellectual disability; a Braille teacher working with older people who are losing their vision may need to respond to issues around hand dexterity. Conversely, the aged care sector needs to be 'literate' in the support needs of people with disability, such that there isn't an assumption that disability automatically means certain kinds of support (such as a nursing home) when other, more disability specific options may be appropriate. For example, it would not be acceptable to place a person with a physical disability into a nursing home simply because funding for their wheelchair was inadequate leaving them isolated and at risk of accidents in the home.

Once an older person with disability enters formalised aged care, support requirements may go beyond the need for a physically appropriate environment, with standardised buildings and equipment such as toileting hoists, audio loops and adjustable beds in nursing homes. Of equal importance are the continued provision and maintenance of aids and equipment, such as hearing aids, magnification aids and mobility devices, and the ability for residential aged care staff to respond appropriately to the needs of older people who are acquiring disability as their circumstances change. This means home care and nursing home staff should understand different communication approaches, the proper troubleshooting and maintenance processes for common aids and equipment and how to access further information about specific supports.

At present, anecdotal evidence suggests that older people with disability do not have their needs adequately met along this spectrum of circumstances: they are rarely given the choice to stay at home with supports, and once they enter a formal aged care accommodation system there is an equally limited approach to meeting disability specific needs. People with disability confront a system which does not provide for their specialised support needs, their aids and equipment requirements, and their requirements for appropriate staff training and capacity building.

If the anecdotal evidence suggests that disability specific ageing supports in general are not being provided, then provisions for people experiencing multiple disadvantage are even more limited. Older women with disability are more likely to be in a precarious financial situation because they have forgone full time work in their younger years to raise families, or have had trouble finding flexible work to suit their needs either because of family responsibilities or disability requirements. Women with disability are more highly represented among the 50 – 65 year old age group of Disability Support Pension recipients, making them less likely to have money saved to meet their support needs post 65 or post entering the aged care support system.

People with disability from non English Speaking Backgrounds (NESB) who are ageing may also experience further disadvantage. At present, it is difficult to find support workers who are culturally aware and trained to meet the culture and language requirements necessary for one to one supports. As they age, NESB people with disability are also more likely to lose a range of informal supports as their parents, siblings and partners – who can provide the bulk of support within some cultures – age and pass away themselves.

Appropriately supporting older people with disability to age well and to maintain their independence and participation within society means implementing a human rights based framework for aged care with real consumer choice. In practice, that means providing appropriate consumer information, enabling choice in purchasing support and a universal entitlement to support when it's needed.

What's the current situation for older people with disability?

Older people make up a significant proportion of people with severe or profound activity limitations. As noted above, they are

rarely given a genuine choice about ageing in place and continuing their participation in the community. This is reflected in the statistics available from the Australian Bureau of Statistics, which notes that:

“In 2011, 537,300 older people, 19%, were identified as having a profound or severe disability. Among people in the 65–69 and 70–74 age groups, less than one in ten and around one in ten people respectively reported a profound or severe disability. This increased to 17% for the 75–79 years age group, rising to 68% for the 90 years and over age group, 58% for men and 72% for women. Older women (22%) generally had a higher rate of profound or severe disability than older men (16%).”

Given these rates, older people with disability are strongly over-represented in aged care facilities, nursing homes and hospitals, even as the rates of disability among the general population increase with age. This is especially true for people with severe and profound activity limitations, who are much more likely to be in institutionalised, medicalised accommodation settings than people of the same age with less severe disability or with no disability at all.

Table 1: Percentages of people over 60 with disability by age group, 2009 Survey of Disability, Ageing and Carers

Age group	% with disability
60–64	35.0
65–69	42.2
70–74	48.5
75–79	55.2
80–84	66.6
85–89	80.4
90 and over	90.0

Table 2: SDAC 2009 - Accommodation used by people with disability between 60 and 79 years of age

Accommodation Type	% total population with	% of total population with severe/profound	% of total population with
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	disability	d activity limit	mild/moderate activity limit
Private dwellings	41.7%	10.3%	24.5%
Accommodation for retirees or the aged	60.6%	17.1%	38.4%
Nursing homes or aged care hostels	96.4%	92.6%	3.9%
Hospitals	96.1%	88.4%	7.7%

