

Submission
No 17

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

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Date received: 29/08/2008

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

SUBMITTED BY Fiona Anderson

DATE 16 AUGUST 2008

Thank you for the opportunity to submit experiences, views and suggestions to the Inquiry into PADP.

My feedback is based on 12 years of experience with one of my children who has a severe physical disability.

Key issues that must be recognised and fixed in NSW PADP review:

- 1 Assess total family disability expenditure not just gross income
- 2 Speed up and increase efficiency of application process by:
 - a) trusting families to know what's needed and when to seek professional input
 - b) streamlining process to change/fix existing equipment

1. Assess total family disability expenditure not just gross income

KEY POINTS	
• Our self-financed expenditure on disability services, equipment and therapy in 12 years:	\$476,070
• PADP expenditure on our son's disability equipment in 10 years:	\$ 23,469
• Proportion of our total disability expenditure funded by PADP:	< 5%

My 13 year-old son has a physical disability. He can't walk, stand, sit, dress himself, go to the toilet, get out of bed or into the car by himself, or use both hands. He has the physical function and competence of a 1 year old, and age-appropriate social, emotional and cognitive function of a 13 year old. He weighs 44 kgs and is nearly as tall as I am. He goes to mainstream school in my wheelchair-accessible van driven by me.

Over the past 12 years our family has personally borrowed and spent nearly \$476,000 on services and equipment to give our son the best chance of an independent good quality life. **That's \$40,000 per year coming out of our gross income. It's an intelligent investment to maximise his chances of becoming a tax-paying contributor to Australian society. However our financial investment is NOT tax-deductible.**

We live on a teacher's income, no pension. A second full-time or permanent part-time income is not possible because there are NO after school support services to care for our son. Our level of debt is not sustainable. We have no way to repay it other than sell our house and move out of Sydney away from family and friends.

How have we financed our enormous expenditure on disability services and equipment?

- Taken out a line of credit on top of our mortgage, reducing our equity in our home by 40%
- Taken half our superannuation on "compassionate grounds", leaving inadequate funds to "retire" on

If disability expenses were 100% tax deductible we would be delighted to never seek State help for our son's essential mobility equipment and would self-finance as long as we had sufficient income.

SUGGESTED ACTION

- 1 State Health department work with Federal Health and Treasury departments to provide simple, realistic criteria for **100% tax deductibility** of privately-funded disability-related equipment, therapy and services.

Benefits: Would enable and encourage higher proportion of families and individuals to self-fund, and free public finances to fund equipment for families and individuals unable to self-fund

- 2 PADP considers an individual or family's **ENTIRE expenditure on disability-related equipment, services and therapies** when considering an application to fund equipment, not just gross income.

Benefits: Governments and Australians have a clear understanding of the full costs of funding disability equipment, services and therapies borne by families, not merely the extrapolated costs borne by PADP

