Ordinary People Ordinary Lives

Standing Committee on Social Issues

Legislative Council

Inquiry into Services provided or funded by the Department of Ageing, Disability and Home Care

As requested, the following information is provided in relation to a question on notice, and to the additional written questions on notice. The Council on the Ageing will be responding separately to those questions that relate specifically to them.

Question on Notice

Page 23, Friday 3 September 2010. Source of the Working Carers figures in the article, "No places for our loved ones to go"?

The source of the Working Carers figures are drawn from Andrew Constance MP, and the Working Carers article states that *"We know from the Shadow Minister for Disability Services, Andrew Constance, that last year there were 1700 requests from carers already in crisis seeking supported accommodation for their loved one with a disability". Only 112 places were available.* It appears that Working Carers sourced this information from a statement that Mr Constance made to parliament on 14th May 2009 where he stated *" What makes these figures even more disturbing is that last year the department received 1,771 applications for supported accommodation"* . Mr Constance's MP comments can be seen at http://www.parliament.nsw.gov.au/prod/parlment/hansart.nsf/V3Key/LA20090514010

Page 29, Friday 3 September 2010. Statistics around divorce/separation and children with disability

The Australian institute of Health and Welfare reported[1] that "*In 1998, 99% of children with a disability aged 0–14 years lived in households. Of these children, 211,900 (or 72%) lived in a couple-parent family, and 83,700 (28%) lived in a singleparent family. Bradbury et al. (2001), using the same data, estimated the disability rate for children aged 5–14 years in single-parent families to be almost double that found in couple families (7.3% compared to 3.8% respectively). This result suggests that 30.6% of children with a disability live in single-parent families, compared with an estimated 18.1% of children without a disability. The link between childhood disability and single-parent families has been replicated in studies from the United States (US)*

[1] Australian Institute of Health and Welfare (AIHW) 2004. Children with disabilities in Australia. AIHW cat. no. DIS 38. Canberra: AIHW.

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and United Kingdom (UK) (e.g.Newacheck 1998), although one UK study found little difference between single- and coupleparent families if maternal education and income were controlled for (Boyce et al. 1995).

Additional written questions on notice

1. Unmet need data

Your submission refers to the summary of findings for Disability, Ageing and Carers from the Australian Bureau of Statistics (2003,p4). This document provides some useful national data on unmet need, stating that the more severe he limitation the higher the proportion with unmet need (page6)

a) **Do you observe a similar pattern to this in the communities you represent?**
The Physical Disability Council of NSW (PDCN) has observed that the 'the more severe the limitation the higher the proportion with unmet need'. When discussing unmet need , particularly in relation to the *ABS Ageing Disability and Carers 2003* paper, it is important to distinguish between unmet need and partially unmet need. The data illustrates that often services, when provided, do not fully meet the needs of clients with a severe or profound physical disability.

In its consultations with communities PDCN has observed that the complexities associated with support, for people with very high support needs, often means that the individualised circumstances /need of the client may be a barrier to accessing support, when services are program based. PDCN advocates strongly for an increase in individual funding for people with a physical disability. PDCN believes that the use of a self-directed support model will significantly reduce the amount of unmet and partially met need, experienced by all people with physical disability, and particularly those with very high support needs.

b) **Are there any other patterns of unmet need that you are aware of, relating to client groups, service types or geographic locations?**
Through Community Consultations and Specific Issue Consultations conducted throughout NSW,

- The strong message received is that people with physical disability from metropolitan, rural and regional areas of NSW are seeking ways to live their lives as valued members of their communities with support that is: relevant to their needs; empowering; person centred; flexible and responsive; and meets their changing expectations.

