When I’m 65; Can my disability come too?

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Australia has an ageing population. We are living longer than ever before in the history of Australia. This is supported by research which suggests that at 65 years of age, the average male can expect to live until approximately 84, whilst women are living to around 87 years old. AIHW (2009)

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Authored by: PDA ©
Executive Summary

Disability has come a long way from the days of institutions when 1 in 10 persons resided in environments of continued and supervised care, according to The International Year of Disabled Persons, (1981). People with disabilities had few opportunities in the community, no access to the public community, limited education and almost no employment and no individualisation. In other words people with disabilities had no real identity and often lived in isolation from families, friends and neighbours. (Crossley & McDonald, 1980).

In 2012 we are looking at a whole new way of seeing people with disabilities. People who are independent, who live, work and play in the community alongside other Australians, given the opportunities to do so. This is supported by the statement from ‘The Way Forward’ (FaHCSIA 2009) report that also highlights that the frequency of disability in Australia has changed too. Compared to the figure in where 6.8% of Australians were disabled because of musculoskeletal disorders like arthritis and back problems, whilst in 2009 only 6.5% reported such a disability. . It is the 6.5% of Australians with a physical disability that PDA will focus on for this paper.

This research paper explores the issues people with physical disability approaching the age of 65 (traditionally a time of retirement) encounter in the context of enormous change in disability in Australia. Specifically, the impact of physical disability as a person ages, and whether people are going to be generally included in ageing Australia or will they be disregarded, ignored or placed into nursing homes or similar institutions as might have been done in former days as seen in the ‘White Paper: Young People in Nursing Homes’ (2011) p6, which states:

“There are many young Australians stuck in nursing homes. This is a serious social issue, which can – and must – be fixed. An estimated 3300 people under the age of 60 live in nursing homes, which are not suited to their needs.”

“These aged care facilities are not designed or resourced to facilitate the active involvement of young people with high clinical needs in everyday activities or support their continued participation in the life of their community.”

The main question this paper seeks to answer is; what happens to a person with a physical disability turning 65? A population that includes all levels of physical disability, those who are ambulant, wheelchair dependant or use other mobility devices, and irrespective of whether the physical disability is congenital or acquired.

The report identifies what if any, are the implications of moving from one funding system to another, and how is someone who is ageing going to fare under the National Disability Insurance Scheme (NDIS). These and other questions have been heard by PDA throughout the various consultations across Australia for the NDIS. This paper focuses on the current situation and possible cross-over of services, the intersection with health and ageing and whether the existing pathways are streamlined or need more attention and if so what does PDA therefore recommend?

3 Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra.
Recommendations

1. PDA believes that the recommendations from the Commonwealth Carer Strategy six priority areas for action, be also applied to the Ageing of people with disability.

The Strategy recommends the following to underpin all relationships:
- recognition and respect
- information and access
- economic security
- services for carers
- education and training
- Health and wellbeing.

2. PDA believes that awareness and training opportunities must be put in place before the roll out of the NDIS, to enable those who have never managed their own workers or their own funds, to take up the challenge and opportunity as it is meant to empower individuals to manage their own lives.

3. PDA believes that much more information needs to be shared between the disability sector and the aged sector in order to present choices and opportunities for those who will need to make decisions about ageing assistance in the near future.

4. That a formal, streamlined intersection between Disability and Ageing and Health be put in place, to ensure that any benefits or services received are not lost in the transition to the other. Such a formal process could go toward a National Strategy on Ageing with Disability.

5. That Centrelink be the organisation used for assessment of benefits and eligibility purposes for people with disabilities and for seniors. Those who require further assessment at age 65 would be referred to Aged Care Assessment Teams (ACAT) which are mobile services to help people to bridge the access gaps that many face. These teams also would work closely with Centrelink regarding benefit issues. This point of assessment can determine whether a person continues with the NDIS or moves to Aged Services or from one benefit to another.

6. PDA believes that the assessment process used for assessing the needs of the person at age 65 should be consistent with ACAT and DSP assessments and be available through a ‘One Stop’ process including referrals, to eliminate confusion and ease the process as much as possible.

7. That an Information Service for people with disabilities and seniors be established to provide any and all information on disability and on Ageing. This should be a free service to all consumers of information.

8. Aged Care programs to be encouraged to adopt and include more rights based approaches to care in the future, in line with increased access and knowledge of rights and justice as a person with disability ages.
Recommendations continued:

9. Development and inclusion of a Commonwealth Advisory Committee of people including National Aids Equipment Reference Alliance (NAERA) people with disabilities and organisations such as Scope, Council on Ageing, Post-Polio

10. PDA encourages the extension of all disability discrimination issues such as access to public transport, access to public buildings and premises, the right to education and further education, workplace reforms and other similarly important strategies, be extended to include all Australians regardless of age.

11. PDA also supports Human Rights Legislation that stipulates inclusion and bridges the gaps in the DDA deficient frameworks. PDA therefore supports the Human Rights Consultation Committee that recommended Australia adopt a Federal Human Rights Act (2009, p 337).