Table 3: SDAC 2009 - Accommodation used by people with disability over 80 years of age

Accommodation Type	% total population with disability	% of total population with severe/profound activity limit	% of total population with mild/moderate activity limit
Private dwellings	68.2%	30.5%	35%
Accommodation for retirees or the aged	75.9%	44.1%	30.5%
Nursing homes or aged care hostels	96.9%	94.2%	2.6%
Hospitals	100%	96.7%	3.3%

Individualised Supports for people with disability in the aged care system

People with disability who are in the aged care system should have the same right to individualised supports as those who will be participating in the National Disability Insurance Scheme. This will aid the transition of those people with disability who move from one form of support to another, and will promote the right of people with disability of all ages to access their supports with maximum control and choice.

AFDO welcomes the Aged Care Reform's focus on increasing individualised support for older people, and the added focus on providing good information for older people about the supports available to them. Given the high incidence of disability within the population of older people, AFDO is keen to see that the aged care system provides disability specific information and supports, leading to disability specific outcomes through individually directed funding given to older people. This means several key steps will need to be taken:

1. Linkages to the NDIS and other disability specific systems of support

For individualised supports for older people to be successful, some will require disability specific supports or assistance with the transition from the disability support system to individualised aged care supports.

Legislation which addresses information provision and the provision of individualised supports needs to stipulate that these should link effectively with other systems of support, such as the NDIS. 'Effective links' should include:

- Cross pollination of information and referral systems, so that aged care supports are listed in disability referral systems and vice versa;
- Disability specific information should be targeted to older people who may be acquiring disabilities, so that they, and their families and carers, can be proactive in getting access to support;
- Clear agreements across systems of support about funding for transition to aged care, particularly for people with disability who may need physical support to move from their home to a residential aged care facility, support to prepare for a move, or support to plan for using an aged care package of funding;
- Because each system will be engaged in responding to the needs of people over 65 who have disability, information sharing about trends, best practice and outcomes should be compulsory.

2. Allowing disability specific supports to be funded through aged care support packages

For many, disability specific supports end at the age of 65. At present, this is because disability specific funding is often tied to receipt of the Disability Support Pension. For example, a person using an electric wheelchair can get funding under aids and equipment schemes while they are on DSP, but there is no funding available after they are automatically placed on an Aged Pension. Once the NDIS is introduced, people with disability who acquire their disability after the age of 65 and people who are using home and community care or aged care facilities full time will be unable to use the NDIS to get disability supports.

Disability specific supports are often crucial to allowing people with disability to age in place and to maintain their physical, mental and emotional wellbeing. With an electric wheelchair and home and community care, a person with physical disability will be more effectively able to remain at home and be independent. Likewise, a person with intellectual disability who needs support to budget and pay bills should be able to access funding which allows them to continue to age in place even once they are using home and community care on a permanent basis.

In practice, this will mean that:

- a) Assessment for supports should include disability specific assessments where appropriate, which are as consistent with the assessment processes used by NDIS as is practical;
- b) Planning for the future should be undertaken as part of individualised aged care packages. This should include an assessment of any projected disability related needs. For example, if it is expected that a person with glaucoma may need assistance with orientation and mobility in time, this should be planned for.
- c) Funding for aged care supports should reflect disability related needs, including aids and equipment, personal support or interpreters, and therapies. Insofar as possible, the supports provided under the aged care system should be equivalent to those provided to other people who use disability supports, and should be entitlement based. For people transferring from the NDIS, equivalence will be easiest to measure; using consistent assessment tools, assessors with lived experience of disability and/or ageing and a good monitoring and evaluation system will

aid equivalency for those who acquire disability or become frail aged as well as disabled.

3. Mainstreaming disability in aged care as an adjunct to supports

As mentioned earlier, some of the issues faced by people with disability in the aged care system are not about a lack of formal supports, but are related to a lack of appropriate staff training or disability appropriate infrastructure within the aged care sector and the broader community. For a truly seamless approach to disability support, these broader issues also need to be addressed.