



**RESPONSE to the DRAFT REPORT on CARING
FOR OLDER AUSTRALIANS**

MARCH 2011

PREPARED for the PRODUCTIVITY COMMISSION

Ms Jordana Goodman
Project Officer
Physical Disability Council of NSW
St Helens Community Centre

Freecall: 1800 688 831

Physical Disability Council of NSW (PDCN) receives funds from Ageing, Disability and Home Care, Department of Human Services NSW. Views expressed by PDCN are not necessarily endorsed by the NSW Government.

Web: <http://www.pdcn.nsw.org.au/> Email: admin@pdcnsw.org.au

CONTENTS

1. Executive Summary
2. Scope of the Inquiry
3. Physical Disability Council of NSW (PDCN)
4. Discussion
 - 4.1 Care and support
 - 4.2 Paying for Aged Care
 - 4.3 Ageing in Place

1. EXECUTIVE SUMMARY

The Physical Disability Council of NSW (PDCN) would like to thank the Productivity Commission for this opportunity to provide further feedback to the issues identified in the Draft Report on Caring for older Australians- January 2011.

As part of the initial inquiry into caring for older Australians in 2010, PDCN provided comment the following issues:

- Housing
- Independence (Service delivery)
- Finances
- Access to the Community as a Site for Social Inclusion
- Public transport

As a peak disability advocacy organisation representing people with a physical disability, PDCN would like to provide further comment on the relevance of proposed reforms identified in the Draft Report into Caring for Older Australians with regard to

- Care and support
- Paying for Aged Care
- Ageing in Place

2. SCOPE of the INQUIRY

(Copied from the Terms of Reference)

The Commission is requested to:

- 1 *Systematically examine the social, clinical and institutional aspects of aged care in Australia, building on the substantial base of existing reviews in this sector.*
- 2 *Develop regulatory and funding options for residential and community aged care (including services currently delivered under the Home and Community Care program for older people) that:*
 - *Ensure access (in terms of availability and affordability) to an appropriate standard of aged care for all older people in need, with particular attention given to the means of achieving this in specific needs groups including people living in rural and remote locations, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities and veterans;*
 - *The Commission is specifically requested to examine how well the mainstream service system is meeting the needs of specific need groups.*
 - *Include appropriate planning mechanisms for the provision of aged care services across rural, remote and metropolitan areas and the mix between residential and community care services;*
 - *Support independence, social inclusion and social participation, including examination of policy, services and infrastructure that support older people remaining in their own homes for longer, participating in the community, and which reduce pressure on the aged care system;*
 - *Are based on business models that reflect the forms of care that older people need and want, and that allow providers to generate alternative sources of revenue streams by diversifying their business models into the delivery of other service modalities;*
 - *Are consistent with reforms occurring in other health services and take into account technical and allocative efficiency issues, recognising that aged care is an integral part of the health system and that changes in the aged care system have the potential to adversely or positively impact upon demand for other care modalities;*

- *Are financially sustainable for Government and individuals with appropriate levels of private contributions, with transparent financing for services, that reflect the cost of care and provide sufficient revenue to meet quality standards, provide an appropriately skilled and adequately remunerated workforce, and earn a return that will attract the investment, including capital investment, needed to meet future demand. This should take into consideration the separate costs associated with residential services, which include but are not limited to the costs of accommodation and direct care, and services delivered in community settings;*
 - *Consider the regulatory framework, including options to allow service providers greater flexibility to respond to increasing diversity among older people in terms of their care needs, preferences and financial circumstances, whilst ensuring that care is of an appropriate quality and taking into account the information and market asymmetries that may exist between aged care providers and their frail older clients;*
 - *Minimise the complexity of the aged care system for clients, their families and providers and provide appropriate financial protections and quality assurance for consumers; and*
 - *Allow smooth transitions for consumers between different types and levels of aged care, and between aged, primary, acute, sub-acute, disability services and palliative care services, as need determines.*
- 3 *Systematically examine the future workforce requirements of the aged care sector, taking into account factors influencing both the supply of and demand for the aged care workforce, and develop options to ensure that the sector has access to a sufficient and appropriately trained workforce.*
- 4 *Recommend a path for transitioning from the current regulatory arrangements to a new system that ensures continuity of care and allows the sector time to adjust.*
- *In developing the transitional arrangements, the Commission should take into account the Government's medium term fiscal strategy.*
- 5 *Examine whether the regulation of retirement specific living options, including out-of-home services, retirement villages such as independent living units and serviced apartments should be aligned more closely with the rest of the aged care sector, and if so, how this should be achieved.*