PDA recommends an Australian Human Rights Act that recognises and fully protects the civil and political rights and that offers a process for engagement by all three branches of government when Parliament legislates to set limits on other civil and political rights should constitute a useful, cost effective means of repairing some of the holes in Australia’s patchwork of rights protection. This would trespass on the domain of state and territory public authorities only when they were performing public functions under Commonwealth Law.” (Human Rights Consultation Committee Report (2009) p377.)
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**Introduction**

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006)\(^4\) and WHO\(^5\) (2002) recognises that disability arises from the interplay between the person (including impairments) and environment (social, cultural and physical). Barriers are defined as an impact on a person as in "hinders...full and effective participation in society on an equal basis with others" Impairments can include "long-term physical, mental, intellectual or sensory impairments" whilst the barriers can be *attitudinal* or *environmental* UNCRPD (2006).

Over the past few years in Australia, there has been much action in the disability sector including the release of a National Disability Strategy across all governments of Australia, also the Productivity Commission consultations, and subsequent reports, individual and collective activism, awareness raising, educating the business sector, governments and the general public, research and reporting, and consultations across Australia.

Most of these actions can be directly attributed to individual and collective action by the disability sector for independence (with some help from other stakeholders such as families, carers, governments, business services, and other sector services) which includes the National Disability Insurance Scheme (NDIS) proposal.

The recent Disability Investment Group (DIG) report (2009) suggested that any new disability structure should be:

> ‘designed to meet existing, unmet and future needs of people with severe or profound disability. (DIG Report Recommendation 1. P 8. (2009)**\(^6\)**

Furthermore the scheme should be based on a social insurance model and fund basic support for life as well as personal care.

Questions that are currently being asked of PDA include, “How will this actually work?”, “How it will impact on individuals, families and services?”, and “How it impacts on those who are reaching the age of 65?” There are also questions that do not seem to have answers at this stage of the early planning, and some of these questions PDA has heard repeatedly “What happens to my disability after the age of 65?”

**Physical disability in Australia**

Physical disability is defined by PDA and usually by the individual themselves, as a person who has a physical limitation or impairment that restricts their lifestyle and/or mobility every day. Physical

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\(^6\)** 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2003. Commonwealth of Australia.**
disability in Australia is a major disability and covers the greatest number of people within the disability sector.

The Australian Bureau of Statistics (ABS) in 2003 when reporting on the number of people with disability in Australia stated:

‘Of those with a reported disability, 86% (3,387,900) had a specific limitation or restriction that is were limited in the core activities of self-care, mobility or communication, or restricted in schooling or employment. Most people with a disability (76%) were limited in one or more of these core activities.’

The ABS report further indicated in the same document that across Australia, the disability sector is ageing:

‘The prevalence of disability steadily increases with age. In 2003, the rate of disability increased from 4 per cent for those aged less than four years to 41 per cent for those aged 65 to 69 years and 92 per cent for people 90 years and older. Similarly, rates for profound and severe disabilities increased with age, reaching over 70 per cent for people aged 90 and over (figure 7.1).’

In 2009, the ABS further reported that:

‘Australia’s population is projected to grow from 21 million people in 2006 to between 31 and 43 million people in 2056 (ABS, 2009:1). And that ....more than 2.9 million Australians (13.3% of the population) were aged 65 years or over compared with under 1.1 million (8.3% of the population) in 1971 (AIHW, 2010).

The ABS also stated in 2009 that by the year 2056 the age group of 65 – 84 year olds will increase dramatically to 6.4million resulting in the number of 85 years and over will rise to 1.7million. If the average person is living longer, the number of people with disabilities would increase in line with WHO Global Report on Disability (2011).

Specifically, “It is projected that there will continue to be large increases in non-communicable disease-related years of health lost due to disability (YLDs) in rapidly developing regions (65, 77, 78). Several factors help explain the upward trend: population ageing, reduction in infectious conditions, lower fertility, and changing lifestyles related to tobacco, alcohol, diet, and physical activity (39, 65, 79, 80).” WHO (2011, p. 33.)

However the 2009 census indicated a decrease in number of person with severe and profound core activity restriction only 162,813. This compared to SDAC data of 2003

The finding from this census, raises questions as to the phrasing and collection of disability data in the census. Specifically whether the oldest cohort with a disability counted in the previous 2003 census had in fact, now moved into the ‘aged’ sector and was therefore seen as a disability as a result of ageing?

**Defining Physical Disability**

‘Physical disability’ is one of the categories of disability specifically identified in the Disability Discrimination Act (DDA 1992), According to S 4.1 DDA, (1992) definition of disability encompasses people with physical disability include:

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Disability, in relation to a person, means:
(a) total or partial loss of the person’s bodily or mental functions; or
(b) total or partial loss of a part of the body; or
(c) the presence in the body of organisms causing disease or illness; or
(d) the presence in the body of organisms capable of causing disease or illness; or
(e) the malfunction, malformation or disfigurement of a part of the person’s body; or

People with physical disability represent a significantly large group of people with disability, in fact is the largest group with 16% of those with a disability having specific core limitations. 10.

