

Submission  
No 54

## **THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)**

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**Date received:** 4/09/2008

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National Disability Services

New South Wales

## **POLICY TO REFLECT PRIORITY: THE VITAL ROLE OF THE PADP FOR PEOPLE WITH DISABILITY, THEIR FAMILIES, DISABILITY SERVICE PROVIDERS AND THE COMMUNITY**

**Submission to the NSW Legislative Council's General Purpose Standing  
Committee no. 2 Inquiry into the  
NSW Program of Appliances for Disabled People (PADP)**

September 2008

### **INTRODUCTION**

The NSW Program of Appliances for Disabled People (PADP) is, first and foremost, a system aimed at enhancing the social inclusion of people with disability within their community. The PADP is also a program by which people with disability can gain and maintain independence, essentially improving quality of life and longevity.

Whilst in principle, the rationale underpinning these benefits to people with disability are inalienable human rights, the function of the PADP in practice is yet to be regarded as an adequate system of provision. In line with the recently ratified *UN Convention on the Right of Persons with Disabilities*,

People with disability and their families highly value the provision of aids and equipment, however this is not reflected in current or previous government policy, where aids and equipment has been undervalued and significantly under-resourced. A shift in policy and an increase in recurrent funding is required to reflect the vital role of the provision of aids and equipment for people with disability, their families, service providers and the wider community.

A lack of timely and appropriate provision of aids and equipment (assistive technology)\* to people with disability impacts on service providers, as service providers may not be able to provide safe, high quality services to people who are not adequately supported by the proper aids and equipment. In addition,

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\* NDS interrelates the terms "aids and equipment" and "assistive technology" as referring to a combination of traditional aids and equipment (such as wheelchairs, hoists, adjustable beds) and more contemporary assistive technologies (such as communication devices).

the resources of specialist organisations, such as the Spastic Centre, the Northcott Society and the Royal Institute for Deaf and Blind Children may be wasted because the length of time between lodging an application and receiving approval means that the applicant needs to be re-assessed before the appropriate equipment can be provided.

It is recognised that the PADP needs to operate within a budget. However, in order for funds to be allocated equitably, eligibility criteria needs to be clear and applied consistently across the State. In addition, the allocation process needs to be streamlined to ensure equipment is provided in a timely manner.

Although the lives of people with disability are very much dominated by public policy, the provision of aids and equipment remains a very private issue of high priority to people with disability<sup>1</sup>, their families and service providers.

## **SUMMARY OF KEY ISSUES AND RECOMMENDATIONS**

NDS supports the Inquiry into the PADP. It is pleasing to see that the issues raised by people with disability, their families and service providers are on the agenda and being investigated.

### *Key issues:*

- Inadequate funding
- Lack of availability of particular essential equipment, particularly high-cost aids such as communication equipment
- Lack of transparency and inconsistent application of eligibility and prioritisation criteria
- Lengthy waiting times and inefficiencies in administering the PADP
- Lack of understanding about disability issues and ongoing needs of clients wishing to participate actively in their community by PADP Lodgement Centre Staff
- Lack of focus on aids and equipment as essential tools of social inclusion and quality of life measures
- Lack of recognition that the timely and appropriate allocation of aids and equipment impacts upon the future health and opportunities of people with disability, their carers and the community

NDS proposes the following recommendations aimed at ensuring the provision of appropriate equipment to people with disability in a timely and equitable manner:

### *Funding and Equity*

- Provision of adequate funding to reflect unmet need, and to reduce financial contributions from people with disability, their families and service providers to procure aids and equipment
- Consistency across all PADP Lodgement Centres

### *Eligibility and Assessment*

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<sup>1</sup> Lyn Dowling, *Equipped for Life – a very private public issue: Policy and equipment in the lives of children and families*, University of Newcastle.

- Clear eligibility criteria and streamlined assessment process
- Reconfiguring the PADP as a system of entitlement rather than eligibility

#### *Prioritisation and Allocation*

- Formulation and publication of clear prioritisation criteria
- Commitment to and measurement of the timely allocation of aids and equipment to reduce waiting lists

#### *Early Identification and Prevention*

- Early identification of those eligible as both preventative measure and demand management strategy

#### *Access and Information*

- The provision of greater accessible information about the process, entitlements and products of the PADP to people with disability, their family and carers, and service providers

#### *Repairs, Maintenance and Support*

- Greater recognition of ongoing maintenance and timely repairs as essential to the PADP
- Establishment of a comprehensive support system for users of aids and equipment, such as a 24 hour helpline and 24 hour repairs service

#### *Staff Development and Training*

- Disability awareness training for all PADP staff in line with the Disability Service Standards and the Disability Discrimination Act
- Ongoing training and support for clinicians prescribing aids and equipment

#### *Accountability and Transparency*

- Greater transparency and accountability of the PADP via the publication of statistics and the establishment of a clear complaints and appeals process

#### *National Consistency*

- Principles of a nationally consistent aids and equipment scheme should be formulated to tackle the current fragmentation and inequalities

## WHAT THE DATA TELLS US

The most recent Australian Bureau of Statistics (ABS) *Survey of Ageing, Disability and Carers (SDAC)* indicates that in 2003:

- One in five Australians (3,958,300 or 20%) had a reported disability
- Of those with a reported disability, 86% (3,387,900) were limited in the core activities of self care, mobility or communication, or restricted in schooling or employment
- One in ten Australians (1,979,150 or 10%) used equipment or an aid to help them cope with their condition or manage with their everyday life
- A further 395,700 Australians living in private dwellings had made modifications to their home to enable them to cope with restrictions to their activity levels or to continue to live in their homes

A significant proportion of these people received assistance in purchasing this equipment.