6 *Assess the medium and long-term fiscal implications of any change in aged care roles and responsibilities.*¹

3. THE PHYSICAL DISABILITY COUNCIL OF NSW

The Physical Disability Council of NSW (PDCN) would like to take this opportunity to thank the Productivity Commission in providing the opportunity to provide feedback on the significant changes to aged services identified in the Draft report on Caring for Older Australians.

PDCN is the peak body representing people with physical disability across New South Wales, from young children and their representatives to aged people. They are from a wide range of socio-economic circumstances and live in metropolitan, rural and regional areas of NSW. The objectives of PDCN are:

- To educate, inform and assist people with physical disabilities in NSW about the range of services, structure and programs available that enable their full participation, equality of opportunity and equality of citizenship.
- To develop the capacity of people with physical disability in NSW to self advocate (ie identify their own goals, and the confidence to develop a pathway to achieving their goals).
- To educate and inform stakeholders (ie about the needs of people with a physical disability) so they are able to achieve and maintain full participation, equality of opportunity and equality of citizenship.

4. DISCUSSION

4.1. Care and Support

Maximum participation in economic, social and community life is a defining characteristic of an inclusive society. Achieving this outcome is more effective when individuals have a good understanding of their localities. Similarly people seeking supported residential or community services are best accommodated in familiar localities. Whether they are from urban or rural localities the risk of depression and social isolation is less if they are able to maintain existing relationships with friends and family. Mechanisms need to be established so that people

¹ Australian Government- Productivity Commission *Draft Report- Caring for Older Australians* (2011)

needing supported accommodation continue receiving support in a familiar locality where they are prevented from having to move large distances to receive a similar standard of support.

Whilst PDCN is not in favour of institutional care for younger people with disabilities, the Draft Report into Caring for Older Australians provides little detail about the relevance of institutional care in the past, at present or in the future for people with disabilities. PDCN believes that without this information, it is difficult to understand the significance of recent government reforms when considering residential aged care for younger people with disabilities. Historically due to limited community services, families have had no other choice but to admit family members to large institutions usually operated by large charitable or disability organisations.

Feedback from an enquiry into aged care conducted in 2005, initiated Government reform with a major commitment to provide community- based supports to younger people with a disability who were either in institutions or at risk of being admitted to one. Negative feedback from this enquiry included the following:

- Younger people with a disability face the prospect of becoming residents in aged care facilities because no other suitable accommodation is available. Many are at risk of admission to aged care facilities because they are cared for by ageing parents and/or they have medical based needs that cannot be supported by community services.
- Staff in aged care facilities may not have received appropriate training or be skilled/experienced in caring for younger people with a disability.
- Social isolation is a grave concern for young people residing in aged care services. The Committee heard that many young people suffer from depression – this may be exacerbated by ‘living with the very elderly or demented and witnessing the death of other people in their homes.’
- In facilities designed for frail aged people or people at the end of their life, there is generally a lack of rehabilitation services, specialist equipment and palliative care for those with degenerative disease and other disabilities.
- The burden on carers can be extremely high and carers may have the additional responsibility of raising a family and earning an income. It was reported that some children take on the role of caring for their affected single parent, or when the healthy parent is working.

- The impact of chronic illness and the stresses of caring on families are considerable. Support groups have found that this can lead to marriage breakdowns which can further exacerbate the care and accommodation needs of disabled people.²

In response to this feedback the Government announced the Younger People in Residential Aged Care (YPIRAC) program. Following the announcement of this program, additional feedback was sought from industry peak bodies, service providers and individuals to guide its implementation. Feedback strongly reinforced the principles of individualised funding and person centered practices, enhancing individual choice and flexibility.