Physical Disability encompasses people with a ranges of conditions such as spinal injuries and diseases, amputation of limbs, Cerebral Palsy, Spina Bifida, Arthritis, MS and more. These conditions are often defined in types and nature, such as:

- Accidental Injury (typified by spinal injury, amputation, burns, scarring and other)
- Congenital Non-Progressive (Spina Bifida, Cerebral Palsy, Juvenile Arthritis, Lupus and other.
- Acquired Non Progressive - includes Polio, amputation, Thalidomide and more.
- Congenital – Progressive – such as Motor Neurone Disease, Muscular Dystrophy, Spinal Muscular Atrophy, Hydrocephalus, Multiple Sclerosis and more.

Whilst each diagnosis of disability and its cause is different there are several commonalities that broadly apply. These include:

- The historical experience of activism and emancipation of disability means many people with physical disability will not choose to move to the aged care sector without careful consideration or left with no other choice at the end of their lives.

- People with physical disability who will fit under the NDIS are a fairly specific group compared to all people with disabilities. Some of this sector will be compensable through traumatic injury such as Spinal Cord Injury, amputations, burns, disfigurements etc. The remainder of the physical disability sector will fit into the non-catastrophic aspect of physical disability and include groups of people with Cerebral Palsy, Spina Bifida, Spinal Muscular Atrophy, Motor Neurone Disease, Parkinson’s disease, Multiple Sclerosis, Polio and post-polio and more.

- Most will be non-compensable and therefore not have funds to use for old age or building a nest egg or retraining for employment reasons.

- Most will have spent long years undergoing medical intervention and possibly special education and rehabilitation.

- Many physical disabilities can span more than one area of disability, for example Cerebral Palsy may involve a communication disability, some may have hearing loss whilst others may be blind.

- People with disabilities in general experience limited opportunities for employment, whilst those with a physical disability experience discrimination on a regular basis whilst seeking employment or education or recreation.

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Currently there is a group of people with physical disability who have the potential to skew the NDIS statistics and it is those who had compensable injury years ago and who are now on a DSP or working. In the future people who acquire disability through catastrophic injury will fall under the National Injury Insurance Scheme (NIIS) however those with non-compensable injuries will fall under NDIS.

Compensation has allowed those compensated for their injuries in some instances to retrain and re-earn and they have comparatively greater assets than the non-injured peers.

In the future people with physical disabilities under NDIS will most likely have reduced assets at retirement age due to reduced earning capacity over their lifetime - the full extent of this is not reflected in the statistics which are across all disabilities.

Mobility related disability seems to be the major age related disability of concern and those with physical disability enter the aged care system with higher care needs to begin with.

People with disabilities have already established their lifestyle supports and if required to enter the aged care sector they do so with much greater need than those without lifelong disability.

People with a physical disability do not see the onset of a physical disability due to age as a reason to access aged care as they themselves do not, preferring in the main to live in the community. This only happens when their disability worsens or there is no longer any support available in the community.

People with physical disability will most likely resist entering the aged care sector or a nursing home unless forced to do so. When this occurs, people with physical disability will have much greater need, earlier, and with fewer assets to co-contribute, than those without disability. “Disabled persons often suffer from discrimination, because of prejudice or ignorance, and also may lack access to essential services. This is a "silent crisis" which affects not only disabled persons themselves and their families, but also the economic and social development of entire societies, where a significant reservoir of human potential often goes untapped.” (UN-ENABLE, 2003-04)

Ageing with a disability

The fact that people with disabilities are now living longer could be attributed to many things. These include: rights and justice, education about disability in general, independence from hospitals and institutions, more knowledge and technology in medicine, medial intervention, therapies and legislation that protects people with disability, as well as support in the community. (AIHW, 2010)

According to the ABS, in 2003, there were 3.35 million people aged 60 years and over (17% of the population), and this was an increase of 350,000 from 1998 (the space of 5 years). Over half of this group had a disability, with 19% having a severe core-activity limitation. ABS (2003).

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12 Life expectancy and disability in Australia 1988 to 2003. AIHW. Australia

13 Life expectancy and disability in Australia 1988 to 2003. AIHW. Australia
In the report from the AIHW, *Life expectancy and disability in Australia 1988-2003*, this issue was examined in detail and concluded that indeed the life expectancy of people ‘living with disability’ had increased. As people in general were living longer, so were people living with disability. Though, this was the case mostly for those with less severe disability, whilst the situation reversed for those with higher severity of disability. However, it is projected that by 2030 the number of people with severe disability will increase to 2.3 million owing to growth in the population and ageing. AIHW, (2010) p40).

Australian data also indicates that females are expected to live longer with more years of disability. For example:

The AIHW (2012) reported:

- Life expectancy has increased dramatically over the last century and continues to increase. A boy born in 2008–2010 can expect to live 79.5 years and a girl 84.0 years *(page 120).*

However,

- Life expectancy at birth for Aboriginal and Torres Strait Islander people is much lower than for non-Indigenous Australians—12 years lower for boys and 10 years for girls *(page 120).*

According to the ABS, in 2009, there were 2.6 million carers who provided care to a person because of disability or old age, of which, 68% were women. Almost one third (29 percent) were primary carers and 20 percent of carers were more likely to be older than 65 years (compared to 12.7% percent of the total population) (ABS, 2009: 5, 10).