In research PDCN conducted in 2008 on *The Impact of Ageing on the Needs of People Disability* [2]survey responses suggested that there was a stark difference between unmet need in

[2] Physical Disability Council of New South Wales (2008) report on the impact of aging on the needs of People with a Physical Disability

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rural and metropolitan areas on issues including:

- Public transport was of particular concern to respondents from the Riverina, Murray, Illawarra and Nepean areas who identified their unmet need for accessible public transport, in particular buses.[3] In contrast, metropolitan areas were more concerned with accessibility of trains as a means of transportation.
- Medical services were another area of unmet need identified by the survey. This need steamed from a geographical bias in the distribution of medical services. Respondent comments suggested that the current shortage of medical professionals, particularly in regional and rural areas, is of concern to a population whose health needs are increasing as they see their health deteriorating."[4] This Illustrates that the lack of specialized health services in rural and regional areas has created unmet need based one geographical location

The research PDCN conducted in 2008 *The Impact of Ageing on the Needs of People Disability* also identified particular patterns of unmet need for people over the age of 50 who were ageing with a physical disability including:

- About 43 percent of people receive personal assistance from spouse/partner or family members. People expressed concern about the availability of personal assistance in terms of current and future need where the health of family carers could decline.
- Most people reported personal mobility through aids, wheelchairs and/or scooters and 43 percent of people drive a vehicle. The lack of accessible parking at shopping and medical centers was evident in the responses. The degree of mobility determines access to social activities, essential goods and services and thus people who are not mobile are restricted to community transport and public transport.
- For some people who use wheelchair accessible taxis the cost, availability and reliability of accessible taxis sometimes prohibit the use in times of need. Overall, people spoke of the need for accessible footpaths and seating in public spaces.
- About one third of people surveyed live in the family home. Eleven percent of people surveyed reported a need for home modifications as personal mobility decreased.
- Overall people expressed concern about the potential for social isolation as their needs increased and the health of family members who provide assistance declines.
- Most people were concerned about the future in terms of financial security. Particular areas that provoke anxiety about insufficient future funding include health, personal care, housing services and facilities.

PDCN has observed significant differences in unmet need for those from Culturally and Linguistically Diverse (CALD) backgrounds. Data in the Productivity Commission's Report on Government Services (2010) illustrated that significantly fewer of potential population of CALD Clients are accessing government services when compared to their english speaking

[3] Physical Disability Council of New South Wales (2008) report on the impact of aging on the needs of People with a Physical Disability p13

[4] Physical Disability Council of New South Wales (2008) report on the impact of aging on the needs of People with a Physical Disability p21

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counterparts[5]. Indeed, significant differences were found across a wide variety of services including: community access services; community support services; accommodation support services; respite services; and employment services.

2. Ageing population and 'telecare' initiatives

Your submission highlights the challenges of providing an appropriate level of service to an ageing population, and that demand for 'ageing program' services currently exceed the available funding. Carers NSW has suggested that 'telecare' initiatives have the potential to help meet the growth in demand for these services in NSW

a) ***What is your view on the potential contribution of 'telecare' to the mix of services available to people who are ageing?***

Over the past decade the United Kingdom has implemented a number of 'telecare' initiatives focusing on the following principles beneficence, non-malfeasance, autonomy and justice whilst aiming at providing:

- Help to people to maintain their independence
- Reducing the number of prescriptions dispensed
- Reducing the numbers admitted to residential care and nursing homes
- Reducing emergency hospital bed days and admissions, and reduce A&E attendances

Issues such as isolation and the impact of an ageing population are already recognised concerns within Australia. Based on international literature it is important that users do not become more isolated following the implementation of 'telecare'. It is recommended that similar pilot programs such as that conducted in the United Kingdom where a number of pilot programs were conducted to explore partnerships between health jurisdictions, local government authorities and private businesses. These programs were designed to further investigate governance arrangements and roles and responsibilities, identifying target population, baseline evaluation criteria, procurement of assistive technology, communications and engagement of stakeholders, assessment and care planning, developing integrated teams, developing pathways and assistive technology, and referral and response protocols.

[5] Productivity Commission (2010) Report on Government Services chapter 14 pp 30-47 http://www.pc.gov.au/__data/assets/pdf_file/0011/93962/57-chapter14.pdf

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b) **Are you aware of any other innovative service models to reduce the pressure off an increasing demand for services resulting from an ageing population?**
Self-directed support for people with disability provides individuals with the opportunity to have control in addressing their particular individual needs. For service providers it can provide the impetus to provide flexible services to meet individual needs. Self-Directed Support has been successfully implemented in several other states in Australia, and overseas. It means that a person with disability is able to purchase necessary supports customised to their specific needs, from any source. The adoption of this type of service model has Increased efficiency in service delivery[6] and Increased client empowerment[7].