The provision of aids and equipment plays an important role for carers, as well as for the person with disability. The SDAC indicates that in 2003 there were 2.6 million (13%) carers who provided some assistance to those needing help due to disability or age.

One in five carers (474,600) were identified as primary carers to people with disability, mainly within their own home. Those who provided care to people with disability were more likely to be older and/or have a disability than those who did not provide care. Of those living in households, the disability rates were 40% for primary carers, 35% for all carers and 20% for non-carers. These figures indicate that the timely provision of appropriate aids and equipment is important for the wellbeing and safety of carers, as well as the person with disability.

Looking specifically at NSW, the ABS *Disability, New South Wales* indicates that in 2003:

- One in five people in NSW (1.2 million or 19%) had a disability
- Most of these people (88%) had a specific restriction consisting of a core activity restriction such as self care, mobility, communication, schooling or employment
- The NSW regions with the highest rates of disability were the South Eastern (25%), Central West (25%) and Hunter (25%) ABS Statistical Divisions
- For 85% of people with disability, physical conditions were the cause of their disability
- People of working age with disability have a lower rate of workforce participation (50%) than those without disability (80%)
- The median gross weekly income of people with disability (\$190) was less than half that of people without disability (\$390)
- More than half of people with disability were reliant on a government pension or benefit as their main source of income
- Two-thirds of people with disability aged over 5 were not able to go out as often as they would like, with nearly half indicating this as being due to their own condition or illness

- One or more mobility aids were used by 150,800 people with disability

An estimated 798,300 or one in eight people were performing a caring role. About 40% of primary carers had a disability.

The labour force participation rate for all carers of working age was 76% for men and 57% for women.

For non-carers, the rates were higher for both men and women, at 84% and 69% respectively. These figures show that disability, in a broad sense, impacts heavily upon carers, particularly in terms of employment participation and social exclusion.

## **PROGRAM OF APPLIANCES FOR DISABLED PEOPLE: THE STORY SO FAR**

### **The NSW Program of Appliances for Disabled People (PADP)**

The PADP was established in 1982.

The role of the PADP is to assist residents of NSW who have a permanent or long-term disability to live and participate in their community through the provision of equipment.

#### ***Departmental Responsibility***

NSW Health has issued a policy which sets out the eligibility criteria for the PADP, as well as the roles of the Department and Area Health Services in operating the PADP.

The NSW Department of Ageing, Disability and Home Care (DADHC) operates an Equipment and Modifications Fund which provides funding for building modifications to allow people to participate in Community Participation or Transition to Work programs.

Under this fund, equipment may be purchased for the use of a single service user or a group of service users attending DADHC programs, excluding equipment which is funded under other Government programs, such as the PADP.

#### ***Funding***

The funding level for the PADP in 200 was \$12.5 million.

In 2005 it was \$21.5 million.

The current PADP funding for this year is \$25.6 million, plus the one-off funding package of \$11 million, detailed below.

#### ***Eligibility***

Eligibility for the PADP is based on the following criteria:

- long term (likely to last more than 12 months) or permanent disability (defined under the *Disability Services Act 1993*);
- need equipment to live and participate in the community (evidenced by a prescription for relevant equipment);
- permanent resident in NSW in the relevant Area Health Service;
- resident in a group home operated by a non-government organisation on behalf of DADHC, DoCS or NSW Health;
- unable to obtain equipment from any other government program;
- no compensation or damages received in respect of the disability;
- no private health fund coverage for aids and equipment;
- discharged from hospital for more than one month and not eligible for the provision of equipment through a loan or on a permanent basis for a hospital or health service;
- income is means tested (for those aged 16 years and over).

There are four income bands for eligible applicants aged 16 years and over which determines the type of equipment which may be provided and the level of the co-payment required from the client.

Applicant in Bands 1-3 are required to pay a co-payment of \$100 per year and are eligible to receive all approved items of equipment. Applicants in Band 4 are required to pay a co-payment of 20% of the cost of the item and are eligible to receive high cost items only.

Residents of DADHC operated group homes are not eligible for funding under the PADP.

### ***Equipment***

The NSW Health policy includes a list of approved items. This list is intended to be a guide for PADP Coordinators and local Advisory Committees as to the broad categories and quantities of equipment which may be provided under the PADP.

Mobility aids and incontinence aids are the two leading expenses under the PADP. The most commonly supplied equipment items provided through the PADP include: showering and toileting aids, wheelchairs, seating support systems, patient lifters, continence aids and communication devices.

### ***Application Process***

A simplified version of the process to acquire aids and equipment through the PADP is:

- Initial eligibility assessment
- Application for aids and equipment
- Waiting list (can vary between a few months and a few years)
- Re-assessment upon approval (this is unfair on client, and hard on services)

Essentially, there are two application processes.

The initial application for eligibility is first assessed by the local PADP Coordinator. Applications are prioritised according to the applicant's need and financial situation (if applicant is under 16 years old, there is no income test of the parents and guardians).