For an example of the ageing population who already have a disability and receive income support from the federal government, the chart on p.10 of ‘DSP Characteristics of Disability Support Pension recipients’ (June 2011), shows that 21.8% of DSP recipients fit within the age group of 60 – 64 which is the largest user group across all recipients.

After speaking with some of the older members of PDA, it is clear that our members are not sure what their future holds in terms of the ageing process and the administration that follows with the NDIS. It has therefore become obvious to PDA that many people are confused about whether the NDIS will stop at an imaginary gate marked ‘Under 65’s only’ or be forced to move to one labelled ‘ageing population only,’ or whether under the NDIS, the process is to be seamless and as simple as choosing which area to stay in or go to. PDA through this document explores this conundrum.

The Productivity Commission Report: Disability Care and Support (2011) recommended the following in terms of permanent disability (which includes a physical disability):

“A person receiving funded support from the NDIS would have a disability that is, or is likely to be, permanent. The definition of ‘permanence’ would include people with long-term functional limitations who may only need episodic support.”

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14 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2009
16 Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra.
The Productivity Commission suggested criteria for inclusion in the NDIS include that the individual will have a "significantly reduced functioning in self-care, mobility or self-management and require ongoing support"\(^{17}\)(3a). The Productivity Commission proposed in the recent report that when a person with a disability reaches age pension age, the individual can choose to either stay with the NDIS or move to the aged care system.

PDA therefore believes that many of its members would be eligible for support under Tier 3\(^{18}\) of the NDIS ‘for whom NDIS funded, individualised supports would be appropriate’ as Tier 3 is for those with ongoing support needs that otherwise may not be able to be met without disability support services paid through taxes. Naturally an assessment process would need to be undertaken for each individual.

Alternatively for those who elect to remain with Commonwealth Aged Care must insist that the quality of care provided in aged care should include a rights based approach as part of Commonwealth funded services in accordance with:

- The Aged Care Act 1997 which requires approved providers of aged care to meet accreditation standards to ensure that quality of care is provided to all aged care recipients.

In addition, the following should be publicised and available to each person within or receiving a service, outlining their rights and responsibilities and resources including:

- The Aged Care Complaints Scheme which provides a free service to address complaints for those receiving services and care and experiencing problems.

and

- Quality of Care Principles 1997 (Parts 2 and 3 of Schedule 1) set out the Specified Care and Services which aged care providers must provide to residents who need them, based on their level of care.

Under the recent National Health Reform Agreement between the Commonwealth and the States and Territories, the Commonwealth is responsible for full funding, policy, and management, delivery responsibility for a consistent and unified aged care system covering basic home care through to residential care.

The Commonwealth Government is continuing to streamline and work to implement these new arrangements, including to the Home and Community Care (HACC) program.

These changes are envisaged to assist in the “creation of a national aged care system and national disability service system.”\(^{18}\)

According to the National Health Reform Agreement of 2011\(^{18}\) these changes will not apply to Victoria and Western Australia as they already have basic community care services in place and will continue to be funded under a joint HACC/Commonwealth funded program.

\(^{17}\) Productivity Commission 2011, Disability Care and Support, Report no. 54 (3a). Canberra.

\(^{18}\) Productivity Commission 2011, Disability Care and Support Report No. 54 p 159. Canberra.
What this means overall is that the Commonwealth will fund those over 65 whilst the States and Territories are responsible for those with disability under 65 years.

PDA encourages the extension of all disability discrimination issues such as access to public transport, access to public buildings and premises, the right to education and further higher education, workplace reforms and other similarly important strategies, be extended to include the ageing population and those with a disability over the age of 65 years.

**Intersections and Pathways:**

**Information**

Article 8 of the United Nations Convention on the Rights of Persons with Disability (2006) known as UNCRPD on – Awareness raising - states that all parties who are signatories to the Convention undertake to:

a) *To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;*

b) *To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;*

c) *To promote awareness of the capabilities and contributions of persons with disabilities.*

*Measures to this end include:*

*Initiating and maintaining effective public awareness campaigns designed:*

- To nurture receptiveness to the rights of persons with disabilities;
- To promote positive perceptions and greater social awareness towards persons with disabilities;
- To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market; (UNCRPD 2010)

Information has been identified as one of the biggest issues in the disability sector, that of where to go for advice, information and services. PDA is experienced at being on the end of these requests and often it is the first place for many people to come to for information including people with disabilities themselves, families, carers and support workers as well as professionals, governments and students to name a few.

Unlike other countries UK and NZ, Australia does not have specific and identified information services that are located in each capital city. There are Independent Living Centres, but these are in the main identified with a medical approach and not social model focussed.

In NZ for instance, the Information Services, located at [http://www.nzfdic.org.nz/](http://www.nzfdic.org.nz/) were established so that they contain all types of information on disability, from where to get support, equipment, building accessible premises, and more.

The writer was part of establishing the NZ Information Services which has become a beacon in disability information provision to professionals, families, business, and governments and to people with disability themselves. At the time, the former ACROD (NDS) set the pathway for cataloguing
the continual flow of information, in order to become professional entities offering a superb information service.

