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(Inq into better support for carers)

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BETTER SUPPORT FOR CARERS  
INQUIRY

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The Physical Disability Council of Australia would like to thank the Parliament of Australia, House Standing Committee on Family, Community, Housing and Youth, for the opportunity to provide input into the Inquiry into Better Support for

Carers consultation.

The Physical Disability Council of Australia Ltd (PDCA) is the national disability organisation, funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FAHCSIA) to represent the interests and views of people with physical disability across Australia. PDCA represents the largest sector of disability in Australia.

#### Physical Disability in Australia:

Physical disability affects the person's mobility or dexterity, often requiring mobility devices or equipment to assist in mobility.. The Australian Bureau of Statistics (ABS) estimates that at least 6% of Australians over the age of 5 years have mobility disabilities.

Physical disabilities can be permanent, episodic or temporary. Physical disabilities can be caused by:

- congenital factors
- trauma including accidents
- infection
- degeneration
- disease
- chronic medical conditions.

Physical impairments differ from one person to another. These differences can range from difficulties with balance, gait and co-ordination; dizziness and weakness; pain or paralysis. Mobility equipment used to assist moving can include crutches, a walking stick or frame, a wheelchair either powered or manual. However some people with physical disability may not use any equipment at all, but are still considered to have a physical disability.

The most common physical disabilities are partial or total paralysis, amputation, spinal cord injury, various forms of arthritis, cerebral palsy, motor neurone disease, multiple sclerosis, muscular dystrophy, polio and post-polio syndrome, spina bifida, to name only a few. Additionally, some respiratory and cardiac diseases and cancer or diabetes may affect mobility. Any of these conditions may also impair strength, speed, endurance, coordination and dexterity.

#### PDCA Framework

PDCA operates from the framework that people with disability should be the decision makers in what happens to them and how. This is reflected in our motto of 'Nothing About Us Without Us' which means that people with physical disability are the principle reason for our existence.

In saying this, PDCA also wishes to express to the Inquiry the importance of

including people with disability in all areas of life in Australia and not the piecemeal approach that has happened over the last 10 years.

During the last 10 years, the Australian Government has focussed its attention more and more, on the role and needs of Carers (whether paid or unpaid) and this has come at the expense of people with disability, who for any number of reasons do not have a voice as loud as that of Carers. This has caused a divide between Carers calling for more support for themselves rather than the people they care for, whilst on the other hand, people with disability urgently need more support in order to be included in our society. By providing more support directly to people with disability, the burden of care will be eased from that of Carers.

**Response to consultation:**

PDCA accepts and understands that in the main, Carers in Australia provide a valuable service to their loved ones, friends and families who are much in need. However, the lack of funds and services is the main issue at the forefront of Carer concerns.

In other words, PDCA believes that the provision of better funding mechanisms including Brokerage, Individualised Funding, etc., would ease some of the burden expressed by Carers, and would help Carers to meet their own needs with less responsibility. People with disability with the assistance of more purchasing power for their own support needs would then be able to purchase the services they need, be more in control, and thus ease the burden for Carers.