The application for equipment can range from requests for a single high cost item to a variety of high-volume, low-cost items provided on a regular basis, such as continence equipment supplied every 3 months. While some applications may be decided by the PADP Coordinator, the NSW Health Policy states that all applications for high cost items, borderline or difficult applications should be referred to the local PADP Advisory Committee for decision. Section 6.1 of the NSW Health policy states that responsibility for PADP decision making rests with the Area Health Service's Chief Executive Officer, who may seek advice from the local PADP Advisory Committee.

### ***Allocation and Prioritisation***

Local PADP Advisory Committees are asked to establish budgets for broad categories of equipment to ensure the provision of a spread of equipment to meet the projected needs of people with a range of disabilities.



Section 19.3 of the NSW Health policy states that the PADP Advisory Committee is responsible to the Health Service's Chief Executive Officer for planning, funds management, prioritisation of applicants on the basis of need and implementation of system improvements. This included the annual assessment of funding requirements by equipment type in consultation with principal local service providers such as the Home Care Service of NSW, the DoCS Area Office and non-government organisations providing personal care services to the PADP target population.

Section 28.2, in summary, includes the role of the local PADP Advisory Committee to establish budgets for broad aid categories, where appropriate, of which should be monitored to determine if budget levels should be modified.

In addition, minimum budget expenditures are set for high cost items.

Section 28.3 of the NSW Health policy sets out broad principles for prioritisation, including:

- the assessment process is to be needs based
- the assessment process is to be person-centred
- the assessment process will recognise the importance of providing services to maintain a person within their own family and community
- the assessment process will recognise the importance of assessing a child's needs within the context of their family, or alternate care arrangements
- the assessment process will recognise the complexity of child disability (particularly prior to age 5)
- the assessment process will recognise the need to reassess and replace or update equipment as a child grows or a person's needs change
- the assessment process will recognise the need to occasionally replace and make reasonable repairs to equipment provided to an individual

All applications are prioritised. Section 28.4 of the NSW health policy states that prioritisation should be determined based on whether an applicant's continuing care and support arrangements and participation in the community are likely to be jeopardised. Further prioritisation criteria would be the threat of institutionalisation should PADP assistance not be provided.

#### ***PADP Statewide Advisory Committee***

The PADP Statewide Advisory Committee was first convened in 1999 to oversee and prioritise the recommendations of the *NSW Equipment Study: Review of the Program of Appliances for Disabled People* in 1998. The Committee continues to be involved in the ongoing review and development of the PADP and meets quarterly.

The Committee includes broad representation from both government and non-government organisations as well as peak clinical groups. Section 17.4 of the NSW health policy details the membership, of which NDS NSW is a representative.

### **\$11 million Funding Boost**

NDS welcomes the joint announcement by the Commonwealth and NSW Governments of a one-off funding package to support people with disability in NSW who require aids and equipment. The total funding includes a Commonwealth Government allocation of \$5 million. This increase in funds, although not recurrent, is an indication that the provision of aids and equipment is an agenda item at both a state and national level. The new funding package will help deliver essential equipment such as wheelchairs, adjustable beds, communication devices, hoists and ventilators to about 5,000 people with disability in NSW.

NDS has lobbied government strongly at both a Commonwealth and State level to address the unmet needs of people with disability in relation to the provision of aids and equipment. This provides a welcome boost to the PADP and is designed to eliminate the current waiting list for aids and equipment in NSW.

NDS is concerned, however, that there is a current delay in clearing the backlog of requests for aids and equipment. This injection of funding is aimed at alleviating current waiting lists, however it has also placed capacity pressure on the staff processing and pre-approving PADP applications as well as equipment suppliers and manufacturers.

NDS recommends that the current one-off funding of \$11 million be the minimum figure injected into the PADP on a recurrent basis. The ongoing demand for aids and equipment can only be addressed by a significant boost in recurrent funding for the PADP.

## KEY ISSUES AND RECOMMENDATIONS

The PADP has undergone two significant reviews, both of which highlighted issues regarding inadequate funding and administration. The first was the Carla Cranny review in 1998, the second was the PricewaterhouseCoopers review in 2006.

### ❖ Funding and Equity

#### ***Adequacy of funding for present and projected program demand***

The current PADP funding for this year is \$25.6 million, plus the aforementioned one-off funding package of \$11 million.

It has been estimated that, in order to meet the existing needs of those eligible based on application for equipment, the PADP budget would need to be approximately \$48 million, recurrently funded.

However, the required funding level is difficult to quantify as many of those eligible under the PADP no longer apply for equipment as their applications have been rejected or the waiting times have been too long in past experiences. See Appendix One for anecdotal evidence of this.

When considering the funding level for the PADP, the cost-benefit of the Program should be borne in mind. The provision of aids and equipment has a significant impact on people with disability, their families and carers and on the community in which they live. The timely provision of appropriate equipment means that people with disability can be cared for in the community rather than in hospitals or nursing homes, improves their ability to be active in the community and employment, and has the potential to reduce hospital readmission for the treatment of conditions such as pressure sores.

#### ***Financial Implications on the Person with Disability, their Family/Carer and Service Providers***

All individuals should, in principle, be able to access appropriate equipment in a timely manner. It is equally important to recognise that an individual's body may change over time as a result of illness or other factors, and that if this occurs, additional items of equipment may be required and existing items may need to be modified or replaced.

Children and young people have particular developmental, maturational and sudden growth patterns that, combined with changing medical conditions, can result in families urgently requiring a number of expensive items in rapid succession. Additionally, people living with severe disabilities frequently require multiple and costly items of equipment.