The YPIRAC program included 6,500 people with disabilities between the ages of 0- 65 years living in institutional care, which included approximately 1,000 people aged less than 50 years. This program was jointly funded for a five year period, with \$122 million from the Commonwealth Government, with an additional \$122 million from the states and territories.³ Initially the program targeted people 50 years and less aiming at meeting the following three objectives:

- **Program Objective One:** Move younger people with disability currently accommodated in residential aged care into appropriately supported disability accommodation;
- **Program Objective Two:** Divert further admissions of younger people with disability who are at risk of admission to residential aged care into more appropriate forms of accommodation.
- **Program Objective Three:** Enhance the delivery of Specialist Disability Services to those younger people with disability who choose to remain in residential aged care or for whom residential aged care remains the only available suitable supported accommodation option.

A recent mid- term review into the YPIRAC program indicated that 580 people had received the following supports:

- 296 people living in residential aged care who wanted to move to other accommodation

² Australian Government- Department of Families, Community Services, and Indigenous *Mid-Term Review, Younger People in Residential Aged Care (YPIRAC) Program* 16/3/2011
http://www.fahcsia.gov.au/sa/disability/pubs/policy/ypirac/Pages/exec_sum.aspx

³ Australian Government- Department of Families, Community Services, and Indigenous Affairs *A Continuum of Care: Summary report of public submissions about support and accommodation for younger people with disability* (2006)

- 125 people living in the community but at risk of entering residential aged care
- 134 people living in residential aged care who remained there with additional support services to be provided through the YPIRAC program. ⁴

Data from the 2007- 08 Minimum Data Set identified the primary disability type of the YPIRAC program as having, and hence very significant to the operations of PDCN:

- Acquired brain injury - 47%
- Neurological conditions such as Multiple Sclerosis - 29%
- Physical disability – 15%
- Intellectual/ autism – 8% ⁵

Resulting from the YPIRAC program the number of new admissions entering residential aged care facilities for younger people, aged between 0- 49 years has reduced by 48.1% between the years 1999- 2008, but has increased very slightly by 1.2% for younger people aged between 50- 64 years⁶. Whilst these statistics are very positive, 4.2% or 6,600 younger people less than 65 years are still being accommodated in residential aged care, and hence reforms identified in the Draft Report into Caring for Older Australians are still pertinent to PDCN. ⁷

PDCN believes that the introduction of the proposed Australian Seniors Gateway' (ASG) may be advantageous in the provision of information, but may conversely inhibit customer choice and self- determinism. It is proposed that the Australian Seniors Gateway will provide information, and also provide assessment, referral, care coordination and record management. PDCN is concerned that with this method of the service delivery, direct communication between the service user and the service providing the care will be inhibited. PDCN believes that all services need to adopt a person- centered approach to maximise the service user's self- capacity and confidence by actively engaging the service user in care- planning and goal- setting. Unless individual goals are appropriate and relevant, there is a risk that goals will not be met, resulting in poor self- esteem and an inability to take self control and gain independence.

⁴ Mid- Term Review of the YPIRAC program

⁵ Australian Government- Australian Institute of Health and Welfare *Disability Series - Younger People with Disability in Residential Aged Care program- Report on the 2008-9 Minimum Data Set* (2010)

⁶ Australian Government- Australian Institute of Health and Welfare *Australia's Welfare 2009, P.169* (2009)

⁷ Australian Government- Australian Institute of Health and Welfare *Australia's Welfare 2009, P.112* (2009)

PDCN recommends a legislative framework for all community and residential aged care services that incorporates a whole-of-government and whole-of community approach, guided by principles of human rights and citizenship, enabling people with a disability to more actively participate in community life. This legislative framework would recognise the value of a truly independent and transparent complaints mechanism and individual and systemic advocacy for both the informal carer and person receiving the care. It would underpin self-directed approaches by specifying the requirement for individualised, flexible responses, maximising choice and acknowledging the role of families and support networks, based on the following principles:

Self-determination- People with a disability, their family and support networks actively participating in making decisions that affect their lives.

Choice- People with a disability, their family and support networks actively expressing their views and preferences about decisions that are made in meeting their goals, lifestyle choices and aspirations.

Inclusion- People with a disability, their family and support networks are embraced as belonging, sharing responsibility, contributing to and adding value.

Transparency- Resources are allocated to people with a disability, or their family and support networks where appropriate, based on the individual's needs, goals and aspirations in a fair and open way.