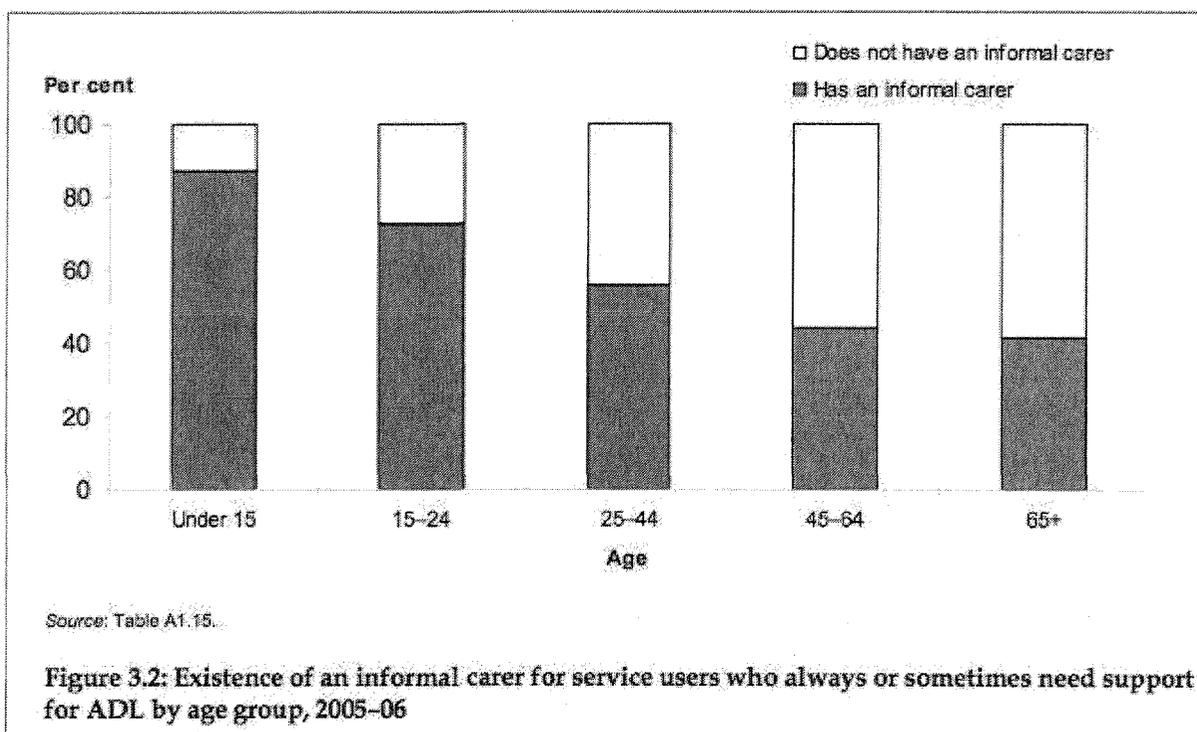


Figure 3.2 represents the proportion of service users within a given age group who always or sometimes need help with ADL, and whether they had an informal carer. For service users under 15 years of age, approximately 87% had an informal carer and always or sometimes required assistance with ADL. With an increase in age, the proportion of users who had an informal carer decreases (to roughly 41% for the age group 65+). This indicates that, proportionally, older service users were less likely to have an informal carer despite requiring assistance with ADL.

It must also be said that the number of people with disability without Carer support is far and away larger than those who use Carer support, and these people are largely ignored in additional Benefit Support and 'One Off payments' post Budget.

For instance the Australian Institute of Health and Welfare publication<sup>a</sup> on Disability Support Services 2005 - 2006 (previous page) shows that not all people with disability use Carer support, in fact the accompanying graph clearly shows that it is younger people who require Carer support, and this would be expected in any family with or without a person with a disability, whilst older persons do not require as much Carer support, even for those 65 years plus.

In fact in many instances our members report that they receive less than 5 hours of paid support per week per household, and many of these same people live on

<sup>a</sup> [http://www.aihw.gov.au/publications/index.cfm/title/10488#full\\_publication](http://www.aihw.gov.au/publications/index.cfm/title/10488#full_publication) Disability support services 2005-06: National data on services provided under the Commonwealth State/Territory Disability Agreement

their own in the community. Very little unpaid Carer support is provided unless it is by a partner or family member.

Response to the statements in the inquiry Terms of Reference:

*The role and contribution of carers in society and how this should be recognised;*

PDCA acknowledges the role and contribution many Carers give to their family members, and for some people with high support needs, this can involve a 24 hour service.

Providing more financial support directly to a Carer is not the answer, especially when the intention is to enable Carers to participate in the workforce (as indicated in the next section) as in many instances the care provided is not enhancing the life of the individual, but rather simply catering to their daily needs.

Providing more services, that are flexible and able to meet the needs of those with severe disability would free up many who have no option but to stay home and provide the services themselves. This would also allow people with disability to be included in external activities away from home which is a normal part of any society.

*The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;*

To PDCA it is clear that the barriers to social and economic participation for carers is the lack of suitable and alternative services and options. If all Carers were to suddenly find employment, there is such a shortfall in services that there would be a social and physical disaster in attempting to quickly address these needs.

Addressing this shortfall of services would allow Carers to return to work, or to participate more in society, to be healthier and more able to cope in life knowing that their child/adult child is safe and participating in appropriate activities.

Other barriers, will include the lack of education opportunities, lack of experience and skills whilst staying at home to care for a child or adult child. By providing services such as respite and more supported accommodation options and Individualised Funding to purchase their own services, Carers will be able

to take opportunities to participate in society.

*The practical measures required to better support carers, including key priorities for action;*

Key priorities for action include:

1. Lifestyle funding assigned to the individual or guardian
2. Options for Innovative and flexible services developed for people with disabilities (not Carers)
3. More supported accommodation places, so older persons do not have to remain with ageing parents
4. Individualised funding packages to purchase support paid directly to person with a disability
5. More emphasis on the person with the disability and less on the Carer
6. Remembering always that without people with disability there would be no role for Carers.

*strategies to assist carers to access the same range of opportunities and choices as the wider community, including*

- *strategies to increase the capacity for carers to make choices*
- *within their caring roles, transition into and out of caring, and*
- *effectively plan for the future.*

PDCA believes in a socially just society of inclusiveness. This includes people with disability and every opportunity must be explored by government/s to ensure that Australia's population of people with disability (over 20.6% of the population) are not without choices because there are no other options other than living with parents.

Carers are caught up in the cycle of negativity that pervades disability, and PDCA sees this consultation as a great opportunity to turn the tables to ensure that everyone has the best options to choose from, including both Carers and people with disability first and foremost.

Sue Egan  
June 2008.