It is important to point out that at present, disability service providers regularly raise funds to cover costs for aids and equipment where the PADP simply does not deliver. Given the current workforce shortages and other demands placed on disability service staff, this practice should be an exception to the rule rather than the norm as it presently is. The Spastic Centre has to date raised more than \$2 million to purchase aids and equipment for people with

disability and their families. They host a major fundraiser each year and receive a small injection of funds from DADHC.

### ***Equity across the State***

Each PADP Lodgement Centre is allocated a budget to pay for the services requested by the applications from local eligible persons. The allocation of funds to each PADP Lodgement Centre is assigned based on a formula that takes account of the relative age distribution and level of disability in the area.

Centralised administration was recommended by the PWC Review of the PADP in 2006. It is clear that the current localised PADP Lodgement Centre system is inequitable in budgeting, processing and prioritisation of applications, leaving many people with disability without essential equipment. A degree of centralisation, combined with the preservation of local relationships, is the key to the longevity and equity of the PADP.

### ***Effects of centralising PADP Lodgement Centres, and the methods for calculating and implementing financial savings from efficiency recommendations***

At present, PADP Lodgement Centres operate within local budgets based on population numbers rather than local needs.

It has been reported to NDS that inequities exist between different PADP Lodgement centres. Some have been flexible and responsive to local needs, whilst others have been bureaucratic and lack understanding.

The inequity of the current PADP Local Lodgement Centres naturally leads one to believe that a centralised process would be preferential and combat such inequities. However, those clients who have shared a good relationship with the staff at their local Lodgement Centres have argued for the local provision of aids and equipment to continue, and rather than centralising the process, greater customer service and equity be pursued. Maintaining personal relationships and understanding is imperative for the timely and appropriate provision of items such as walking frames and continence equipment.

The understanding of high cost items, such as specialised seating and communication devices, goes beyond local level of knowledge and beyond the scope of local population-based budgets. A degree of centralisation of these items may lead to greater efficiency and effectiveness.

### ***Future departmental responsibility for the PADP***

Essentially, unless funded adequately, departmental responsibility is not overly important as an initial step, but rather as a consideration for future planning, particularly at a national level.

### ***❖ Eligibility and Assessment***

The PADP should be a system of entitlement rather than eligibility.

The current underlying rationale and limited funding of PADP is essentially restrictive. NDS recommends that PADP be changed from a system requiring proven eligibility to automatic entitlement through demonstrated clinical need.

There is currently no single statewide application form that ensures equity and compliance. NDS recommends that a consistent application form be produced.

NDS recommends that the current PADP eligibility requirements be reviewed to include people with disability residing in group homes.

#### ❖ **Prioritisation and Allocation**

Under the PADP, equipment is available based on priority according to need and financial considerations. NDS recommends that where a person with disability cannot meet the co-payment of \$100 per year (or 20% of the costs of the item for those in Band 4), an appropriate appeals process must be put into place.

There are 27 PADP Lodgement Centres across NSW. Each PADP Lodgement Centre maintains waiting lists. In May 2005, NSW Health made its first attempt to measure the PADP waiting list, which was estimated to be \$5.5 million of vital equipment being waited for.

#### ***Impact of client waiting lists***

Many factors contribute to the prolonged periods where people with disability are without appropriate equipment, these include:

- a complex and fragmented system of government and non-government support
- increasing levels of complex need requiring specialised and bespoke equipment
- the reactive rather than proactive systemic responses
- the rising market price of assistive technology
- fragmented funding processes that leave people with disability, their families, local equipment services and service providers in a weak purchasing position in the equipment market place
- cost inefficiencies in relation to repairs, maintenance and recycling of equipment
- lack of qualitative and quantitative data to address the ongoing issues and trends effectively

Failure to provide aids and equipment in a timely manner means that people with disability and their carers experience greater difficulty or may not be able to go about their daily activities such as work, school, leisure and shopping. While they wait for equipment, some will be admitted to hospital because they have developed pressure problems or deformities, some will experience additional pain and access additional personal support services, some will relinquish their independence and family tension may arise.

A person's ability to benefit from services providing therapy, accommodation support, respite and employment is enhanced by the greater personal

independence that aids and equipment provide, often reducing the demand for more costly personal assistance.

NDS members have advised that they often bypass the PADP to request equipment and raise funds themselves to pay for critical equipment.

NDS suggests that enabling people with disability, their carers and service providers wishing to privately procure aids and equipment be able to access same rates from suppliers as those enjoyed by the PADP.

#### ❖ **Early Identification, Prevention and Recognition**

The value of the PADP extends beyond the individual. Significant economic and social benefits from investing in the timely and appropriate provision of aids and equipment are also important to consider – the rates of return in areas like health and educational outcomes are much higher from early investments than those made later in life.

For many carers of people with disability, the most important recognition of their role and contribution in society will come from acknowledging the care role is not their alone – they need to be informed about options and assured access to formal support services when required.

Carers of people with disability embark on a lifetime engagement with the aids and equipment system and make significant financial and other sacrifices to acquire it. For families, equipment is expensive and the need is constant. Without the correct equipment, the invaluable role of carers is inevitably compounded with both the person with disability and carer at risk of injury. Caring responsibilities pose challenges to social and economic participation. These challenges are highlighted by the Australian Institute of Family Studies (AIFS) study *Caring and Women's Labour Market Participation*, which showed that the impact of caring responsibilities by women comes at a personal financial cost with 70% of carers surveyed receiving the Carer Allowance and over 53% receiving the Carer Payment who were not employed said they wanted to work.