Australia is badly in need for such a network of information services and before the NDIS is rolled out. PDA believes that this should be established in order to answer and address the hundreds of questions that will need to be answered. Such an information network would be best placed to be independent of any other organisations and be able to discuss the NDIS and all that it entails.

**Income support**

In Australia, a person with a disability, assessed by Centrelink as being unable to work may be eligible for support. The Disability Support Pension requirements state a person must be:

- 16 years of age or over at the time of claiming and are under age pension age, and
- an Australian resident and in Australia when you claim, and
- either:
  - permanently blind, or
  - assessed as having a physical, intellectual or psychiatric impairment of at least 20 points and are either:
    - participating in the Supported Wage System, or
    - unable to work or be retrained for work of at least 15 hours or more per week at or above the relevant minimum wage within the next two years because of your impairment, and you are assessed as either having a severe impairment or as having actively participated in a program of support.

An individual with a disability may also need to have a Job Capacity Assessment, which is a way of finding out if you are able to work, how much time or effort can you work and what help you need to work and keep a job.

Other types of pension or factors that may need to be considered when applying for a pension from Centrelink:

- Age Pension for over 65 years
- Carer Payment (for an adult who supports a person with a disability)
- Carer Payment (child who supports a person or parent with a disability)
- Disability Support Pension – issued to an individual assessed as eligible
- Parenting Payment (Single)

The Aged Pension will be granted from differing age rates according to the person’s year of birth. For instance before 1935 the eligibility is aged 60 for women and 65 for men. These rates are increasing over future time. For example someone born in 1957 will not be eligible until they turn 67, and this is the case for both men and women. These rates change from 2017 onward.  

However it is not as simple as turning 60 or 65 and then changing to an Aged Pension. Within Centrelink there are circumstances that allow a person to stay on the DSP, but what of the services and supports that are also received as a person with a physical disability, such as aids and equipment, taxi subsidies, HACC services, parking permits, continence supplies and more.

**Ageing impact**

In Australia people ageing with a disability are showing signs of deterioration. For instance the Post-Polio Syndrome is one such example where people who had contracted polio in earlier years are

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now reporting decline in their health and fitness. This group particularly is a good example of a section of society that was in the main, independent, and often hidden until recently when the post-polio syndrome started to appear and as a result requires medical and therapeutic care, sometimes orthotics and often a person who has walked for most of their life may need to use a scooter or a wheelchair or other mobility device.

A study by Balandin and Morgan\textsuperscript{20} in 1997 that found that people with Cerebral Palsy were also experiencing signs of deterioration such as walking, digestion, breathing and more, as they aged. This yet again indicates that the ageing process of a person with a disability often exacerbates more disability.

As a consequence, many people with disability who are ageing will enter the sector with potentially far more support needs, than the average person ageing without a disability. This has implications for services and support systems in the aged care sector, and further implications for carers who will be needed, especially in light of an already identified shortage of carers in Australia in both the disability sector and the ageing sector.

**Carer and support networks**

It is already estimated that there is a shortage of carers in both the aged care and disability sectors. The implication for this is that many people with disability will not be able to remain in the community without the support of these carers, unpaid or paid, family, friends, volunteers or paid workers.

Combined with an increasingly ageing population in all developed societies, the role of the carer has been recognised as an essential one to assist in independence for individuals who wish to remain in their own homes, including people with disability and the ageing sector. The report *Caring for Older Australians* \textsuperscript{21} (2011) by the Productivity Commission stated that there are likely to be fewer informal carers relative to the growing older population. This is the same situation for those who provide assistance to people with disability.

The Productivity Commission document ‘*Disability Care and Support*’ (2011) stated in their report that:

> "The expansion in the system associated with the NDIS would increase the demand for disability support staff. Moreover, workforce pressures are likely to rise as the aged care system expands (and as economy-wide labour force growth subsides with population ageing), further increasing the demand for workers." P.38

This is a shared pathway for those ageing and those ageing with a disability. PDA believes that much more needs to be done to encourage and support the caring profession to become more professional and aware by insisting on training qualifications for all carers, regardless of whether they are paid or unpaid.

PDA acknowledges the recent SACS Award increase for community sector workers, and believes that this will go a long way toward attracting more people to the area. PDA also believes that training and policies to protect the worker and the client should be placed on those who provide personal support services. Likewise, individuals who hire support persons privately must also be made aware of Fair Work Australia Act 2009 and their obligations to workers, if employed.


PDA also believes there needs to be National Standards for Personal Support to ensure priorities and to be available to both individual people with disability, support persons and those employing support persons. This would also be useful to family members who are carers also.

Conversely, PDA also believes that people with disabilities who require personal support and appropriate workers, should also receive awareness training in how to be an employer, whose rules are to be followed and the acknowledgement that a carer or support person, is working in the individuals own home and therefore abide by the needs of the individual with a disability.

Aids and equipment
Most people with a physical disability will use some type of assistance device at some time in their lives. As people age, more support from equipment may be needed and unlike those who enter a nursing home and are therefore not always ambulant, people with disabilities of all ages, are as ambulant as they are able, and intend to remain that way given the support they need.

To deny a person who has a disability, regardless of age, the equipment they need, is cruel and does not do justice to the rights based approach of Australia as a signatory to the UNCRPD or assist in the capabilities of people with disabilities to be included in society.