Accessibility- Information, policies and processes are clear and understandable to maximise the person and their family and support networks' ability to take control of their own support.

Citizenship- People with a disability, as members of the community, exercise their equal rights and responsibilities.

4.2. Paying for aged care

PDCN would like to provide the following comments regarding payment options

- A. Funds through government sources need to be made available for people who may be need supported accommodation due to financially disadvantaged, rather than cross subsidising this shortfall through the fees and charges of other residents.

- B. All methods of payment including subsidies, co- payments and fees be based on the financial means of the individual;
- C. That regulatory restrictions on the number of community care packages be removed, and be replaced with a selection of community services that can be easily accessed by the individual;
- D. That the distinction between residential high care and low need be removed, and that funds previously allocated to residential low care be reallocated to community based services,
- E. That the proposed Australian Aged Care Regulation Commission identifies a minimum number of beds for both urban and rural localities for people with limited financial means. As part of this determination the following sub- groups would also need to be considered:
- People from culturally and linguistically diverse backgrounds
 - Aboriginal and Torres Strait Islander people
 - Veterans
 - Socially disadvantaged
 - Financially disadvantaged
 - Older people living in rural and remote locations
- F. That existing residential aged care service providers currently not obliged to provide supported accommodation places, are not necessarily excluded from this requirement in the future;
- G. To prevent social isolation introduce mechanisms where people needing supported accommodation do not need to move long distances to an alternative Aged Care Planning Region to receive care.
- H. That the proposed Australian Aged Care Regulation Commission identify scheduled fees for residential and community- based services;
- I. That any financial assessment needs to be conducted with dignity and respect, and comply with privacy and confidentiality requirements.
- J. That personal information in whatever format is used in accordance with the *Privacy Act 1988*.
- K. That supported accommodation is based on a twin room with shared bathroom facilities at a minimum.

People with physical disability often rely on government benefits such as the Disability Support Pension as their sole or partial means of income and consequently they often struggle financially with the many additional costs required when one has a physical disability. These costs include the costs of personal care services, additional travel expenses, costs of aids and equipment, and large expenses required to modify the home.

Over the past twenty years governments have introduced a number of different programs to help offset this, but often long- wait lists, and restrictive eligibility criteria, access to these programs may not be available. Current pension provisions are inadequate and ineffective in providing recipients with an overall sense of short term or long term financial security. Pension rates are inadequate in meeting general day to day needs, without even taking into account the added expenses associated with disability.

Labour force data identifies stark differences in unemployment and labour force participation rates between people with a disability and people without, showing that people with physical disability are more than twice as likely to work part time. Subsequently many people with a disability rely on income support payments as their sole, main or supplementary source of income. Consequently home ownership or the accrual of superannuation and/or financial assets is not possible or otherwise minimal.

Without his ability to accrue lifelong savings it cannot be assumed that younger with disabilities have the same capacity to pay for aged community and/ or residential services. As a consequence government authorities need to adopt flexible mechanisms that recognise financial disadvantage. It is understood by PDCN that the regulatory mechanisms for aged care residential services already contain this requirement.⁸

4.3. Ageing in Place

Social participation is recognised globally as a key element of healthy ageing. People facing economic, physical and social barriers can experience increased levels of depression and loneliness coupled with reduced access to services and other avenues of support.

To ensure that all members of the community can effectively age in place, it is fundamental that housing and local communities provide universal access to facilitate access to all members of the community. Recent important government reforms to enhance access, has included the adoption of disability access standards and a ten year strategic plan to guide the

⁸ Australian Government- Productivity Commission *Draft Report- Caring for Older Australians Appendix E* (2011)

implementation of universal housing design. Compliance with Disability (Access to Premises) Standards 2010 is essential when providing building improvements to any of the following facilities:

- Accommodation
- Local streetscape and infrastructure
- Transport networks
- Retail and commercial outlets and
- Health and medical facilities

The National Dialogue on Universal Housing Design will provide increased options following implementation of the following:

- Establish nationally agreed performance and technical guidelines for Universal Housing Design;
- Promote greater understanding of the value of Universal Housing Design within the community;
- Promote the education and training of the residential building and property industry in Universal Housing Design practices;
- Identify appropriate incentives and mechanisms to assist in achieving the agreed target.