The New South Wales Council of Social Security (NCOSS) stated, in relation to self-directed support for people with disability, in its submission to this Inquiry "*NCOSS believes this to be a more effective and efficient way of providing support, instead of fitting often square pegs into round holes in a service system experiencing overwhelming demand.*"[8]

These results in Australia and around the world suggest that the self directed service model will reduce pressure on the aged service sector, particularly for people who are ageing with disability.

3. Attendant care services

Your submission states that the demand for attendant care services increased by 12% in 2006/ 07 and that there is a level of unmet need for these services (page 6)?

Background information

A National Attendant Care Program was introduced in 1993. Attendant Care services are designed to target people, aged 16 to 65 years, who have a physical disability, who have the capacity to manage their own environment and direct their own carers, and who require more than 15 hours but less than 35 hours of personal care support in a week. The target group includes but is not limited to people with a physical disability caused by spinal cord injury, cerebral palsy, limb injury/amputee, stroke/CVA, multiple sclerosis, muscular dystrophy, polio and spina bifida. Clients may also have sensory or mental impairments. However, clients must be able to exercise control over their environment and to direct and supervise their attendant carers. Where the disability presents difficulties such as severe speech impairment, the client may use a friend or advocate to direct attendants if they wish.

People who have only a limited ability to make decisions and direct those who assist in meeting their personal care needs, may require accommodation support in a more structured environment, such as community-based accommodation with appropriate support

[6] Williams R (2007) Individualised funding summary review of its nature, impact and key elements of success pp 18-20 Julia Farr Association , Adelaide, Australia

[7] *Disability & Society (2003) Individualised Support and Funding: building blocks for capacity building and inclusion Vol. 18, No. 1, pp. 71–86*

[8] Inquiry into services funded and provided by Ageing, Disablity and Home Care: NCOSS Submission 2010

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and training. People with severe and/or multiple impairments may find it impossible to live in the community with a maximum of 34 hours of attendant care per week. These people may require more extensive levels of assistance and alternative forms of accommodation support.

An ADHC Attendant Care Program was introduced in 2007. Under this program individuals may be eligible for an Attendant Care Program package if they: are between 16 and 65 years old live in their own/family home or in their own leased/shared accommodation (people living and intending to continue living in supported accommodation such as group homes or residential care facilities are not eligible); are able to manage living in the community by accessing community supports; need more than 15 hours per week of personal assistance to complete activities of daily living; are ineligible or not suitable for other DADHC provided or funded accommodation services in the short to medium term.

The Attendant Care Program is a suitable option for people with:

- a physical disability whose needs can be substantially met with personal care support and who can be involved in managing their care; or an Acquired Brain Injury (ABI) and a physical disability (or who need physical assistance to complete tasks of daily living); or
- a neurological degenerative condition including a rapidly degenerative condition; or
- ventilation dependency (over 24 hours) in which case the package may be jointly funded and managed with NSW Health.

a) Why do you believe the demand for these services is increasing?

Differences between the eligibility of the Commonwealth Government Attendant Care Program (ACP) originally provided in 1993 and the program currently provided by Ageing, Disability and Home Care (ADHC) NSW Department of Human Services maybe slight, but clearly the national program placed greater importance on the capacity of the individual receiving service to be independent. It was stated *'that service users needed to be able to exercise control over their environment and to direct and supervise their attendant carers'*. [9]

With the increased flexibility in eligibility in the Attendant Care Program provided through the ADHC from 2007, PDCN concludes that this has encouraged people with disabilities who previously were not eligible to now apply, and hence significantly increase the demand for the service. As it is, in NSW in 2001 there were approximately 250 people with disabilities on the Attendant Care Program wait-list [10], increasing to 589 applicants registered on the high in-home personal support services register in the 2007- 08 financial year. [11]