People with physical disability are now looking at the availability and range of equipment that is needed to live a quality of life in the community and is available worldwide. However, much of this equipment is either not available in Australia or is too expensive for health budgets and results in a delay in receiving equipment, not receiving the best equipment for needs, issued with inappropriate equipment, or none at all.

This applies to the ageing sector and the disability sector. As more information becomes available through the Internet and email, the expectations of people rise and therefore the NDIS is becoming that dream far off that everything will be better under the NDIS.

It is hoped therefore, that under the NDIS, there will be better provision of a range of aids and equipment allocated to people who need them, regardless of their age as for too long we have witnessed carers of people who are ageing, struggling with store bought wheelchairs, when mostly they are not aware of lightweight and foldable equipment on prescription.

It is recommended that national research into aids and equipment should be undertaken to determine best practice in the provision of equipment to those who need it. This should include better distribution and allocation of equipment processes and policies.

Gender
Everyone ages! Men and women both age but not always at the same time or with the same experience. According to Women with Disabilities Australia (WWDA) 2010:

‘Gender affects the equal right of men and women to the enjoyment of their human rights. Gender refers to the social differences and relations between men and women which are learned, vary widely among societies and cultures, and change over time.’

22 Submission from Women with Disabilities to Productivity Commission Inquiry: Disability Care and Support. (2010). Australia
The UN Convention of the Rights of Disabled Persons, (UNCRPD) article 6. also addresses gender issues and states that:

‘Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.’

This means that responses to men and women who have a disability and are ageing, will need to take into account that services and supports must become aware of these differences and not practice a ‘one service or size fits all.’ This should be written into all policies and be continually taught to students of Disability Studies and similar.

**Awareness**

The NDIS alone gives cause for the need to raise the awareness of people with disability in Australia. The Information Service proposal could also be a part of the strategy to address the need for more information and how to go through the massive amount of change that will be taking place.

People with disability are often the ‘victim’ through lack of awareness of being treated differently, discrimination knowledge and rights perspectives through to self-advocacy or peer advocacy. In order to be fully included and equitable in any society the bar of ‘Awareness and Information’ must rise, and be aimed at educating the community as well as people with disability in order to prevent discrimination and create a more inclusive society.

The benefits of a more inclusive society will mean more employment and engagement opportunities for people with disability and greater acceptance of difference in society.

PDA believes disability peak organisations are best placed to be the information providers and contracted to raise the awareness of the NDIS, the Aged Care sector and much more during the transitional times ahead.

PDA would be pleased to be involved in any efforts to set up Information Resources across Australia prior to the roll out of the NDIS.

**Housing**

Housing and accommodation that is accessible for people living with a physical disability is in a critical need situation. Public rental accommodation is rarely accessible and there are no government requirements to be accessible. The only housing options usually open to people with physical disabilities will be purpose built accommodation usually provided by State Governments, religious organisations, and not for profit organisations. Rarely do we see privately funded accommodation options for people with physical disability.

It must be acknowledged that there are no living options available to people with disability without a very long wait, owing to the shortage of private housing that is suitable. Lack of ample supported accommodation and support for community living for people with physical disability under 65 years means than most have to remain living with families or friends, or access inappropriate accommodation. In cases where housing is not available in the community, the next option is to be placed into residential aged care (AIHW, 2009a in Productivity Commission, 2010).23

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Adaptable Housing (Requirements already implemented by councils [not all councils] in NSW) should also form part of any Commonwealth and State/Territory efforts to address this as a nation-wide issue.

The goals of adaptable housing sit alongside the following principles:

- **An approach to building homes using a range of planning, design, construction and attitudinal refinements to create living spaces which:**
  1. Meet the needs of people across a range of abilities and ages;
  2. Are capable of adaptation to meet the changing needs of its owners over time;
  3. Are well integrated within the community;
  4. Can be economically adapted in the future, as our life circumstances and renovation needs change. (Smart Housing Universal Housing Design, 2001)

**Self-Directed Funding**

Self-Directed Funding is a relatively new approach to funding in Australia with people with disabilities, who traditionally having had services provided by government funded organisations.

This is a ‘dream situation’ for many, who have long wanted the independence to organise their own lives at their own time and pace. However, it is thought that some people may prefer to simply receive the service as they know it now; whilst someone else worries about the administration and reporting that will also be required. This comes down to personal choice and will become a reality under the proposed NDIS.

Anecdotal evidence is showing that there are positive benefits and lifestyle outcomes when people receive and direct their own funding. People are showing they are happier with the additional flexibility of organising their own lives, better care outcomes and relationships and at this stage there is no evidence to suggest this will cost more than bulk funding arrangements. In fact it may cost less under the NDIS once it is established and running well.

With this information in mind, PDA believes this should be the case for those who are ageing with their disability also. In so far as their lifestyle is organised with self-directed funding before turning 65 there appears to be no evidence to suggest that the individual should move to aged care services.

Conversely, many in the aged sector could benefit significantly by being offered the opportunity to receive self-directed funding. This means that families could plan to live successful lives without placing loved ones into a nursing home simply because there is no affordable care support. Being able to direct whether to pay for independent support or family support, would open many options and take the financial burden off governments for Nursing home places.

