Submission
No 16

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

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Submission to the PADP Inquiry

Submitted by Heike Fabig

I am the mother of three young children. Two of them have an early onset, non-degenerative and as yet un-identified form of autosomal recessive hereditary spastic paraplegia (HSP). This is a physical neuro-muscular disability which closely presents like Cerebral Palsy. My daughter (currently 2 years and three months) is severely affected physically – she has the physical skills of a 4 month old – but no cognitive or social disability, and no developmental delay (yet). My 7 year old son is less physically affected but has developmental delays since he missed out on many early physical learning experiences.

Based on my experience as a parent/carer, I would like to submit the following three points to the PADP Inquiry

- PADP should follow the advice of the professionals it requires input from
- PADP should streamline the process for upgrades and repairs to Equipment previously supplied by PADP.
- The NSW Government, in co-operation with the Federal Government where necessary, should make all disability-related purchases 100% tax deducible (and where possible, GST free) and make PADP 100% government funded.

For your information, I will submit my final point (about tax deductibility) to both Mr. Bill Shorten's, Parliamentary Secretary for Disabilities and Children's Services, Mrs Jenny Macklin, Minister for Families, Housing, Community Services and Indigenous Affairs and Mr. Wayne Swan, Treasurer of the Commonwealth of Australia, and their respective Inquiries.

Point One - PADP should follow the advice of the professionals it requires input from

Example

My OT wanted my young daughter Billie (2.5 years old) to have a powerchair. Research shows that introducing powered mobility is beneficial (and may avoid developmental delays) and should be introduced at the age where a child would normally acquire independent mobility. My Occupational Therapist approached PADP with research proving its use, and a clear opinion this particular child would benefit from a powerchair see video evidence on DVD supplied). PADP would not even consider it and stated categorically that it does not fund powerchairs for very young children (i.e. children under the age of 5).

What then is the point of having these professionals involved? We might as well cut them out of the process altogether. Either PADP makes bureaucratic decisions, and then people should just be able to hand in their wish list and leave PADP to play benevolent Santa, or therapists make a decision that a person needs something, and then they should get it, within 3 months, no nonsense, no age-limits, finance limits or whatever.

In order to request equipment from PADP, an Occupational Therapist, Physiotherapist or Speech Therapist (I will refer to them as Therapists further) needs to assess the applicant's need and write a detailed report why the person would require such item.

Yet often enough, PADP rejects such applications – generally based on financial reasons. This is a waste of time and money, and an insult both to the person applying for the equipment and the therapist. If PADP wants active input in the process, then they have to base their decisions on science not money.

PADP should **make a choice about the kind of programme it wants to be**.

Either professional input is important, in which case PADP should consider an application purely on the basis of **need**. If a therapist decides a person needs an item, they should receive within a 3 month maximum period.

Or PADP makes PADP makes purely **financial decisions** as to what it will fund and under which criteria. There is then no need for all the various committees with practitioners meeting once a month to decide if you can go on a waitlist. People would work out with their therapists what is required and all PADP would need is a computerized queue system.

Point Two – Streamline the process for upgrades and repairs to Equipment previously supplied by PADP.

Example

A friend of mine had to wait 3 months to get a broken footplate fixed. Her son's wheelchair was supplied by PADP, so she needed an OT's report to state that the chair's footplate was broken. It can take weeks to see an OT, and then takes some more for them to finalise and submit their report. It then takes many more weeks for PADP to approve the repair of a footplate, and some more to contact the wheelchair supplier and actually get it fixed. In a case like this, the parent is perfectly capable of identifying a fault with the chair and there need to be no time waisted by a therapist to write a report of an obvious and necessary repair.

Were PADP has **already approved** a piece of equipment for a certain use, any **repairs** and **modifications** to continue this very use should be following a simple process where. There is no need to involve and OT here, as this was done in the initial assessment.

This maximizes PADP's initial investment and saves both time and money for PADP and the therapists – and crucial time for the person stuck with an piece of equipment that does not fulfill their needs.