NDS recommends that the provision of aids and equipment be considered within a holistic, whole-of-life, person-centred context, with a greater focus on early identification as both preventative measure and demand management strategy.

#### ❖ **Access and Information**

NDS acknowledges the intention of the NSW Government to launch a website in 2009 for clients and clinicians with information about EnableNSW and about the availability of specialist equipment, as well as the introduction of a statewide information line which has been in operation since October 2007 to provide advice to members of the public and clinicians.

Carers benefit from being given assistance to develop the skills to recognise, understand and manage the nature and complexities of a disability. Carers

need access to ongoing and consistent training, education, information and resources.<sup>2</sup>

NDS recommends that greater information be provided about the PADP in accessible formats for people with disability and their families, particularly the NSW Health policy on the PADP. People from Culturally and Linguistically Diverse backgrounds, and Indigenous people should be provided with appropriate program information and equitable access.

NDS advocates that the PADP be adequately supported by greater awareness about products and entitlements for people with disability and their families and carers.

### ❖ **Repairs, Maintenance and Support**

In 2003/2004, maintenance and repairs accounted for approximately 4.9% of total expenditure. All aids and equipment acquired through the PADP remains the property of the Area Health Service, and therefore the onus remains on NSW Health to undertake repairs and maintenance.

The PADP should be an inclusive and enabling policy. To achieve this - beyond initial debates around eligibility, assessment, prioritisation and allocation - the role of maintenance, repairs and support for aids and equipment users cannot be underestimated.

NDS is concerned that fundraising efforts by disability services providers is placing a strain on staff and service delivery as well as people with disability and their families, particularly in relations to ongoing repairs and maintenance. NDS advocates that where an individual is eligible under the PADP but provided with equipment outside the Program by a non-government organisation, repairs and maintenance should be funded under the PADP.

In the long term, this will provide savings to PADP by ensuring equipment provided by charities is maintained in good working order and potentially preventing the short term need for new equipment to be provided under the PADP.

If equipment procured under the PADP requires maintenance or repairs, people with disability are required to contact their local PADP Lodgement Centre, which operates during normal business hours from Monday to Friday. See Appendix One for anecdotal evidence of this.

NDS recommends greater recognition of ongoing maintenance and timely repairs as essential to the PADP. The establishment of a comprehensive support system for users of aids and equipment, such as a 24 hour helpline and 24 hour repairs service similar to the NRMA or RVAC should also be investigated.

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<sup>2</sup> National Disability Services, *Submission to the House Standing Committee on Family, Community, Housing and Youth Inquiry into Better Support for Carers*, 2008.

### ❖ **Staff Development and Training**

NDS advocates that all training and staff development initiatives be funded by the NSW Government, as opposed to putting a strain on the already stretched PADP budget.

#### ***PADP Lodgement Centre Staff***

NDS has been repeatedly advised of the lack of understanding about disability from staff at local PADP Lodgement Centres, often resulting in poor responses to aids and equipment requirements.

NDS recommends that ongoing disability awareness training be provided for all PADP staff in line with the Disability Service Standards and Disability Discrimination Act.

#### ***Clinicians***

The skills and experience of clinicians prescribing aids and equipment may vary considerably, particularly for some items that may need to be customised. NDS recommends that all clinicians prescribing aids and equipment be given up-to-date specialised training and ongoing development and support. The proposed Common Equipment Prescription Guidelines would assist with this.

### ❖ **Accountability and Transparency**

Currently, inadequate data exists to determine the real level of need and the real cost of equipment in NSW, as well as the significant contributions made by families and others. Added to this, the accuracy of waiting list data is questionable and unreliable.

NDS recommends that to promote continuous improvement, reliable information and data be collected as a foundation of good management, accountability and performance. Performance standards and benchmarks should be introduced as an instrument for assessing the effectiveness of the PADP in responding to demand, meeting needs of consumers and the effective use of available resources.

### ❖ **National Consistency**

NDS is currently investigating the operational mechanisms of a nationally consistent scheme. NDS has written to the Australian Government seeking the development of a properly resourced national aids and equipment strategy for inclusion in the next Commonwealth State/Territory Disability Agreement (CSTDA) and recently held a meeting in Canberra on the issue to which the Hon. Bill Shorten, Parliamentary Secretary for Disability and Children's Services was invited.

Both the Commonwealth and State/Territory governments administer schemes that provide aids and equipment to people with disability, as do a number of non-government organisations. Overall, however, the existing network of schemes is under-resourced and contains significant gaps. In its 2003 study, the Australian Institute of Health and Welfare found there to be "a



limited range of equipment, problems with cost, availability and shortage of referral services in remote areas of Australia, and a decline in equipment supply from traditional dispensing units such as hospitals. Systems for the provision of equipment appear to be nationally fragmented." The overall situation since then has not markedly improved.

As has been previously mentioned, aids and equipment have a vital and natural connection with many of the services covered by the CSTDA. Yet, aids and equipment are excluded from the CSTDA.

The need for a national approach to assistive technology is a key issue for NDS's National Committees on Children, Young People and their Families, and on Ageing and Disability. It is also a policy priority for the Australian Blindness Forum with which NDS works closely.