**Transport**

People with disabilities cannot afford to purchase vehicles at the same rate that people without disability can. The ABS reported in 2006-6 that only 39% of working people who need assistance, drive themselves to work, compared with 68% of people without a need for assistance. (ABS, 2006:8)

Accessible Public transport in Australia benefits everyone, regardless of age and/or disability. Some cities are better than others in their provision of accessible transport, however in recent times disability activists in Victoria forced the government to allow them to travel free on all public transport, because of the perceived failure of government to make all transport accessible.

A review in 2007 undertaken by the Federal Government through Allen Consultants found that public transport accessibility under the 25 year compliance period, had ‘improved.’ PDA would like to point out that it had ‘improved’ from nothing to something and this in itself is a failure!
People with physical disability do not agree with these findings and are pressing for more improved access to the community as services and supports open up. PDA believes that this will become more intensive once the NDIS is implemented. Rights in society include public transport for all, including the ageing population who will require accessible transport also. Supporting people with disabilities to have better lives will fall somewhat flat if access to their own community is not improved.

For years, the ageing community have benefitted from the hard work of people with disabilities to gain access to premises, access to public transport and parking and recognition of needs which covers all age groups and sectors and as the ageing sector grows so too will their demands for more accessible services and transport will be one of them as they are no longer able to drive.

Social isolation

Social isolation is experienced at all levels of life, but people with disabilities experience this more than most, due to the lack of access to the community and therefore opportunities to share and meet.

People with physical disability are less likely to be in a couple relationship with their own children in every age range. These statements supported by ABS, (2006) indicate that people with disabilities are less likely to have partner relationships or children at any stage of their life. This has implications for service provision.

It is apparent that for people with disability the potential for social isolation is much larger than that for the general population. The Shut Out report (Australian Government, 2009a in Productivity Commission, 2011b: 2.3) found that people with profound core activity limitation (a measure of the degree of impairment) were almost ten times more likely than the rest of the population not to access activities outside the home.

Service implications

It is difficult to say what service implications there will be until after the introduction of an NDIS or until it is exactly mapped out from a Pilot study and the results published, or at the very least a document outlining what it is to look like, or long and frequent discussions with the service providers, disability sector and governments.

To date there are no indications how organisations will receive their funding, no indication of what support mechanisms will be in the community, (for people with disabilities first and foremost) or for advocacy in general.

Whatever the shape of the NDIS, there can be no doubt that the implications for services will be:

- People with disability living longer
- People with disability more empowered and therefore demanding more and better
- People with disability not wanting to ‘retire’ to a Nursing Home in the same numbers as previously done; and
- People with disabilities will have higher support needs as they age as they deteriorate with age.

Intersection with Ageing

Many people with physical disability already receive their support through the aged care system and many of this group acquired their disability before the aged pension age. However there are shared intersections between disability and ageing that do not seem to be in place and will need to be to ensure the successful transition between the services.
Intersections between disability and aged care services will need to include rights based approach, preservation of dignity and respect, maintaining mobility and independence, receiving appropriate aids and equipment and to be able to freely live in the community of their choice.

It is acknowledged that there are differences between the two sectors as historically one group came from a need for independence whilst the other sector faced losing independence. The objectives and philosophies, needs and aspirations of people in the two systems, appropriate funding sources, and the areas of greatest competence such as in the case of Dementia and Mental Health.

Even though the data suggest that patterns of need vary with age, age at onset, type of disability and availability of informal care and that people with early onset disability may have higher levels of need at earlier ages, none of these factors could reliably be used as indicators of need.

The recommendations from the Productivity Commission included that “People should be given much greater power and choice in a new system, with the objective of giving people greater flexibility and control over their lives — with the ultimate goal being greater wellbeing.” (2011) p 343
Three Case Studies:

Case Study 1. FP
Male – physical disability since aged 31. Spinal Cord Injury at C7 level.
BA (Hons) in Psychology. NSW Public Servant and own business 1984 – 2008
F is still active as a volunteer in NGO’s.

I’ve already reached and passed 65 (I’m now 73) and have done so without the need for personal care or other assistance (apart from money, but not much of that) from government agencies.

When I was younger, 31 to say 60, I could and did live completely independently. I could also travel independently.

When my shoulders started to wear out I moved initially to a Roll Aid which I could take off the wheelchair so it again was just a manual chair when at home and so continue to be fully independent. Some 7 years ago I moved to a power wheelchair and could no longer swap my chairs at the bedside to allow me to transfer into and use my commode/shower chair, and my wife has done the swap over since then.

In addition, my hand function and general strength is deteriorating which means my ability to do my own personal care is on the brink of being lost. And, of course, housework and general tidying up is beyond me, which is not really an issue while my wife is healthy.

I fear that when the time comes, as it inevitably will, that I can no longer manage my personal care myself that no assistance (well, not enough anyway) will be available. My wife is adamant that she will not be doing my personal care, and why should she?

I don’t have the income to afford to pay for my own attendants. So I fear that the only alternative will be a nursing home and I’ve seen enough of them to know it would be hell. I would like to see something like the Attendant Care Scheme as it operates in NSW available to older people with disability when they need it, as it is for younger people.

