

**Australian Federation of Disability Organisations
Submission to the Community Affairs Committee
Inquiry into Planning Options and Services for People
Ageing with a Disability**

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About the Australian Federation of Disability Organisations (AFDO)

The Australian Federation of Disability Organisations (AFDO) has been established as the primary national voice to Government that fully represents the interests of all people with disability across Australia.

The mission of AFDO is to champion the rights of people with disability in Australia and help them participate fully in Australian life.

People with Disability – Rights and Recognition

In 2008, the Australian government ratified the United Nations Convention on the Rights of Persons with Disability (the UN CRPD). Under the UN CRPD, the rights of people with disability are articulated not as ‘new’ human rights, but as reinterpretations of the rights we all hold dear. For example, the right to freedom of movement is inherent for people without disability, and is generally only violated when someone actively breaches it. A person with disability has their right to freedom of movement violated if they cannot access the aids and equipment they need to move freely, such as a wheelchair or a white cane. They also experience violation of their right to freedom of movement if they are locked away against their will or placed in a group home where their bed time is set.

Human rights are critical to all of us. Any discussion of planning for the ageing of people with disability also has to discuss human rights, so that we talk about a system which allows people to live a dignified life of participation in the community, with a right to assume they will experience general good health and safety. Merely making sure that people with disability can ‘fit into’ a rigid system of supports which does not respond to their needs and preferences does not meet the human rights of people with disability.

RECOMMENDATION: That all recommendations from this inquiry be predicated on the notion of human rights rather than cost or systemic efficiencies.

Demographics – Who are People with Disability who are Ageing?

According to the 2003 Survey of Ageing, Disability and Carers¹, rates of disability rise from around 20% among people aged 35-44 to 40% among those who are aged between 55 and 69. The Australian Institute of Health and Welfare² notes that gains in life expectancy have not created an equal experience of disability; women are far more

¹Australian Bureau of Statistics, 2006, *Disability, Ageing and Carers: Summary of Findings:2003*, viewed online at: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features12003?OpenDocument>

² Australian Institute of Health and Welfare, 2008, *Disability in Australia: Trends in Prevalence, Education, Employment and Community Living*, viewed online at: <http://www.aihw.gov.au/publications/index.cfm/title/10495>

likely to live longer with disability than men. Like others in the community, people with disability are from diverse backgrounds: an estimated 37% of people of Aboriginal and Torres Strait Islander heritage experience disability³, and one in every four people with disability are from first or second generation Non-English Speaking Background (NESB)⁴.

People with disability are less likely to be employed and more likely to have low incomes and live in poorer socioeconomic areas when they live in capital cities⁵. In general, people with disability are shifting to a regionalized population, mostly because disability is associated with ageing, and ageing is associated with retirement and less urban lifestyles⁶. While they do not experience 'mainstream' material deprivation, people with disability are less likely to feel socially connected and included⁷. Little work has been done to establish how materially deprived people with disability are of things which are basic necessities to people with disability, such as medications or aids and equipment.

RECOMMENDATION:

As the population of people with disability ages, the particular needs of this population will need to be factored into planning to ensure that:

1. Particular focus is given to women with disability and people with disability living in regional areas, while remaining mindful of the need to provide quality support for people from Non-English Speaking Backgrounds (NESB) and people with disability who have Aboriginal and Torres Strait Islander heritage;

³ Australian Institute of Health and Welfare, 2009, *Introduction to Disability and Disability Services in Australia*, viewed online at: <http://www.aihw.gov.au/disability/natpic/index.cfm>

⁴ National Ethnic Disability Alliance, 2009, *Fact Sheet 1: People from NESB*, viewed online at: http://www.neda.org.au/page/fact_sheets.html

⁵ Australian Institute of Health and Welfare, 2009, *The Geography of Disability and Economic Disadvantage in Australian Capital Cities*, viewed online at: <http://www.aihw.gov.au/publications/index.cfm/title/10703>

⁶ Australian Bureau of Statistics, 2006, *People with a Need for Assistance, 2006 – A Snapshot*, viewed online at: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4445.0Main%20Features12006?opendocument&tabname=Summary&prodno=4445.0&issue=2006&num=&view=>

⁷ Mission Australia, 2007, *Left Out and Missing Out: Disability and Disadvantage*, viewed online at: <http://www.missionaustralia.com.au/downloads/social-policy-reports/189-left-out-and-missing-out-disability-and-disadvantage>

2. Experiences of long-term financial disadvantage are factored into planning; for example, it would not be adequate to use the private health system as a means of widespread service or equipment delivery;

3. People with disability who are socially isolated will require more professional and formalized support arrangements as they age. Some people with disability in this situation may have found themselves receiving formalized support for the better part of a lifetime. These people may feel that they have little or no choice about the type and quality of supports they receive and their ability to participate in the community. Building the capacity of these people with disability as they age is critical.