[9] NSW Department of Ageing, Disability and Home Care (2003) Attendant Care Program (ACP) Manual of Procedures and Guidelines
[10] Australian Institute of Health and Welfare- Disability Series (2002) Unmet need for disability services: effectiveness of funding and remaining shortfalls, P. 191
[11] NSW Parliament- Department of Ageing, Disability and Home Care (Budget Estimates 2007- 08) Questions on Notice

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Based on figures in the 2008/ 09 ADHC Annual Report, ADHC was providing 740 ACP places in 2008/ 09 financial year [12], which is well on track with the expected rollout of ACP places identified in *Better Together 2007- 2011.* [13] In the PDCN submission figure 4.11 from the AIHW Welfare Report 2009 is identified to reinforce feedback stating that 'attendant care users have increased 12% over 2007/08', Reference to this figure is correct but our submission should read 'attendant care users have increased 12% over the financial years 2003/04 - 2007/08. Reference 13 in our submission should identify the following document: *13. Australian Institute of Health and Welfare (2009) Australia's Welfare Figure 4.11 P. 165.*

The following data on the provision of personal care services in NSW illustrates a significant increase in the number of Attendant Care Places between 2007 and 2009, with a decrease in the number of people on the High Need Pool, but needing a larger amount of service delivery than High Need Pool clients in the previous year.

- In NSW community support included the following in the financial years 2007- 08:
    - 430 places in the Attendant Care Program
    - 16,000 clients accessed 1.4 million personal care service hours
    - 590 clients in the High Need Pool accessed 542,000 hours of service, as follows:
        - 590 clients accessed a total of 448,000 personal care service hours
        - 400 clients accessed a total of 60,000 domestic assistance service hours
        - 120 clients accessed a total of 33,000 respite care service hours
        - 30 clients accessed a total of 600 home maintenance service hours [14]
- In NSW community support included the following in the financial years 2008- 09:
    - 740 places in the Attendant Care Program
    - 16,000 clients accessed 1.4 million personal care service hours
    - 520 clients in the High Need Pool accessed 580,000 hours of service, as follows:
        - 500 clients accessed a total of 480,000 personal care service hours
        - 300 clients accessed a total of 61,000 domestic assistance service hours
        - 75 clients accessed a total of 31,000 respite care service hours
        - 20 clients accessed a total of 690 home maintenance service hours [15]

[12] Ageing, Disability and Home Care- NSW Department of Human Services (2009) Annual Report, P.52
[13] NSW Department of Ageing, Disability and Home Care (2007) Better Together 2007- 2011, P. 18
[14] Ageing, Disability and Home Care- NSW Department of Human Services (2009) 2008/ 09 Annual Report
[15] Ageing, Disability and Home Care- NSW Department of Human Services (2008) 2007/ 08 Annual Report

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b) What is the impact on families of not receiving attendant care services where they may be required?

Attendant care services assist a person with a disability to perform tasks they would normally be able to do for themselves such as:

- Showering, bathing, oral hygiene, dressing and grooming
- Personal hygiene including bowel and bladder care
- Dietary intake;
- Medication use
- Fitting and use of aids and appliances, hearing and communication devices
- Mobility and transfers
- Health maintenance, such as the application splints and
- Exercises or stretches.

People with disabilities unable to access Attendant Care Services are at increased risk of premature or inappropriate admission to long term residential care, being dependent on family members, severely impacting on the health and social being of family members, and being unable to participate in activities of normal living such as earning an income. The Physical Disability Council of NSW believes that sufficient and appropriate supports need to be made available to maintain normal healthy family relationships.

A study recently conducted by the Australian Institute of Family Studies illustrates the emotional, social, financial and physical impact on family members that care for a person with a disability. These findings include:

- Carers had significantly worse mental health and vitality and higher rates of depression than the general population
- The risk of carers and family members experiencing a depressive episode of 6 months or more was greatest in the first year of caring.
- Almost twice as many carers were in poor physical health than the general population
- Almost one in three female carers aged 50 or less had separated or divorced since they started caring, while one in seven over the age of 50 had separated or divorced since they started caring
- Compared to families from the general population, a higher proportion of families of carers suffered from greater financial hardship
- Carers who had multiple care responsibilities or who were also caring for children had worse mental health outcomes. [16][10]

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