Submission No 63

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

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Inquiry into the Program of Appliances for Disabled People (PADP)

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To: The Director General Purpose Standing Committee No. 2 Parliament House Macquarie St Sydney NSW 2000 Fax: (02) 9230 3416

Submission to the Inquiry into the Program of Appliances for Disabled People

Dear Committee Members,

Thank you for giving me the opportunity to make this submission to the Inquiry into the NSW Program of Appliances Disabled People. I am a PADP consumer and have been a member of the NSW Health PADP Advisory Committee since 1999 representing the National Disability Services (NDS), which was formerly known as ACROD NSW, as well as a member of the Prince of Wales Hospital PADP Advisory Committee since 2002 as a consumer representative.

I provide the following information and recommendations and trust the committee will give it due consideration as I believe the content highlights a number of issues that impact on all stakeholders including equipment suppliers, equipment assessors and prescribers and particularly people with a disability and older people.

Background

The PADP is greatly valued by people with a disability and older people as it provides essential equipment, aids and appliances, including continence supplies, to support people to live in the community and to prevent admission to nursing homes or care facilities.

As the Australian States and Territories are generally responsible for providing disability services, the PADP is one of a number of NSW Government services provided to support people with a disability and older people. Although disability programs and services are the responsibility of the NSW Department of Ageing Disability and Home Care (DADHC), PADP is administered and funded by NSW Health but receives limited funding from DADHC.

Issues:

1. Adequacy of funding for present and projected program demand

The PADP is just one of a number of NSW Government programs that supports people with a disability, and older people, to live in the community and to prevent admission to a nursing homes or care facility. It is widely recognised that PADP has always been underfunded resulting in eligible people with a disability and older people waiting long periods to receive essential equipment, aids and appliances. It is not uncommon for people to be waiting more than 12 months with reports of eligible people waiting up to four years.

PADP underwent two separate reviews. The Carla Cranny Review in 1997, and the PricewaterhouseCoopers Review in 2006, with both reports highlighting inadequate funding with recommendations to increase the levels of funding to meet the current and future demand.

The disability sector representatives on NSW Health's PADP Advisory Committee have always advocated for an increase in PADP funding. However, although NSW Health has agreed more funding is required, it has always maintained that it requires appropriate data on the demand for PADP before it could approach the NSW Government and NSW Treasury to seek an increase in PADP funding.

The Carla Cranny Review recommended the development and implementation of a PADP Information System to capture the data and enable NSW Health to understand the demand on PADP, the funding required to meet the current and future demand on PADP.

Unfortunately, the PADP Information System that was initially developed and implemented in 2001/2002 was inadequate. It could not produce relevant reports and could not interface with other NSW Health information systems and databases. This created an extra workload for the PADP Coordinators who had to enter the data into different systems to extract the required reports. NSW Health engaged computer programmers to try to resolve the problems but the PADP Information System is still inadequate. However, since the release of the PricewaterhouseCoopers Review, NSW Health has been implementing many of its recommendations and has agreed to develop and implement a new PADP Information System.

It is anticipated that the new PADP information system will address the needs of PADP, and the other programs within Enable NSW under its new structure. It is imperative NSW Health uses the data and information to also keep track of equipment, aids and appliances that have been returned to PADP for reallocation, forecast the demand on PADP, create service uniformity across NSW and seek appropriate funding from the NSW Government to meet this demand.

However, there is other ways of establishing the demand on PADP without the use of a centralised information system, such as collecting the details of PADP applications from each PADP Lodgement Centre or Were Area Health Service. It is understood the Ministry of Health has always understood what the demand on PADP is but failed to allocate an appropriate recurrent budget to meet the demand.

It is false economy to not adequately fund PADP to meet current and future demands. The NSW PADP has similarities with the UK equipment programs, of which underwent a review in 2000 (and subsequent update in 2002) that released the report titled Fully Equipped.

Fully Equipped is a well researched document that outlines the benefit of appropriate funding and investment in equipment for people with a disability.

Fully Equipped: The Provision of Equipment to Older or Disabled People by the NHS and Social Services in England and Wales can be downloaded from: http://www.audit-commission.gov.uk/reports/NATIONAL-REPORT.asp?CategoryID=&ProdID=BD34429B-F1B2-4E50-8A82-7A60A7A45302

Fully Equipped 2002 [update] Assisting Independence http://www.audit-commission.gov.uk/reports/NATIONAL-REPORT.asp?CategoryID=&ProdID=2103ACC1-7512-46a0-B74C-3D28724585FE

2. Impact of client waiting lists on other health sectors
People with a disability and older people require a variety of support services to enable them to live in the community and to have the opportunity to actively participate as citizens. The basic services include housing, personal care and/or respite services, home modification and maintenance and PADP for equipment, aids and appliances.

Unfortunately, sometimes the provision of these services is fractured due to being uncoordinated or underfunded instead of being provided with a 'Whole of Government' approach with a 'person centred' focus.

