

Submission
No 77

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

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Faye Galbraith

To General Purpose Standing Committee 2,

Please accept my submission to the PADP Inquiry.

I am the mother of two children, both of whom have a severe, undiagnosed disability. Jack (8) and Ben (5) cannot walk, talk or sit unsupported, they have a vision and hearing impairment and complex medical needs - Chronic Lung Disease, Scoliosis and Hip Dysplasia, Jack has Cyclical Vomiting Syndrome and a variety of other medical problems. Jack and Ben's already serious difficulties have been greatly exacerbated by the inability to access appropriate equipment within a reasonable timeframe.

For the purpose of my submission I will refer to people with differing abilities and diverse needs as having a "disability", it is however my view that "disability" is created by our failure as a society to accommodate diversity and remove barriers to equitable access. This failure is due in no small part to the lack of appropriate government policy aimed to facilitate inclusion for those with diverse needs.

The provision of aids for people with disabilities is woefully inadequate and a very real **obstacle to social inclusion**. Social inclusion should - in a wealthy democracy such as ours - be a basic human right. It is my belief that the NSW government cares little for the rights of those with disabilities, one only has to read the two most recent policies (Maintaining Respite Capacity and Allocation of Places in Supported Accommodation) of another state government department - The Department of Ageing, Disability and Homecare (DADHC) to understand how this government views the rights of people with disabilities and their families and the entrenched attitudes that exist within government toward those with disabilities and the **lack of value placed on diversity**. The provision of equipment to children (and adults) with disabilities is a major barrier to social, cultural and educational inclusion, it is however part of a bigger picture. A picture of chronic, **systemic neglect** and the disempowerment of those with disabilities and their families. That families often have no option other than to seek charity in order for their child to have access to a wheelchair is further evidence of a government that lacks commitment to the principle of **inclusion**. It is my belief that it is the **governments role to seek to remove barriers to inclusion, not create them as in the case of PADP and other government disability policy**.

My family receive the Carer Allowance of \$100 a fortnight (barely enough to cover medication costs) for Jack and Ben, I rarely ever receive Carer Payment. I report our income to Centerlink each fortnight and usually receive \$0 of the Carer Payment, sometimes I will receive around \$6, financially this makes life very difficult, like most people we have a mortgage to pay and ever increasing bills. Any increase in the co-payment would only add further pressure. It is inappropriate to charge a co-payment for the small amount of funding that is allocated for incontinence products.

It is a sad indictment on our governments - past and present - that people with disabilities are not supported and facilitated to have as normal, equitable a life as possible. In fact it can be said that actual **"disability" only arises when society fails to accommodate differences and fails to facilitate equality by removing barriers to equitable access**, these barriers can be social, economic or physical. PADP is a barrier to inclusion, the poor provision of aids/equipment is an obstacle to those with differing abilities thus creating the "disability".

I find it astounding that in a relatively wealthy, developed nation such as ours people with disabilities (in NSW) have to sometimes wait years for essential equipment, a wait of over a year for a wheelchair is commonplace and should be completely unacceptable in any modern democracy. The difficulty in accessing aids and equipment is a human rights issue that must be rectified in order for us to create **inclusive social policy** for people with disabilities - one where people with disabilities can participate fully in everyday life, on par with their non-disabled counterparts. Inclusion is only possible if the provision of equipment to people with disabilities is adequately funded, currently it is so chronically under-funded that people have to apply for charity in order to purchase a wheelchair.

My family have applied to charities on several occasions for equipment for Jack and Ben as the PADP waiting list is so long, The Steve Waugh Foundation funded floor-sitters for Jack and Ben and The Variety Club has paid for several pieces of equipment, I don't know what we would have done without these philanthropic organisations and we are very grateful that these charities exist, particularly as we can't rely on the public system. It is however a shameful indictment on the NSW Government that parents are forced to rely on charity and goodwill in order for their child to have access to something as basic a wheelchair or bath/shower aid.

I arranged for several questions to be asked at last years Budget Estimates Hearing (transcript attached) on this topic. I wanted - and had expected - a response in regards to the issue of people with disabilities being reliant on charity for essential equipment such as wheelchairs (Question 1 of the transcript attached). The response from the Health Minister was dishonest, it alleged that people only apply for charity because the "items being requested exceed the cost of the most clinically appropriate item." This is a complete fabrication as most people seek charity because of the unreasonably long PADP waiting lists, put simply their child cannot wait for over a year for a wheelchair. It is even more shameful that the NSW Health Minister would not own up to this. The response indicates a total **lack of transparency and accountability** from the Health Minister.

From a very young age Jack and Ben had very low muscle tone yet despite their high physical needs they have had to wait a long time to access adequate, supportive seating, something that has no doubt contributed to their Scoliosis, Hip Dysplasia and Chronic Lung Disease (due to aspiration and poor positioning whilst eating). Inadequate provision of equipment is a barrier to inclusion for children like Jack and Ben, it affects them being able to learn new skills and **maximise their potential and independence**, It prevents full participation in education and leisure pursuits and adversely affects quality of life. It has at times been unsafe feeding Jack as he requires supportive seating in order to eat safely and prevent aspiration.