### ***Streamlining and Integration***

The Hon. Reba Meagher, NSW Minister for Health, has announced that EnableNSW will function with the aim of bringing together the administration of five disability support programs including PADP, the Artificial Limb Service and three Home Respiratory Programs (Home Oxygen Service, Ventilator Dependent Quadriplegia Program, Children's Home Ventilation Program). NDS welcomes this attempt at streamlining policy.

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### **About National Disability Services**

National Disability Services (NDS) is the peak industry body for non-government disability services. Its purpose is to promote and advance services for people with disability. Its Australia-wide membership includes 630 not-for-profit organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services - from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.

NDS NSW provides advice to the NSW Government in relation to all matters affecting the provision of disability services.

## **APPENDIX ONE**

### **Supplementary PADP Submissions from People with Disability, Families, Carers and Service Providers**

## FEEDBACK ONE

This feedback is from a long time sole parent carer of a man with cerebral palsy who is now 38 years of age.

The carer feels that the waiting game for approval and lodgement to gain PADP funding and equipment is detrimental to overall health and welfare of both her son with cerebral palsy and also the carer herself. This particular carer has had major health events that have impacted significantly on her ability to care for her son, however she has maintained full time care of her son.

Example's of PADP lodgement and equipment acquisition:

1. Commode chair received at 4 years of age, when at the age of 20 (15 years later) carer put out allot of money to upgrade a bathroom to be suitable for caring for her son. Asked for a new commode chair, one that was adult sized and could fit over a toilet, the response from the PADP was that she had already been given one and would not be issued with another one.
2. Speaking about the process for gaining a new wheelchair the carer emphasised the importance of having a fully functional custom made chair, due to her son's scolioses causing significant spinal deformity and bed sores. The process from beginning to end to get a new chair lasts for more than 3-4 years. First a prescription for a wheelchair needs to be formulated to apply to the PADP, then to get lodgement and approval with the PADP, then to wait time for the funding o be approved and then wait for the seating team to get the chair made. In the mean time health effects occur as a result; her son's scolioses is getting worse with more frequent bed sores.
3. The difference between manual chairs and electric wheelchairs and their turn around times. The carer has witnessed a difference in her own wait time for a new chair and other peoples wait and has been informed that this comes down to whether the chair is a manual wheelchair or an electric wheelchair.
4. The carer had OT consultations to find a standing frame to assist in overall health benefit due to breathing and circulations difficulties. The carer sourced and purchased a second hand hoist to ensure health benefits were realised now instead of through a lengthy time frame. This purchase was also required due to OHS requirements within the home, so that the primary carer could maintain full time support and care of her son. The other option in this circumstance dure to the carer's health was to move her son to supported accommodation against her will.

The carer is in the middle of getting a wheelchair for her son, as at this point he is experiencing breathing difficulties, bed sores and increased scolioses. At the moment he has a four year old chair, and is in the process of applying for a chair: process started June 2007 and at this stage at July 2008 a second appointment has occurred and will be looking at chairs in the next few weeks. Then another review from the seating team will need to take place and then the lodgement to the PADP can take place with no official time line. In the

past lodgement takes 12 months and then building the chair takes another 6-12 months. This makes the process for getting a new chair last up to three years, which disregards health effects of having a person with cerebral palsy sitting in a chair that does not fit for extended amounts of time. This leads to increased deterioration in his health and also diminishes his quality of life and ability to access the community.

## FEEDBACK TWO

I am writing to highlight the difficulties and frustration I have experienced over the past eighteen years with the administration, operation and personnel of the PADP system. The constant delays in approving and supplying equipment and repairs are most unrealistic. These in my opinion are caused by insufficient funding by the NSW State Government through NSW Health and no one willing from either PADP or OT departments to take a stance about the inadequate funding that is so inherent of the failing system. Every time any of my equipment needs servicing and replacement of parts I am told that the equipment is too old and if there is no available equivalent than those items will be withdrawn, put simply, I will be without that particular equipment. When my electric bed broke down (a nylon moving part snapped) it took Mt Druitt PADP eight weeks to repair it. A new piece could have been sourced from the manufacturer or even made locally but PADP decided to replace all of the electrics on the bed and this added unnecessary time delays to a simple process and wasted much money because the part used about 50cents worth of material and would retail for about \$2-\$5 at most. Their policy of not fixing anything under \$100 leaves clients out of pocket or out of adequate service. They did not even bother to contact the original supplier of the bed to see if availability was possible. At one stage I was told that the bed would have to be replaced in entirety, but as there were no funds available it would be at least six months before I received a new one if one was available then. When the crane (that puts the base of my wheelchair consisting of wheels, motors, computers, batteries and seat base board of my wheelchair, some 120kg weight into the rear of my Camry wagon) broke down it took Mt Druitt ten weeks to get the necessary replacement part because of their own incompetence and inflexible method of dealing with suppliers and replacement parts. The required part was always (and seemingly forever) on an overnight flight from Melbourne but PADP would not pay the part supplier the \$800 for 90 – 120 days while he had to pay cash for the part and like many others have their funds tied up and can't afford to carry the lengthy PADP payment procedures. Meanwhile I was struggling trying to get my wheelchair into my car. This left me in much greater pain than usual and at greater risk of sustaining further life threatening injuries and permanent loss of the little mobility I have left but this did not phase PADP, they simply did not care to show any concern for me, my equipment, my car or my ongoing well-being; just as long as they did things their way because there was never ever going to be any alternative as far as they were/are concerned!!! Surely this incident requires some investigation. Past history has been that this crane can break down during loading or unloading leaving me without the use of the crane, the 'chair or the car; you don't need a science degree to work out how such an outcome has a detrimental impact on me. If at any time the crane

