

The Program of Appliances for Disabled People

Carers NSW Submission to NSW Health

1. Family carers in NSW

Carers NSW is the peak body representing an estimated 750,000 family carers in NSW. These are family members and friends who support and care for someone with a disability, a chronic condition, mental illness or frail aged person. The level of support they provide ranges from intermittent to full-time care, including personal care, assistance with communication, mobility and transport.

1.1 Carers and the PADP

The Program of Appliances for Disabled People is an essential program for family carers in NSW as equipment and aids provide a fundamental support to them in their caring role. Carers NSW staff, including Carer Support Officers in the Commonwealth Carer Resource Centre, and project staff, often hear from carers about the impact of equipment on their finances, health and caring role.

It is for these reasons that Carers NSW is providing this submission on the discussion paper produced by Pricewaterhouse Coopers for NSW Health.

Carers NSW welcomes this long awaited and much needed review of the PADP. We also support the ongoing campaign by the Physical Disability Council of NSW to improve this fundamental service providing aids and equipment for people with disabilities and their families in NSW.

A brief outline below of the financial and health impacts of caring serves as background information on our comments regarding the discussion paper. These are the areas where the PADP are of most benefit to carers and factors to be considered in the review of the Program.

1.2 Impacts of Caring

Recent statistics from the Australian Bureau of Statistics demonstrate that family carers are financially worse off than the general population in NSW. This results from the combined effects of the costs associated with disability and caring, lost employment opportunities due to the demands of caring and living on a fixed income.

To summarise, the ABS¹ estimated that in 2003 in NSW:

- 76% of carers were workforce age

¹ ABS (2004) 'Survey of Disability, Ageing and Carers: Summary of Findings' NSW Tables, Australian Bureau of Statistics, Canberra.

- 64% of primary carers were not in the labour force, compared with 32% of non-carers
- 55% received a government pension or allowance as their main source of income, compared with 23% of non-carers
- primary carers had a median household income of \$224 per week compared with \$435 for non-carers

A number of national reports have shown that the cost of disability is significant and has a measurable impact on families. Stollznow Research, in a 2005 report commissioned by Carers Australia², found that single-parent carers of children with disabilities had a household income 46% of the Australian average and spent nearly 10% more of their income on medical costs. In addition reports by the Taskforce on Care Costs³ and by Carers Australia⁴ found that the costs of caring were far in excess of the Carers Allowance.

The health impacts of caring are also significant and in many cases can be directly prevented or eased with the provision of aids and equipment that reduce the physical strain on carers.

Carers Australia conducted a survey of carers in 1999⁵ finding that:

- 55% of carers reported tiredness or exhaustion
- 34% reported upper body problems
- 13% had high blood pressure and other heart problems
- 10% had arthritis

One of the most commonly cited reasons for the above conditions in carers was from providing mobility assistance. This was particularly the case for long-term carers and carers of children with disability.

1.3 Current PADP Issues

There are a number of issues that carers frequently raise with Carers NSW, either through the Commonwealth Carer Resource Centre or through project staff at Carers NSW. These issues can be summarised as follows:

- delays in processing applications and receipt of equipment – this is particularly an issue where people are returning home from hospital but cannot receive community services until appropriate equipment is in place
- long waiting lists – sometimes waiting lists are so long, in fact, that by the time people get the equipment they need, it is no longer appropriate for them
- inappropriate equipment – this is particularly an issue for children and can hinder growth and functioning
- inconsistency in waiting lists and the types of equipment/appliances available between regions

2 Stollznow Research (2005) A crisis in caring, or a system that works?

3 Taskforce on Care Costs (2005) Creating Choice: Employment and the Cost of Care

4 Carers Australia (1998) Caring Costs: a survey of tax issues and health and disability related costs for carer families

5 Carers Australia (2000) 'Warning – caring is a health hazard: Results of the 1999 National survey of carer health and wellbeing, Carers Association of Australia, Canberra.

2. Reviewing the PADP

In light of these recurring issues for families of people with disability, we make the following comments on the PADP discussion paper in the areas of funding, equity and information.

2.1 Funding the program

There is ample evidence that care in the community of people with disability and ageing people is likely to increase in the coming years. This relates to concurrent social and demographic trends including deinstitutionalisation or non-institutionalisation and the move to community care, the ageing of the population and the projected increase in the disability rate of people over 65.