Income Support

Although income support is not directly related to disability supports, income support often helps to ensure the participation of people with disability within the community. As people with disability age, changes to their financial circumstances can significantly affect their ability to support their own participation in society.

There are currently 720,000 people on Disability Support Pension⁸. As of 2008, 306,331 recipients, or 41.8% of all recipients, were over the age of fifty five. This means a significant number of people with disability will be transferring to the Age Pension in the next decade. With the onset of disability often beginning in this age group, the high ratio of people entering Disability Support Pension then transferring to Age Pension should continue to remain a feature of the income support system.

Transfers between income support payments

The transfer to Age Pension is relatively seamless, although Age Pension recipients do not have access to Pensioner Education Supplement, and may not have access to Mobility Allowance if they are studying rather than working. Consistent education materials and staff training within Centrelink are important to ensure these people understand the changes to their circumstances. Additionally, people on Disability Support Pension – Blind have the choice to remain on that pension after they qualify for Age Pension, or they may shift to Age Pension – Blind. For many, the decision to stay or move is highly dependent on their income, assets and superannuation. Again, clear

⁸ Department of Families, Housing, Community Services and Indigenous Affairs, 2008, *Characteristics of Disability Support Pension Recipients – 2008*, viewed online at:

http://www.fahcsia.gov.au/sa/disability/pubs/policy/DSP_rpt_2008/Pages/default.aspx

information needs to be made available to people with disability as their circumstances change.

With the introduction of the Welfare to Work provisions in 2005, many people with disability who are able to work more than fifteen hours a week are now placed on other payments, such as NewStart or Youth Allowance. These payments are significantly lower in their base rate, offer limited additional benefits and are usually associated with a requirement to look for work. A shift from this type of payment to Age Pension needs to be especially well understood, because the changes are most significant to the wellbeing of the person with disability.

Recommendation: That Centrelink review all information related to income support payments (including staff training practices) to ensure that it meets the needs of people with disability who are ageing.

Changes in income support policies

The planned shift in the age limit for eligibility for Age Pension from 65 to 67 will have a significant impact on the numbers of people with disability applying for Disability Support Pension. At present, the Disability Support Pension requires that a person be unable to work more than 15 hours a week, and that they prove they have made genuine efforts to find employment or re-skill themselves before they can receive Disability Support Pension.

As we know, the numbers of people with disability rises as age rises. Many people in their early to mid 60's will find themselves acquiring a disability, and unable to retrain or find work in their last years of employment. Theoretically, these people may be assessed as capable of working more than fifteen hours per week and placed on other payments such as NewStart. This is deeply concerning because the costs associated with acquiring a disability cannot be adequately covered by the significantly lower payment rate of NewStart. For example, a person requiring a walking frame, medications for arthritis and various small tools to help open jars, cook or open doors may find themselves significantly disadvantaged by a lower payment rate.

In some instances, the costs of disability are covered for Disability Support Pension recipients but not those on allowances such as NewStart. A person who needs to visit an audiologist and receive hearing aids will get free treatment and equipment if they have a Pensioner Concession Card, but will have to pay thousands of dollars if they are on an Allowance rather than a Pension.

Recommendation: The Federal government should examine the interaction between the increased age of eligibility for the Age Pension and the changes to Disability Support Pension eligibility criteria to ensure that they do not adversely

affect people acquiring disability in their early to mid 60's. Information regarding the impact of these policies should be made publicly available.

Transition within Support Systems

Often, people with disability are taken out of the disability support system – including supports for employment, accommodation, recreation and access to disability advocacy services – to be placed in the aged care system, which primarily offers health, accommodation and home care support. This is an artificial distinction for many people with disability, who have often needed ongoing support in terms of accommodation, health care and home assistance. The shift to an aged-care system simply means that staff in aged-care organizations may not understand their needs, especially if those needs are from a disability which is not related to ageing, such as psychosocial disability (sometimes known as mental illness), HIV/AIDS or intellectual disability.

Likewise, people with disability do not stop needing ongoing specialist disability support to access recreation, interpreter services or disability advocacy because they have become older. Access to these supports should continue as a person ages, and staff within these settings should be trained to understand the needs of older people with disability.

Furthermore, some disability types – such as certain kinds of intellectual disability – have a higher risk of early onset of ageing related conditions like dementia. These people may find themselves in a state of limbo in which no disability-specific support and no ageing related service has quite the right mix of skills and supports to assist their participation in society and to maintain their quality of life.

RECOMMENDATION:

That the government recognize that it is fundamental that people with disability have a choice in the supports they receive. No person with disability should be placed in a particular 'box' because they have reached a certain age and it will save the disability system money, cost shifting nor should anyone be kept in the disability system because they are 'too difficult'. Time for planning and access to good information are critical to allowing people with disability to articulate their needs when it comes to transition. The level of flexibility within and between systems needs to be examined in detail, and best practice in respecting and meeting the choices of people with disability should be promoted.

People should be able to age in place.