should become faulty again I will have to resort to using a manual 'chair (this poses further risk to me as I have a lot of damage to my spinal column and nerves apart from the spinal cord injury) while PADP procrastinate about repairs and more than likely I will again be under threat of having the crane withdrawn from use with no suitable replacement or method of getting my disassembled wheelchair into or out of my car. The overhead crane on the cars roof for the manual 'chair has not worked since December '06, it too needs repairing but I don't have money for it. I am really struggling with my pathetic Centrelink pension and just finding enough money to live on is nearly impossible these days. I need to replace my 20 year old car not buy something that PADP should have replaced long ago. The problem compounds; my original manual 'chair supplied in 1991 broke in 1995 and was repeatedly repaired at my cost while I was at Uni but it remains held together by bits of wire and not satisfactorily useable due to metal fatigue and breakage. PADP have refused to replace it. When the same old chair broke a front wheel fork during the Sydney Games in 2000 I had to fund the repairs myself because PADP refused to help me. Out of frustration I eventually bought a second hand 'chair that was not built to my specification and a ROHO seat twelve months ago and paid \$500 for the 'chair and \$300 for the ROHO seat, money that I did not have and should not have had to find but for PADP's refusal for assistance; the old 'chair was unsafe and it needed to be replaced before it broke again. I use a manual 'chair to get into my doctors surgery because my motorised 'chair is too big for the tight corners of the surgery rooms.

My current electric wheelchair weighs 160kg, it is now 2 years old and when I rang for a works order number for repairs (standard practice when needed) in January this year after puncturing a tyre and ripping the tube I was confronted with more of the same rudeness as always by Mt Druitt PADP staff. It was too much bother for them to assist me, they were aggressive, said they would not email or fax the order number for repairs to the repairer, that as it was just a puncture I should be able to fix it myself, it did not need an order number and they weren't going to supply one, then it was to be repaired at my cost, when I said it was a workshop repair and not something I can fix because of the 'chair set-up and weight and that I had already driven 2kms on the damaged tyre to get home before I was able to phone them and the wheel needed assessment for damage and possible replacement this explanation meant nothing to them. They later changed their tune and said I would have to wait until the following week for an order number and the repairs would then be completed, I explained my program did not allow for that time frame nor did it allow for me to be without the use of my 'chair. They eventually relented and supplied the works order number but not before claiming I had received extra sets of tyres and tubes at the time the 'chair was supplied to me as is their current policy. However, I was never issued with additional tyres and tubes and it is now some eight months after the one and only tyre puncture I've had in 18 years of wheelchairs **AND I have still not been supplied with extra tyres and tubes for it.** PADP's hostile behaviour centred around me calling on a now old phone number originally issued as first line enquiry for assistance and now kept secret for some unknown reason and not to be used by clients; I rang them on the only phone number I could find but it was the wrong number. How pathetic and petty of them to react in this way to a request for help. Very soon I am going to need to replace the original tyres as

supplied with the 'chair because they are approaching excessive wear and right now I need the air cell in my seat replaced because after five years of use it is leaking but like everything that involves PADP I put off dealing with them because of their rudeness and arrogance and I don't have time or room for that in my life, nor should I or any other person dependant on PADP. **Life is too short and not to be wasted with rudeness from PADP!!!**

My OT use to tell me that there might be other equipment on the list of supplies from PADP that I should look into with a view of them being supplied but every time an application goes in it waits up to 12 sometimes 18 months before it goes to committee

for basic approval and then the 'system' takes up to 2 years to provide approved items; that's if the equipment is considered a number 1 priority, if it's not number 1 but is perhaps a lower priority it may never be provided even if it has been assessed and approved by an OT and seen as highly needed or beneficial to the patient. Bear in mind that OT's and doctors are reluctant to say what is needed for patients these days for fear that lengthy delays or 'no supply' situations will leave them red faced and ridiculed, it's considered to be bad for business.

Wheelchair suppliers are asked to requote on approved purchases 2 and 3 years after initial patient measuring. After the need for the new wheelchair had been established, the OT took 3 months to make an appointment for measuring and the quote was supplied and submitted to the PADP committee, approved for priority 1 and sat for two years before it saw the light of day again; then it had to be re-quoted and re-assessed on the new price scale and then it waited for the next government budget injection of funds before it was ordered from the supplier, and with other orders ahead of it then took 4 months in production time. PADP constantly adds unnecessary, lengthy delays in equipment procurement and hang on to funds when items of equipment are seen as essential and necessary for patient rehabilitation and to restore quality of life and freedom of mobility and the chance to participate with family, friends and community. These things just mentioned should be treated with the utmost urgency not shoved into the bottomless pit of inability to supply.