This equates to a greater need for informal care, as reported by the National Centre for Social and Economic Modelling in 2005⁶. It was projected that the number of people aged over 65 needing care in the community will increase by 160 per cent to 1,390,000 people by 2031. Their carers are most likely be ageing themselves and living in the same household.

These demographic changes present challenges to existing programs such as the PADP to keep up with the increasing demand.

Given the current shortfalls of the funding for the Program it is essential that a commitment is made by the NSW Government, not only to increase funding to a workable level but to incorporate demographic pressures on community care programs into future funding.

2.2 Benefits of PADP

Timely and appropriate assistance with aids and equipment can have enormous benefits, not only for the lifestyle of the person requiring assistance but also of their family carers. Many of the health problems associated with caring (see above) can be addressed and even prevented through the provision of aids and equipment.

The preventative benefits of the PADP could include reduced expenditure on acute health care, residential aged care, supported accommodation for people with disabilities and other community care services. The timely provision of appropriate equipment and aids can only benefit and support an informal caring relationship.

2.3 Access Issues

The following comments relate to the issues raised in Table 2 of the Discussion Paper.

- Information about the PADP should be made available through a number of channels and in a range of community languages. The current indication in the discussion paper is that people who are already connected with services or in support groups find out about PADP through word of mouth. Advertising only through the NSW Health website precludes some of the key target groups for the PADP scheme, such as older people and financially disadvantaged people, who are less likely to use the internet than others, from accessing the service.

There should be posters and brochures available in hospitals and Community Health Centres. They should be accessible for Aboriginal and Torres Strait Islanders and a range of community languages. It is most likely that these groups are under-utilising the PADP services as they generally have lower levels of access to other services, which may act as

6 Percival R & Kelly S (2005) 'Who's going to care? Informal care and an ageing population', National Centre for Social and Economic Modelling

in information and referral source to the PADP.

It is a matter of concern that information about the PADP does not reach a potentially large group of people in need of aids and equipment and their carers. Furthermore this does not allow for any collection and reporting of unmet need.

It has been reported at Carers NSW that young carers rarely know about the PADP and that the process of accessing aids and equipment is arduous for this group of carers as it is complicated and requires a lot of liaison with different health professionals and administrators.

- The development of a single state-wide application form that can be downloaded from the website is recommended as it would create greater state-wide consistency and potentially reduce administrative costs. It is important that if people apply on line, however, that they receive information straight away about how long to expect the application to take.

2.4 Eligibility Issues

The issues on eligibility outlined in Table 3 are essentially about equity of service provision in an environment of limited resources. We are able to respond to some of the questions raised.

- Universal access for children should be maintained. This is to account for the fact that families with children with disabilities face significantly higher costs than other families (including modified vehicles and homes, medication, specialist health care) and this can endure for an extended period of time as the child grows.
- Bands 3 and 4 could potentially be removed from the eligibility guidelines. However there could be other options available, for example to increase the co-payment for large expenditure items, with an option to pay off the amount over an agreed period of time.
- Given that one of the greatest concerns carers have with the PADP is the time taken to get equipment once they have applied, any strategy that could reduce that time should be considered. Increasing the cost limit of applications that need to be considered by the Advisory Committee appears to be a feasible strategy.
- Use of government contracts to purchase in bulk seems to be a good idea.

It is most important when making policy decisions about the banding system to take account of other factors that influence a person's ability to pay for aids and equipment. For instance, if there is more than one person in the family requiring care this will impact on their capacity to pay, and should be considered as part of an assessment.

2.5 Management and Administration Issues

In relation to the possible options raised in Table 4 of the discussion paper, Carers NSW considers the following to be viable:

- More effective use of existing stock through the development of a central database would be a welcome development.
- The grandparenting clause should be removed. For equity reasons, any exemption from the co-payment should be for reasons of extreme financial hardship.
- In cases where the family suffers extreme financial hardship (this may be particularly significant for Aboriginal and Torres Strait Islander families) the co-payment could be waived to ensure that they are still able to access necessary equipment and aids.

3. Conclusions

The PADP provides an essential service for family carers assisting a family member with disability, chronic conditions or who is frail aged. We welcome the current review and the opportunity to comment on the discussion paper.

We wish to stress our concerns regarding the adequacy of funding for this fundamental program and also about equity in terms of access to information and equipment through the PADP.

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