Creating individual choice

AFDO is a keen proponent of a Disability Inclusion Allowance, a payment directly to a person with disability which allows them to choose which supports they receive and when they receive them. AFDO is advocating for this Allowance as part of the Productivity Commission inquiry into Disability Care and Support, which could see lifetime supports offered to people with disability who acquire a disability before the age of 65.

RECOMMENDATION:

That the Federal government closely examines the interaction between individualized funding such as a Disability Inclusion Allowance and the ability to choose where and how to age. Additionally, this inquiry should keep a watching brief on the work of the Productivity Commission inquiry into a Lifelong Disability Care and Support System.

Participation in the Community

Choice in formal supports

As stated above, people with disability often rely on specialist supports to participate in the community. These supports may include personal attendant care, Auslan interpreters, interpreters for languages other than English, and home help. In many cases, this support is provided informally by family members or friends, and may diminish as a person ages and their supporters also age. The need for professional supporters who understand the needs of older people with disability should be given extensive consideration.

Again, it is vitally important to consider the need for genuine choice among older people with disability, so that they do not simply have access to one level of support or even one source of support workers. Choice should be promoted no matter where a person lives, and whether they have specific needs related to gender, a Non-English Speaking Background (NESB) or Aboriginal and Torres Strait Islander heritage. Any consideration of the development of a workforce to support older people with disability should also consider the development of training and advocacy for older people with disability, who may not be accustomed to more formalized supports if they have been reliant on informal family support for most of their lives.

RECOMMENDATION:

Serious examination of workforce development and training in both the disability support system and the aged care system should be undertaken to ensure that the diverse needs of people with disability will be met in years to come.

RECOMMENDATION:

That training and advocacy programs designed specifically for people with disability who are ageing should be developed and appropriately implemented.

Aids and Equipment

Some people with disability use specialized aids and equipment to ensure their participation in society, such as a dog guide or a communication board. Staff in the aged care sector should be trained in interacting with aids and equipment, and organizational policies and procedures should reflect that they are understood and welcomed.

There are myriad sources of aids and equipment accessed by people with disability. These can include government programs to subsidise part or all of the cost of equipment and home renovations, programs offered by service providers to produce one-off pieces of equipment and hospital programs which offer short or long term loan of medical aids. While this patchwork system requires broader attention than can be offered through this inquiry, it is important that people with disability who are ageing are not:

- a) denied access to disability aids and equipment schemes on the basis of their age;
- b) denied access to disability aids and equipment schemes on the basis of their need to move from one form of accommodation to another.

More generic equipment can also have features which assist access and participation. This includes televisions which are enabled with captions for people who are Deaf or hearing impaired, telephones with large buttons for people with low hand dexterity, and computers which have in-built screen reading software for people who are blind or vision impaired. Because of the high incidence of physical and sensory disability among people who are older, programs and services aimed at older people should be made aware of such equipment, and appropriate purchasing policies should be put in place.

RECOMMENDATION:

Aged care organizations should ensure that all staff are trained to be familiar with, and welcoming of, aids and equipment used by people with disability. In addition, aged care organizations should adopt appropriate purchasing policies to ensure that universally designed equipment (with in built accessibility) is purchased at every opportunity.

RECOMMENDATION:

Government, the disability sector and the ageing sector should work together to ensure that aids and equipment remain accessible and portable as people with disability experience transitions due to ageing.

Housing and accommodation

Young People in Nursing Homes

AFDO notes that the aged care system is already providing inadequate stop-gap solutions for young people who should be in the disability support system. This is particularly the case for young people in nursing homes. While government efforts have focused on young people under the age of 50 to move young people with disability from nursing homes and prevent some others from going into the system, more still needs to be done to remove relatively young people between the ages of 50 and 65 from nursing homes.

RECOMMENDATION:

Government should ensure that all people with disability under the age of 65 are given appropriate alternatives to nursing home accommodation, including a range of options which offer real choice.

Universal Housing Design

Work is currently underway to create a voluntary universal housing design code for the building industry, which could be used to design homes which are accessible to everybody. The introduction of such a code would allow older people with disability to stay at home using less intensive supports for a longer period of time, and would also benefit older people without disability by allowing friends and family continued access to their homes.

People with Disability Living in Supported Accommodation

Many people with disability spend large parts of their lives in supported accommodation services such as group homes or supported individual units. AFDO has grave concerns about the use of large scale institutions, hostels, boarding houses and group homes for people with disability because they promote social exclusion and provide opportunity for abuse and neglect. However, it should be acknowledged that some people with disability may choose to stay in these environments as they age.

RECOMMENDATION:

It is AFDO's firm belief that appropriate encouragement and skills development can assist people in supported accommodation to transition to mainstream aged care accommodation as necessary, and that this should be the first solution tried,

not the last. This should be reflected in both policy and practice across Australia. Choice is paramount, however, and a personal choice to stay in supported accommodation should be respected and upheld by governments and support agencies.