I believe there are two main areas that are impacted from PADP client waiting lists. Firstly, although it is regularly reported in the media that there are long waiting lists of people to be admitted to a public hospital for medical treatment, it is understood that there are people waiting to be discharged from hospital, but are unable to do so due to lack of funding for the PADP equipment, which is costing NSW Health approximately \$1000-\$1500 per bed per day.

Secondly, people with a disability and older people living in the community that use the NSW Home Care Service, or other non-government personal care services, often require various types of equipment for the carers to assist them. I have heard of situations where people are under threat of having the service withdrawn because they are waiting on PADP equipment.

I believe there is definitely a negative financial impact on other health sectors, particularly the hospital system due to PADP waiting lists. It would require auditing and some research to obtain the figures on other health sectors. However, it would be difficult to capture the emotional and possible financial impact on people with a disability and older people from not being able to be discharged from hospital due to not been provided with equipment, or the anguish of being under the threat of losing the personal care service and being admitted to a nursing home or care facility.

Equipment suppliers and therapists that undertake equipment assessment and prescription are also adversely affected by the client waiting lists. Depending on the length of time a client has been waiting for the equipment, aid or appliance to be funded, the item may no longer be available for a variety of reasons or the client's needs may have changed.

In many situations it will require the duplication of the entire equipment trialling, assessment and prescription process involving the PADP customer, the therapist/prescriber and a number of equipment suppliers. This can be very inconvenient to the PADP customer and obviously increases the operating costs to the equipment provider and increases the workload of the therapist/prescriber.

3. Effects of centralising PADP Lodgement Centres and the methods for calculating and implementing financial savings from efficiency recommendations

The PricewaterhouseCoopers PADP review report includes Section 7.3 Major Recommendations - one operation in NSW:

Recommendation 1

It is strongly recommended that all PADP functions be transferred from the current Lodgement Centres to one state-wide administration covering the state, and;

Recommendation 2

A feasibility study should be commissioned by NSW Health to investigate the cost and challenges associated with establishing a single state-wide service to replace the current hospital based operations.

The PricewaterhouseCoopers review makes an argument for the centralisation of the PADP administration as it is expected to save money on PADP Lodgement Centre salaries and administration costs, suggested Area Health Services would prefer not to have the responsibility of PADP administration and that there would be little impact, except on the convenience of some PADP customers and clinicians that have a good relationship and service from half the local PADP Lodgement Centres.

I understand that many PADP customers and clinicians have major concerns about the proposed centralisation of the PADP administration and losing local PADP Lodgement Centres. Although PricewaterhouseCoopers may be able to calculate a financial saving to the PADP, the impact on PADP customers and clinicians should not be simply dismissed. Consideration should be given to the financial implications for PADP customers and clinicians from the impact of a new PADP system, particularly if it increases the workload of clinicians.

I strongly agree with Recommendation 2 and request that if and/or when PADP administration is centralised that it be phased in or run in parallel with the current PADP system to ensure that its introduction is as seamless as possible.

4 Appropriateness and Equity of Eligibility Requirements

Currently the PADP eligibility criterion assesses applications on disability, income and the concession card type. There is currently four income bands, with priority given to applicants on Band 1 that have the Disability Support Pension (DSP) Concession Card or the Health Care Card up to Band 4 for applicants with a taxable income in the preceding financial year was above \$39,941 (single) and \$67,899 (couple or family) adjusted for dependents are eligible to apply for high cost items only.

All people with a disability are eligible to apply for equipment, aids and appliances from the PADP, however, due to the lack of adequate PADP funding, much emphasis has been placed on developing, maintaining and implementing an eligibility criterion.

As previously mentioned, people with a disability and older people require a variety of support services to enable them to live in the community and prevent early entry to a nursing home or care facility. They also have extra unavoidable costs of having a disability that other members of society do not have. Unfortunately, these extra costs are generally not calculated or considered by the government departments or services, including PADP, that assess applications with an 'eligibility criteria' that focuses on a person's income and assets and what type of concession card they might have.

People with a disability that require various types of equipment, aids and appliances, including continence supplies, may also have extra costs for personal care services, respite care, medication and health-related products. Transport costs can be a major expense particularly if wheelchair accessible taxis are their only means of accessible transport and especially if the person is living in a regional or rural area with vast distances to travel. There is also extra electricity costs associated with operating essential equipment like electric beds, pressure care mattresses, charging wheelchair batteries, operating ventilators etc.

Also, people with spinal cord injuries, multiple sclerosis and other medical conditions are affected by the extremes in temperatures due to having compromised neurological systems and require running heating/cooling systems for longer periods of time incurring higher costs for operating these systems.

Disability alone should be the benchmark for PADP eligibility, however, PADP should not be available to people that are eligible to receive equipment, aids and appliances through other programs such as the Lifetime Care and Support Scheme or funding via financial compensation. However, when there is a comparatively small compensation payment, such as the maximum payment from the NSW Sporting Injuries Insurance for catastrophic injury e.g. quadriplegia or paraplegia, it may be spent quickly. I suggest recipients of relatively small compensation payouts should not be excluded from accessing PADP permanently, with a post injury time limitation of 5 years before they can access PADP.