 **PAGE 2 Table illustrating all disability-related expenses we have financed over 12 years**

DISABILITY- RELATED EXPENSES 1996 – 2008

ITEM	Child 1		Child 2		PAID FOR BY
	WITH disability	without disability	WITH disability	without disability	
1 power wheelchair – age 5-10	\$ 18 000	nil	nil	nil	PARENTS
1 manual chair – age 5-10	\$ 9 000	nil	nil	nil	PARENTS
1 power wheelchair – age 10 - 13	\$ 12 000	nil	nil	nil	PADP
1 manual wheelchair age 10 – 13	\$ 8 000	nil	nil	nil	PADP
Wheelchair repairs and maintenance	\$ 7 500	nil	nil	nil	PARENTS
Power wheelchair battery replacement 1 per year x 12 years	\$ 7 200	nil	nil	nil	PARENTS
Power chair repairs	\$ 600	nil	nil	nil	PADP
Emergency repairs/growth to power wheelchair	\$ 1 269	nil	nil	nil	PADP
Installation of van seat modification – Turny	\$ 13 000	nil	nil	nil	PARENTS
Purchase tradesman's van, modified for wheelchair accessibility	\$ 84 500	Sedan - \$17,500	nil	nil	PARENTS
Shower chair	\$ 800	nil	nil	nil	PARENTS
Grab rails in bathroom, kitchen, bedroom, garage	\$ 780	nil	nil	nil	PARENTS
Removal of malfunctioning wheelchair van restraint system	\$ 390	nil	nil	nil	PARENTS
Wheelchair locking system in van	\$ 6 000	nil	nil	nil	PARENTS
Seating for home, school, transport	\$ 11 000	Booster seat - \$300	nil	nil	PARENTS
Modified games and toys to stimulate physical and cognitive development age 1-9	\$ 11 000	Regular toys \$3 500	nil	nil	PARENTS
Computer hardware and software modified for accessibility	\$ 9 000	Computer - \$2 500	nil	nil	PARENTS
Dwelling modifications to enable full access to/inclusion in family home	\$ 80 000	nil	nil	nil	PARENTS
Private surgery in Melbourne (2.5 year wait list for public surgery in Sydney)	\$ 6 800	nil - broken arm treated at public hospital	nil	nil	PARENTS
Orthopaedic shoes, soft orthotics, AFOs	\$ 10 000	Regular shoes \$3 000	nil	nil	PARENTS
AFOs	\$ 1 600	nil	nil	nil	PADP
Private osteopathy, chiropractic, Hyperbaric Oxygen, medical GP, nutritional supplements, speech therapy, body & arm splint, OT, music therapy, Conductive Ed	\$ 55 000	\$2 000	nil	nil	PARENTS
Swimming aids	\$ 1 000	\$45	nil	nil	PARENTS
Specialised bike	\$ 1 600	\$150	nil	nil	PARENTS
Therapy aids (therapy table, rehab equipment)	\$ 8 500	nil	nil	nil	PARENTS
Physical therapy ongoing review and tuition, therapy clinic travel and accommodation	\$ 110 000	nil	nil	nil	PARENTS
2009 elevating power chair to meet social inclusion/adolescence independence needs	\$ 25 000	nil	nil	nil	?
2009 manual wheelchair – for inaccessible environments (no footpath near home)	\$ 8 000	nil	nil	nil	?
TOTAL	\$499,539	\$28,995	\$28,995	\$28,995	
TOTAL PAID BY PARENTS	\$ 476 070	\$28 995	\$28 995	\$28 995	
TOTAL PAID BY PADP/STATE	\$ 23,469	nil	nil	nil	

- 2 **Speed up and increase efficiency of application process by:**
- a) **trusting families to know what's needed and when to seek professional input**
 - b) **streamlining process to change/fix existing equipment**

PADP management of equipment maintenance, repair and growth needs streamlining to provide service and improve efficiency. The current process requires intervention nearly every step of the way by an occupational therapist or specialist for no logical reason. It is inefficient, cost-ineffective and creates huge wait lists for people who need functioning disability equipment so they can live their daily lives. We have no options: No wheelchair, no school. No school, no work. No work, no income.

EXAMPLE

PADP funded my child's second power wheelchair when he was 10. At 13 he started to grow very quickly, in a textbook version of male adolescent growth spurt aged 13-14. Within weeks he outgrew his wheelchair and was in considerable discomfort sitting all day in the chair at school. His school work declined.

PADP doesn't accept that as the "expert case manager" I know when my son has outgrown his wheelchair or when it needs modifications. The following illogical process we had to go through just to "grow" the wheelchair resulted in my son suffering pain and discomfort for 6 months:

- PADP requires an OT to write a report about what is the problem/what is needed, such as a simply that a child has outgrown his wheelchair and it needs to be modified, evidenced by photos
- In March we went on the Northcott waitlist to see an OT to write a report
- After 3.5 months we and Northcott OT consulted wheelchair supplier OT to identify possible solutions
- Northcott OT writes report to PADP identifying problems/solutions
- Parent phones PADP 2 weeks after report lodgement to be told there would likely be a 3-4 month wait for approval, regardless of child's pain and suffering squeezed into too-small wheelchair for 6 hours per day and regardless of Federal funding injection to "*eliminate the current waiting list for disability aids and equipment*" (source: NSW Health Minister Media Release 15 July 2007)
- Parent contacts offices of NSW Minister for Health and Federal Minister for Disability Services
- PADP approval for wheelchair modifications received the following week
- Wheelchair parts ordered in and chair booked in for repairs in September – ETA not specified

Total length of time taken: 6 + months

SUGGESTED ACTION

1. Streamline and speed up process - where PADP already approved/funded purchase of equipment, ALL repairs, adjustments, modifications to ensure equipment can be used as intended should be automatically approved without need for OT waitlist, report, applications, time off work with no pay to attend appointments, time away from school, etc. This means PADP must trust parents to actually know when a problem exists, such as a flat battery, wheels fall off, child won't fit in chair.
2. **Benefits** - Much faster service delivery, more cost-effective use of professional therapists' time and PADP budget/process
3. **SUGGESTED PROCESS**
 1. Parent notify PADP of problem, include photos if relevant, by mail or via online upload form
 2. PADP supplies auto acknowledgement of parent notification
 3. Parent arranges with supplier/repairer to fix problem, supply quote and notifies PADP start date
 4. Supplier/repairer fixes chair and invoice PADP for payment

Total estimated length of time: 2-4 weeks