Or the NDIS, if we ever get it, made available to people like me, who have saved the taxpayers many thousands of dollars by struggling on and doing it myself, when we finally need it.
**Case Study 2: LZ**

LZ, referred to as Zee, turns 65 at her next birthday and she is not sure what will happen to her under the NDIS. Zee is a high level paraplegic through an illness in her childhood which left her paralysed from her trunk down. Zee uses an electric wheelchair; lives independently in a State Government provided town house in a city suburb.

Zee uses a power wheelchair for mobility, has a hoist for getting in and out of bed, and handrails in the bathroom/toilet, ramps front and back of the town-house as well as many other items provided by the hospital and state government after appropriate assessment by a professional.

She receives the Disability Support Pension from the Federal Government with a rent allowance as well as other support (from the State Government) to live in the community independently. She receives taxi vouchers for subsidised taxi travel and has a parking permit for when family or friends take her out to appointments (state government). A Pensioner Concession Card from the Federal Government is also provided which enables Zee to see her doctor and have him bulk bill. This also means prescriptions are at the lower PBS price.

Zee has a HACC funded service to assist in housekeeping for 1 hour per week, and a personal support person 14 hours per week, which is taken up with bathing, toileting and other personal hygiene issues, once in the morning and once in the evening. Zee relies on her personal support person or housekeeping person to arrange for meals to be prepared and stored in her freezer that she is able to microwave at a later time.

When Zee turns 65, according to the Productivity Commission Final Report she would be eligible to elect to stay within the NDIS or alternately to move toward the aged care services with an Aged Pension.

As Zee is quite independent she shares her time with volunteering in the community as a Treasurer/Secretary for a local disability organisation, and because she spends at least 8 hours per week at the organisation itself, volunteering in other ways also, Zee receives a Mobility Allowance each fortnight to assist with travel costs.

Zee is concerned that if she moved to the Aged Care sector, she would not be able to remain in the community as independently as she is now. She has major reservations about the NDIS primarily because there are still unknowns for those who are ageing and has decided to remain with disability to wait for the NDIS and to see what is available to her as a person who is ageing with a disability.
Case Study 3 – AL

Volunteer in disability organisations

AL is blind and like all of us, is getting older. AL is a member of PDA from Tasmania. In recent times AL has been diagnosed with Parkinson’s disease and we asked her a few questions on getting older.

• With the onset of Parkinson’s disease how do you think you will cope at home?

“I will need help eventually with cleaning, shopping and, perhaps more suitable transport arrangements in the future; its early days now and with my medication I manage well.”

• What support will you need as the disease progresses?

I expect I will need some personal care if my mobility deteriorates.

• Do you have independent financial support (for example superannuation, or any retirement insurance?)

I have a small amount of superannuation due to part-time lower paid jobs during my working life.

• Do you receive a pension, if so what type?

DSP Blind.

• Will you still get this pension when you are over 65?

I believe if I indicate that I want to stay on DSP Blind rather than go on to DSP Aged Blind as I think it’s called I can do so.

• Do you envisage needing to move to a Nursing home in the future?

Not if I can receive services in my own home.

• How do you feel about this?

I want to keep my independence and stay in the community. I shall guard my right to do so as fiercely as necessary. I don’t give in easily.

At the moment staying active is what I’m aiming for
Conclusion

This policy paper, prepared by PDA on the topic of ageing with a physical disability is a completely new direction in policy for PDA. Ageing has traditionally focused on physical disability as a part of the ageing process. PDA presents this document from the perspective of people who are currently living independent lives in the community and approaching the age of 65 years as we move toward a National Disability Insurance Scheme.

As the implementation of the NDIS draws closer, it has become evident through members of PDA and external stakeholders, that people are concerned about what will happen to them when the NDIS is fully implemented and the sector ages beyond 65.

A key goal of the NDIS is enablement, which is hoped to increase the participation and opportunities over a lifetime for people with disabilities Australia. However PDA believes that not enough is known about the NDIS to allow us to critique the future impact on our members and details are in short supply of what it is to look like and how it will work.

With such a diversity of physical disability, ranging from spinal injury (catastrophic and congenital), amputation, cerebral palsy, spina bifida, arthritis, muscular dystrophy and more, we believe that people with physical disabilities will span across all 3 Tiers of the NDIS.

In line with information from the recent document ‘Realising the economic potential of senior Australians (2011) which states that “The emerging cohort of seniors will be different to previous generations of older Australians. This cohort is predicted to be significantly larger and has the potential for more productive middle years of life.”’ PDA believes this to be true of those with a physical disability as well, and with careful consideration and implementation the NDIS has the potential to see these ideals come to fruition.

PDA embraces the position that all stakeholders should be included through all of the pathways that will need to be taken in the building of a whole new system of looking at disability in Australia, and reminds all decision makers of the following:

I fear that the only alternative will be a nursing home and I've seen enough of them to know it would be hell.”
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12. (Smart Housing Universal Housing Design, 2001) in *Introduction to Lifecycle Housing – Sustainable housing development through Universal Design* - Disability Council of NSW (no date)


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