Although the NSW Government's budget is finite, it needs to give a higher priority to people with a disability and older people and recognize the positive outcomes of providing appropriate and timely equipment, aids and appliances and invest in PADP to ensure it meets the applicant's needs.

Around 2003/2004 NSW Health introduced a 'one off' annual \$100 copayment for eligible people receiving items from PADP. As it was a 'new charge' a 'grandfathering' policy was introduced and the copayment is only required to be paid by people that started accessing PADP from 2003/2004.

The \$100 copayment policy has become an administrative nightmare for many PADP Lodgement Centres. Many PADP coordinators were (and possibly still are) requesting/charging the copayment from PADP customers that had been accessing the program pre-2003/2004.Most of these customers were (and possibly still are) making the copayment because they were unaware of the 'grandfathering' policy.

There are a number of NSW Government health services that have a larger recurrent budget than PADP that are not means tested and do not require a copayment from the customer such as breast screening program.

When considering the extra unavoidable costs of having a disability I believe it is unfair and equitable that the NSW Government introduced, maintains and, regularly maladministers this \$100 copayment policy and I seek that this review recommend that the \$100 copayment be abolished.

Furthermore, in July this year Australia ratified the UN Convention on the Rights of Persons with Disabilities, making Australia one of the first Western countries to ratify the Convention. Australia joins 29 other countries around the world in a move that aims to promote a global community in which all people with disability are equal and active citizens.

I applaud the Australian Government for ratifying the UN Convention on the Rights of Persons with a Disability, but if all people with a disability in Australia are to be considered equal and active citizens, then all levels of government must work together to provide appropriate funding to ensure people with a disability are not only thought of as being equal and active citizens but have the opportunity to do just that.

5. Future Departmental Responsibility for the PADP PADP is currently funded and administered by NSW Health but generally a 'disability program or service' would expected to be funded and administered by the Department of Ageing Disability and Home Care (DADHC).

I see no problem with the current administration of PADP by NSW Health, however, I agree that PADP should sit within the responsibility of DADHC. However, as PADP is under review and is currently being restructured, I believe the transfer of PADP to DADHC should only take place if it can be established there will be a positive outcome in PADP's funding, administration and service delivery.

As previously mentioned, as the Australian Government has ratified the UN Convention on the Rights of Persons with a Disability, I believe the Australian Government has a responsibility to work with the Australian States and Territories to ensure there are adequate funding and uniformity in the administration and eligibility criteria of the equipment programs.

6. Any other related matter

There are a number of other related matters associated with the PADP administration that need to be reviewed.

PADP Administration Hours and Staffing Levels

PADP Lodgement Centres are administered by the local Area Health Services and the operational hours and staffing levels vary. Due to the workload and staffing levels it is not uncommon to have the telephone call continually answered by an answering machine and messages left on the answering machine may not receive a response for two or three days.

PADP is an essential service and adequate administration hours and staffing levels are important. As many people with a disability and older people are totally reliant on their equipment, aids and appliances for mobility and independence, it is important that PADP is able to respond to calls when equipment breaks down and requires urgent repairs. In my experience it is common for equipment to break down on Thursday or Friday's, or in the evenings.

With PADP currently under review, and with a proposal to centralise the administration, I believe there needs to be appropriate administration hours and staffing levels and I strongly recommend the implementation of an 'Out Of Hours' PADP service to report equipment breakdowns and that NSW Health establish contracts with services that can provide urgent equipment repairs or replacement parts.

The Need for a Whole of Government Approach to Providing Disability Support Services

The NSW Government provides support services for people with a disability and older people to live in the community through DADHC, which administers and funds the personal care services through the Attendant Care Program and the Home Care Service, community services through the Home and Community Care (HACC) programs, accommodation services through the Department of Housing and Home Modification and Maintenance Scheme etc with NSW Health administering services such as the PADP, Artificial Limb Service, Ventilator Dependent Quadriplegia Program, Home Oxygen and Community Health etc.

Unfortunately these services are generally not provided with a 'Whole of Government' approach and the lack of appropriate funding for one service can sometimes put pressure on other services. Occasionally when people with a disability or older people are accessing a number of services there may be a dispute between the services as to which one has the responsibility for providing the specific service.

To highlight this issue, further to my comments provided in .2 Impact of Client Waiting Lists on Other Health Services, I have heard of people with a disability or older people being under threat of the personal care service being withdrawn

because they do not have the equipment for the care workers to assist them as the equipment is being supplied by PADP but the customer is on a waiting list.

People with a disability and older people should not be placed in this situation where they are made to feel like the 'meat in the sandwich' and potentially losing their personal care service and possibly being admitted to a nursing or other care facility.

I believe the NSW Government needs to ensure its disability services provide a more cohesive and seamless service with a Whole of Government approach. Although it may be outside the PADP review Terms of Reference I would like to recommend the introduction of a Disability Department to operate as a 'one-stop shop' for people with a disability where they could access all the relevant disability services and programs without the need to make separate applications for the above-mentioned services they require.

Again, thank you for giving me the opportunity to make this submission to the PADP inquiry and I would be happy to clarify or discuss any of the above-mentioned issues contained in this submission.

Regards,

Greg Killeen