

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

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SUBMISSION TO **NSW Parliamentary Inquiry into the
Program of Appliances for
Disabled People (PADP)**

BY **Association for Children with a Disability NSW
(ACDNSW)**

DATE **26 August 2008**

About ACD NSW

The **Association for Children with Disability NSW (ACD NSW)** is a non-profit organisation run by parents of children with disabilities. We help families gain knowledge and confidence to provide the quality of life their child deserves by:

- Providing support and information for parents, carers and families of children with any disability
- Raising public and political awareness of the issues faced by parents, carers and families of children with a disability
- Advocating for improved services and equipment for families of children with a disability

Summary of ACD NSW views

ACD NSW members consistently report significant, ongoing concern with lengthy waiting time on PADP region waitlists, due to inadequate funding and inefficient processing methods.

ACD NSW's proposals are based on providing **appropriate aids and equipment** to families of children with disabilities **within a defined timeframe** and **without causing further economic distress to families** as a result of their children's disabilities. Families with a child with a disability face costs not borne by individuals who care for someone later in life for a shorter time frame, such as caring for an ill spouse. Families of children with disabilities face life-long astronomically higher costs exacerbated by long-term loss of a first or second income as it is so difficult to maintain employment combined with caring for a child with severe disability. Subsequently the family (dual or single) income capacity to generate retirement funds is also greatly reduced, if not impossible.

Summary of key issues

1. Timeframe of supply of equipment/aids
2. Process of evaluating, recommending and funding equipment/aids
3. Role of PADP – administrator or assessor
4. Financial burden on families of funding equipment/aids
5. Better administration – forward planning to meet anticipated needs

Key issues

1. **Timeframe of supply of equipment/aids**
2. **Process of evaluating, recommending and funding equipment/aids**
3. **Role of PADP – administrator or assessor**

These three issues are considered together as specific changes to **2) the process** and **3) role of PADP** will result in improvements to **1) timeframe of supply**.

Lengthy waits for supply of essential equipment or aids have a particularly damaging effect on growing children, for example:

- A child can suffer pain, discomfort and muscular-skeletal damage if forced to sit for hours every day in a wheelchair that is too small
- Scoliosis can worsen without use of a prescribed sleeping, seating or splint system, undoing the beneficial effects of therapy and surgery and leading to secondary, sometimes life-threatening medical conditions caused by the structural damage to the skeleton and resultant pressure on lungs, stomach.

From an economic perspective alone, it is illogical to publicly or privately fund surgery or therapy on a child with a disability and then reduce or overturn the efficacy of this treatment due to lack of timely supply of supportive equipment. When a child is growing is when the most care needs to be taken to give him/her every possible chance to maximise ideal development. As well, ACD NSW is just as concerned at the signal sent by the NSW health system to the child and his/her family: that their needs are not considered important enough to warrant timely supply of necessary equipment/aids.

When seeking funding of an item of equipment, it is necessary to understand that **PADP is not the only waitlist** a child's family will be placed on:

1. The first waitlist will be for a therapist, usually an occupational therapist, to make an appointment to assess the child, review the problem, identify and organise a trial of possible solutions. This can take 12 months.
2. The therapist then has to write a report to PADP specifying the problem, best solutions and likely outcome for the child. This can take a further 3 months.
3. This report then goes on a waitlist for submission to PADP regional assessors, who decide whether to recommend the equipment for funding. This can take 6 months.
4. If successful, the family's request for equipment then goes onto another waitlist until sufficient funding becomes available. This can take another 12 months.

The entire process can - and often does - take 1-2 years. During this time the child will be using equipment he or she has outgrown and can be sitting or lying in excruciatingly uncomfortable conditions with consequent damage to the muscular-skeletal structure, the child's health, fatigue levels, capacity to learn at school and ability to continue with therapy. With growing public awareness of the rights of people with disabilities, PADP may one day find itself held to be legally liable if lengthy delays waiting for equipment result in deterioration to a child's condition.

Recent example

A young child with a physical disability who cannot crawl or walk was recently recommended to obtain PADP funding for a power wheelchair. The recommendation, based on review and assessment of the child, was undertaken by a qualified occupational therapist employed by The Spastic Centre NSW. In essence, the OT proposed that supplying the child with an independent mobility tool would enable greater independent learning and reduce risk of developmental delay, mitigating the likelihood of the child requiring additional learning disability intervention during school years.

The OT report supported its recommendation by referral to academic research demonstrating the benefits of supplying independent mobility to young children to increase their capacity for age-appropriate development. However, PADP rejected the application because it considered the child was too young and the parents had to self-fund the child's power chair (along with an accessible van and home modifications). PADP did not base its decision on science, professional recommendation or need. Exactly what did PADP base this decision on?

ACD NSW view

PADP requires a professional therapist to assess a child and provide a report. If a professional therapist has assessed the child and advised an appropriate course of action/item of equipment based on PADP criteria, why is there any need to go to another waitlist for PADP to review the therapist's recommendation for PADP to decide whether to accept and proceed to funding the item?

PADP must decide whether its key role is to administer the process, or whether it holds an assessment role.

No family chooses arbitrarily to buy wheelchairs, walking frames, accessible vans, specialised seating, communications device etc. Such decisions usually involve significant emotional stress by the family, as they be the defining indicator that their child has a significant, permanent disability, ie cannot walk or talk.