A simple process can be created whereby a parent or a person with a disability notifies PADP of a need for upgrade or repair (ideally via a simple form to be mailed or an online form). PADP supplies a swift acknowledgement of this notification, this allowing the parent of person with a disability to arrange the required work. The supplier or repairer supplies a quote to PADP, which approves or negotiates on price until agreed. The work is then undertaken and PADP invoiced.

Point Three - Make all disability-related purchases 100% tax deducible (and where possible, GST free). Then make PADP 100% government funded.

My kids are my responsibility – wherever I can, I will self-fund, and have done so. I feel this is my job, and allows me a more flexible approach to my children's needs. With some relatively simple measures the state can help me (and other parents) to look after my kids needs. This then frees up PADP for those who can not self-fund, and with more people self-funding and no longer using PADP, there will be no need for PADP recipients to co-fund equipment.

For example, here are some of the costs we've dealt with over the last7 years – all of which we have self-funded:

- Kaye walker ($500)
- Manual wheelchair ($3,500)r
- Special potty ($70)
- Toilet hand rail ($120)
- Bambach saddle seat ($850)
- AFOs ($30 each, that makes $700 a pair, we are coming up to our 5th set)
- Orthopaedic shoes ($275, they last about a year)
- Orthotic shoe inserts ($175)
- AUSLAN books ($45)
- Technical Aid for the Disabled modified bike ($250)
- Horse riding for the Disabled ($70 a yea, two years)
- Special swimming classes ($50 a term, for 4 years)
- Conductive Education ($30 a session, weekly, for 5 years)
- LifeStart membership ($250 a term, for 3 years)
- School fees for Independent school ($3,000 a term)
- Remedial lessons at school ($120 a term)
- Extra travelling costs to drive to independent school (school is 20km from home, drive twice a day)
- TheraTogs splinting and support system ($520)
- Special Tomato seating ($645)
- Gym mats to practice rolling and crawling on ($175)
- Bumboo seat ($20)
- Pram inserts for support ($75)
- Hand splints ($65)
- An electric wheehchair ($13,000 – we got lucky and bought a demo model)
- Wheelchair accessible people mover (Toyota Tarago) ($ 52,450)
- Portable ramp to get the wheelchair in and out of car (S1,000)
- Special straps to secure the wheelchair in the car (about $250 – waiting for detailed quote)

For most of my disability-related purchases I have **no choice**; no choice over the product, no choice over the price. There is only a very limited range of paediatric electric wheelchairs designed for very young children available in Australia. There are only three cars that can hold a family of five and be converted to be wheelchair accessible. There is only one ramp that fits into a car. There is only one place which offers Conductive Education, only one saddle seat company. The local public school was very honest in admitting they would not cope as well with my child as the in depended school we chose, who have an elaborate system of daily remedial lessons (partly funded by the Federal Government, the rest paid by me).

And this does not take into account the hundreds of little things that we have bought for our son, and his preschool so they did not have to buy it – easy use pencils, scissors, lunch boxes and storage containers he can actually open, little stools for him to sit on at preschool, long socks that fit over AFOs, toys he can actually play with (big puzzles, a train table for him to stand on in his AFO's and walker so he could build a train track and play with Thomas the Tank engine, etc), endless soft but big key-rings to hang off anything that comes with a zipper, new door handles he can open, miles of Velcro and thread (to replace buttons on shirts and pants so he can get independently dressed), software and computer games, CD with educational songs (such as phonics and time tables) endless amount of shoes (as he wears them down due to his foot-dragging gait).

And then there is the task of making our house wheelchair accessible – knocking down a wall, raising a floor, new deck, making all doors flush , widening doors, build a ramp at the front entrance of our house, redo the driveway – these are all significant costs. To give you an idea of the work we have done, please have a look at the attached sheet. * ? We have moved from a fully owned (tri-level) house to a new, wheelchair accessible house with a $300,000 mortgage.

While we are happy to bear those costs – we call them investments – for our children, life would be considerably less stressful if all these expenses were fully tax deductible and/or GST free. They are not luxury expenditures, but basic, fundamental things our children need. Parents and people with a disability already take on a disproportionate amount of the costs associated with a disability.

Introducing such a relatively simple measure as making all disability related costs tax-deductible would allow many people to self-fund equipment thus leaving the health system – and PADP in particular - to fund items for people who cannot privately do so.