Before leaving paid employment and before I needed a wheelchair I was involved in material procurement, manpower requirement and workforce distribution, machinery allocation, scheduling, dealing with contractors, media publishers, pricing policy, product training and problem solving of engineering projects. For 16 of the last 18 years that I have been in a wheelchair I have sat on many committees and participated in advising 3 levels of government (sometimes directly) on disability access issues related to buildings and transport. I have been effective in town planning in the Blacktown CBD and surrounding areas and I have received two Australia Day Awards from Local Government and other awards for my community work being overall winner in category in 1996 and nominated for Citizen Of The Year; I believe I could make a worthwhile contribution as a community representative on any PADP local committee should an invitation be extended to me but it grieves me greatly to see so much time wasted in procrastination and poor decision process as experienced with PADP. **I am not convinced that one big centralised PADP will make all the present problems disappear and solve all the inherent bungling of a neglected, under-funded, and ill managed scheme that PADP has become. It will almost certainly end in one almighty bottleneck**

with even less equipment and repairs filtering through the system and longer delays in supply. It's simply unacceptable that clients of the system are so disadvantaged and inconvenienced when it comes to equipment supply and repair of what is essential mobility aids and meant to give some quality of life and increased participation with family and community. PADP personnel are at best glorified clerks with seemingly little or no mechanical aptitude or knowledge of how mechanical things work and they show complete contempt for anyone that does have that knowledge and experience. PADP should be about more than just supply of equipment, it should embody empathy for the lives it touches, it should have and be seen to have concern for its clients welfare, after all, is it not an extension of government for the people? or have I got something confused or wrong here?

I'm guessing by now you have sensed my frustration with the present system is very high. Living with progressive disabilities is really difficult enough without having a government body that is there for support and help adding to that frustration.

Since St Joseph's Auburn, Westmead, Blacktown, Mt Druitt, Nepean and Hawkesbury were combined into one body the service aspect has gone noticeably downhill and rife with patient abuse and lengthy delays a regular occurrence. Am I dissatisfied with outcomes from PADP? You can bet I am. My only remaining concern now is will I be further disadvantaged with future supplies from them and suffer recriminations for speaking out so openly? I hope not. I hope that my criticism is seen as constructive with the possibility of improving this service for the benefit of those who through no fault of their own need to avail themselves of the equipment on offer. With regard to the \$100 contribution from patrons/recipients this is far too disadvantaging to a single person on a pension of just \$269 per week and should be reduced in such cases to not more than \$30 maximum which in itself is extremely difficult to find these days. The only way forward for this under resourced facility is to have more suppliers of similar types of equipment thus providing increased competition and lower prices at the other end. It cannot be expected to improve on supply times without more funds being provided to it from the Governments budget. When dealing with and planning for disability and ageing in the community it should be remembered that the cost is far greater than the sum of its individual parts in terms of supply of goods and services and also in terms of suffering and the experience of the affected parties involved. In other words, the hidden cost of disability has greater impact as a person ages; I'm talking about the social isolation by being cut-off from family, friends and the community. Having suitable equipment is essential in any attempt of maintaining established relationships and building new friendships.

I sincerely hope that the information I have provided here is put to good use in re-constructing a properly managed PADP system.

### **FEEDBACK THREE**

I have now been fortunate to avail myself of the services of Macarthur PADP on 2 occasions and yes I have had to wait about a year for each of the chairs I now have.

My first chair was one that fitted into the back of my wife's car for shopping trips etc, the second one which I have had for about 2 months is a powered chair with chin control to allow me some level of independence.

The service I received from the PADP service based at Camden Hospital was first rate, yes I would have liked my chair earlier but I realise that it is needs based.

I have reservations about the centralisation of PADP because the personal touch will be lost and I feel that this is a very important part of any health related initiative.

## **FEEDBACK FOUR**

Adequacy of funding for present and projected program demand

- Funding needs to be adequate for immediate approval especially for people who are at risk physically or medically
- Highest priority for funding is currently placed on risk of injury to client and second highest is risk of injury to carer. The current level of funding is able to often fund those items where there is an immediate perceived risk of injury to the client, however often there is a wait for other items, including items where there is a perceived risk to the carer.
- Items where there is an impact on independence and function may have a significant waiting period

Impact of client waiting lists

- risk of client injury, deformity or aspiration
- risk of carer injury and stress
- risk of delaying independence
- risk of client or carer admissions

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

- lack of understanding re local community issues
- currently equipment can be accessed from the local pool for trial making it easier to re-issue equipment from the pool (this is a financial saving)
- If suppliers were also centralised this would have a huge impact on country services as it is difficult to arrange trialling and servicing from a supplier in a capital city. This would have a huge impact on the timeframe in which equipment can be organised.

Appropriateness and equity and eligibility requirements



- It is important that all PADP lodgement centres adopt the same criteria for eligibility and prioritisation as this ensures equity across the state

## **FEEDBACK FIVE**

TADNSW design and constructs custom equipment for people with disabilities. TAD's mission is to provide low cost custom equipment solutions through the engagement of skilled volunteers to build the equipment after staff therapists and engineers establish the design specifications.

Our engagement with PADP is indirect, in that often our clients must to seek funding through PADP before placing an order for the equipment we have designed, costed and quoted. The delay in obtaining this funding assistance through PADP can be considerable and 6-12 months is taken as normal.

Over 50% of TAD's equipment projects are for children under 12 years of age. The delays in PADP funding approvals often make it a necessity to reassess a clients requirements in terms of their measurements because of a child's growth in the intervening period.

Similarly the cost of materials can also rise sharply creating costs that exceed the original quote. A recent example for a bathing aid, original quote \$200 for materials. During the 12 months awaiting funding the cost of stainless steel rose by almost 60% and so the new cost of materials now exceeds \$320. This example does not even consider the cost of additional administrative overheads to keep the project alive or to cover the cost of reassessment by therapy and engineering staff.

PADP works, but ever so slowly. Delays in processing funding applications create numerous hidden overheads and probably add substantially to the costs of service delivery in the NFP sector.