Decisions to obtain equipment are based **purely** on meeting the needs of their child, with the aim of supporting the child's short-term and longer-term inclusion in regular family and community life and maximising the child's capacity to improve, learn and enjoy better quality of life. Equipment can enable the family to better meet the child's needs and improve the quality of family life. For example paid care workers will not lift a "client" over a certain weight; therefore to access support service families need appropriate equipment, such as a hoist. As well as meeting legal obligations, a hoist reduces some of the daily muscular-skeletal strain family members incur transferring the child.

ACD NSW Recommendation 1

If families in conjunction with professional therapists identify a need for equipment to support their child or the family and supply a report to PADP identifying the need, equipment support and likely outcome, PADP should not need to review or assess this independent report.

PADP should simply acknowledge the report and recommendation for equipment and indicate a timeframe for supply. This should actually result in cost savings for PADP due to reduced process.

4. Financial burden on families of funding equipment/aids

The PWD 2006 report recommends recipients of PADP equipment whose income falls in certain "tiers" be required to provide a co-payment of up to \$1000 per item per year. For example, a family whose child requires her first power wheelchair prior to starting school will be required to pay \$1000 towards the cost of PADP funding a power chair.

But what else will that family pay in that year from their gross income that PADP chooses to ignore?

Power wheelchairs can only be transported in limited vehicles, specifically vans. So if the family is to take the child and her power chair anywhere, they will need to buy and possibly modify a van.

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| Accessible van estimated cost: | \$60 000 - \$100 000 |
| Manual wheelchair + custom seating for use in non-accessible environments, school excursions, during repairs to power chair | \$8 000 |

The family is very likely to have to **modify their home**, if privately owned or being paid off. (If they are renting privately they will not be able to modify their home at all to be wheelchair accessible – likely to become a greater problem as housing affordability declines). If they are lucky they may received minor funding in time to assist with home modifications. If they wish to include the child in regular family life, they will need to make a bathroom, bedroom, living area, kitchen, entry/exit and outside area accessible.

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| Home modification estimated cost: | Between \$30 000 - \$180 000 self-fund |
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A child with a disability severe enough to require a power wheelchair is also likely to require:

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| Communications equipment | \$1 000 co-payment |
| Home computer, software, accessible peripherals | \$2 000 - \$5 000 self-fund |
| Customised seating at home | \$1 000 co-payment |
| Shower/toilet aids | \$1 000 co-payment |
| Ongoing therapy modalities (speech, physical, OT, rehab, nutritional, autism spectrum therapies, hippotherapy, conductive education, osteopathy, ABR,) | Can be up to \$40 000 per annum self-fund |

This list alone totals expenditure by this family of up **\$103 000 to \$334 000** depending on necessary modifications, equipment. Only a small proportion (20%) of this expenditure would be partially tax deductible certain items (for example mechanical wheelchair ramps in vans are not tax deductible, for some strange reason).

Most of this self-funded expenditure on disability-related equipment or services would come from the family's gross income, any savings or more commonly would be accessed by borrowing against home equity and accessing superannuation on "compassionate" grounds.

ACD NSW recommendation 2

Until all self-funded expenditure on necessary equipment, services and therapy due to the effects of disability are 100% tax deductible – something the NSW Government should be discussing urgently with other states and the Federal Government – any attempt by PADP to recoup costs from the consumer must ensure capacity to pay or co-pay is determined by:

Any proposed PADP means testing of income clearly **identifies capacity to pay by family/individual by taking account of their total gross expenditure** on equipment, therapy and other items related to disability, not just the proposed payment towards a single item of equipment, and that this expenditure is considered within a 10 year time frame.

5. Better administration – forward planning to meet anticipated needs

It seems every family with a child with a disability reinvents the wheel searching for information about what equipment they are likely to need in the short and longer-term. Most families get this information informally from other families or increasingly through ACD NSW's guide to services/information "Through the Maze". It is rare for a family to cite a therapist/government agency as the source of such "forward planning" information.

Example

While many families "make do" with the limited resources they have caring for their child at home, if they need to access any Homecare services they are required to have appropriate equipment, such as a hoist, to minimise lifting by Homecare staff.

No one tells families that, so they go on the waitlist for Homecare, are eventually assessed and told by Homecare they cannot receive services until they get a hoist or other equipment. Families then go on a waitlist for an occupational therapist to write a report to PADP recommending support equipment. This report is supplied to PADP, the families wait until a PADP regional committee decides whether to approve the request for equipment funding and then wait again for funding to be available to supply the equipment. Once they have the equipment, they may receive some Homecare services.

ACD NSW recommendation 3

PADP should engage Occupational Therapists, or work closely with DADHC Occupational Therapists, to provide advice to families through home visits and consultations to enable families to anticipate the needs of their child as their child grows.

A program of the kind proposed will have the added benefit of assisting PADP to source equipment from outside its region, enabling better reuse of existing equipment, with subsequent cost-savings.

Sources of information

1. Anecdotal evidence – ACD NSW
2. [Carers Virtual 2020](#)
3. [WhatCarersNeed wiki](#)
4. CPeacial Parents online support group (closed group)