

### Living Longer Living Better: Aged Care Reform in Action

# Prepared for the Australian Government - Department of Health and Ageing

### **May 2013**

## **Prepared by the Physical Disability Council of NSW**

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#### Who is the Physical Disability Council of NSW?

The Physical Disability Council of NSW (PDCN) is the peak body representing people with physical disabilities across New South Wales. This includes people with a range of physical disability issues, from young children and their representatives to aged people, who 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 identify their own goals, and the confidence to develop a pathway to achieving their goals (ie self advocate).
- 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.

The Physical Disability Council appreciates the opportunity to consider, and make comment on proposed reforms as part of the Living Longer Living Better- Aged Care in Action.

#### **Discussion**

The Physical Disability Council of NSW (PDCN) acknowledges and supports the following six principles identified in the Home Care Program Package Guidelines – Consultation Draft for the future implementation of Consumer Directed Care (CDC), but believes that due to the importance, that these need to be incorporated into the *Aged Care Act 1997 (Cth)*:

- Consumer Choice and Control
- Rights
- Respectful and Balanced Relationships
- Participation
- Wellness and Re- ablement
- Transparency

Whilst PDCN recognises that reforms included in the *Living Life Living Better* initiative are unlikely to have a significant impact on younger people with a physical disability, PDCN supports programs such as the Home Care program and DisabilityCare that provide access to community supports rather than seeking care through institutional residential settings.

For a person with disability less than 65 years neither low nor high residential care facilities are appropriate. Young people with disability living in nursing homes are one of the most marginalised and isolated groups of people in our society. They generally lead impoverished lives, characterised by loneliness and boredom.

A Victorian study of 330 residents under 60 years found that young people in nursing homes:

- Experience increased levels of social isolation from peers (44% receiving a visit from a friend less than once per year)
- Have limited community access (21% went outside seldom or never)
- Have reduced opportunity to participate in community-based activities such as shopping, leisure activities, or visiting friends and family (34% almost never participated).

Future admission of younger people with disabilities to aged care residential facilities contravenes programs such as the Younger People in Residential Aged Care (YPIRAC) which are aimed at trying to reduce the number of younger people already accommodated in residential care facilities, and preventing the unnecessary admission in the future.

National data identifying the number of younger people with disability living in residential aged care facilities shows an alarming increase from 6,449 in June 2005 to 6,456 in June 2010. <sup>2</sup>

Following the completion of the first stage of the YPIRAC initiative in 2011, a review of this program recommended that in the future health, disability and aged services need to work collaboratively to ensure that individual needs are comprehensively met with quality outcomes.

Whilst PDCN acknowledges the many benefits of innovative and digital technologies particularly for people living in rural and regional locations, PDCN believes that technologies

<sup>&</sup>lt;sup>1</sup> Monash University – Summer Foundation (2011) Younger People in Nursing Homes

<sup>&</sup>lt;sup>2</sup> Younger People in Nursing Homes – National Alliance, Statistics accessed 16/05/2013 http://www.ypinh.org.au/statistics

such as telehealth could become too invasive, and subsequently PDCN recommends that protections and safeguards need to be established that ensure the dignity, privacy and confidentiality of personal information that comply with the *Privacy Act 1988* (Cth).

The incidence of poverty is significantly higher among people with disability with 45% experiencing poverty as a result of being reliant on government benefits or part-time employment. This limited earning capacity is exacerbated by everyday household expenses, such as the cost of electricity, and many other expenses associated with having a disability such as the cost of transport, medical expenses and aids and equipment.

As a consequence many younger people with disability are unable to save sufficient funds to invest or purchase a house. Due to these financial concerns PDCN endorses the following recommendations included in the submission prepared by the NSW Council of Social Services (NCOSS) relevant to accommodation payments and fees:

- 1. That a threshold amount for accommodation lump sum payments be set, above which any lump sum payment amount would be reviewable by the Aged Care Pricing Commissioner.
- 2. That the Commissioner is responsible for ensuring that accommodation payments are commensurate with costs of accommodation.
- 3. That the value of Home Care packages and supplements be escalated annually, and be kept in line with movements in the Consumer Price Index.
- 4. That a maximum basic daily fee charged to users be set for each level of Home Care package, increasing progressively by level.
- 5. That any determinations of financial hardship by the Secretary must take into account housing, health care, utility, and family related expenses.
- 6. That any fees paid for services provided by the Home and Community Care Program, and the Home Support Program, is included in the annual and lifetime cap on care fees. <sup>3</sup>

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<sup>&</sup>lt;sup>3</sup> NSW Council of Social Services (2013) Submission: Proposed changes to the *Aged Care Act 1997*