Suction Machine

A couple of years ago we needed to apply for a **suction machine** for Jack, I spoke to PADP about this and was told that the waiting list was "on hold" as there was a dispute between "respiratory" and PADP in regards to who should fund such equipment, apparently this dispute had been deadlocked for over two years and my son was unable to receive the assistance he needed because of a dispute between two NSW government departments. There were no interim provisions for funding until the dispute could be resolved, no-one would fund a suction machine, simple as that.

Gastrostomy Buttons

PADP initially refused to supply Jack with more than two **Gastrostomy Buttons** per year (guidelines stated that he was entitled to two), this meant that once Jack had used the two buttons and required a third he would have to go to Westmead Children's Hospital to have it inserted there, unnecessarily wasting valuable hospital resources. I wrote a letter to the Health Minister to point out the financial costs involved in having to rely on the public health system for something I could do easily and quickly at home. Jack is now supplied with the necessary amount of Gastrostomy Buttons. This is just an example of PADP acting as dogmatic gate-keepers to funding and a policy that is cost ineffective and makes no sense in practice.

Feeding Pump

Jack requires the use of a **feeding pump** during episodes of Cyclical Vomiting, these episodes can last for over a week and occur frequently, during these times Jack needs to be kept home from school and requires very slow feeding (over 24 hours) in order to prevent vomiting. We need "giving sets" in order to be able to use the pump, however I was told that PADP (where we now live) could not supply the giving sets for this particular pump as PADP Penrith had paid for the pump (it was supplied by PADP Penrith when we lived there). I was told I would have to apply for a whole new pump and that this would have to be supplied before they could supply the giving sets, this would be a long wait. What an utter waste of money - and how wasteful and inflexible that PADP would rather fund a new pump (again) in excess of \$1200 rather than simply supplying the relevant giving sets. I will reluctantly be applying for another pump shortly. What a ridiculous waste of public resources and tax-payers money. This is an example PADP financial mismanagement, duplication and bureaucratic nonsense.

Portable Feeding Pump

I have heard from several people that PADP refuses to fund **portable feeding pumps**. One of the obvious benefits of a portable feeding pump is that it facilitates **inclusion**, however PADP's refusal to be flexible and meet individual needs is once again to the detriment of children in need of PADP assistance, often at no additional cost. It seems that the rules are the rules regardless of whether or not the rules make sense. **Bureaucracy at it's worst.**

Shoulder Keepers

I applied for **Shoulder Keepers** for Jack's Standing Frame as he was not standing safely without them, it took PADP eight months to inform me that they would NOT fund them. I called PADP and asked why it had taken an incredible eight months to let me know that they would not fund the shoulder keepers, the PADP Manager told me that they had been "trying to find out who paid for the standing frame", it was funded by Variety Club as PADP had refused to fund it - they did not deem it a necessity. A Standing Frame improves bone density for a child like Jack who does not stand or weight bear. Rather bizarrely we had to wait eight months when a simple phonecall to myself was all that was required - I could have told PADP who funded the standing frame, a thirty second phonecall could have answered the question. I complained to the Manager of PADP that I would have to apply elsewhere (charity) and would probably have to wait several months on top of the eight months Jack had already waited to be able to use his standing frame safely, the Manager confirmed that they would still not fund the Shoulder Keepers. I complained to the Health Minister's office and the Shoulder Keepers were funded. PADP also cited another reason for the eight month delay being that they had recently merged. Worrying to say the least considering further upheaval is **planned** - how will they ever cope?

Powerchair

Ben has waited over a year for a **powerchair**, in that time his Scoliosis has worsened. Without mentioning the obvious ethical issues involved, this it is possibly another example of "don't pay now - pay more later." The government should understand that failing to supply appropriate equipment now often leads to more pressure on another government department later ie. The Health Department if spinal surgery is warranted. Instead of funding the equipment the NSW Health Department then has the added burden of funding the equipment AND surgery/hospital stay.

It is also extremely unjust and unethical to deny children timely access to adequate, well-fitting equipment. That a child must be a certain age to apply for powered mobility through PADP contradicts all research and literature that states the best outcomes are achieved if the child has the independence of powered mobility from an early age.

Wheelchair repairs for WYD pilgrims compared to wheelchair repairs for NSW residents

Jack recently needed a part on his wheelchair repairing, he was unable to sit properly as the lateral was broken, this meant that he hung out way over the side of his wheelchair. It took many phonecalls and **two and a half months** to get this fixed, a shameful contrast when you consider that during the **World Youth Day** week a wheelchair repairer was employed to fix wheelchairs on the spot for "pilgrims" (see attachment "World Youth Day services for pilgrims with a disability"), why should my child who lives in NSW have to wait over two months? Had I prior knowledge that this service were to be provided for World Youth Day I would have travelled into the city with my son hanging out the side of his wheelchair, dressed as a pilgrim in a WYD t-shirt and had his wheelchair repaired on the spot. I'm sure that WYD pilgrims were given the false impression that NSW residents have access to good services. They don't. I sent a letter to Minister Keneally (WYD Spokesperson and Disability Minister) asking when these services would be available for residents of NSW, I never even received a reply.

Standing frame and no-one to fix it

The issue of equipment is not solely the problem of PADP, many families - including ours - now find it very difficult to access therapists for our children. Jack has needed his standing frame adjusting for several months now however he has not seen a Physiotherapist for over a year, in that time he has been forced to use an ill-fitting standing frame. Jack and Ben previously had access to Physiotherapy, Occupational Therapy, Speech Therapy and a Caseworker, now they have access only to an Occupational Therapist, she is a very good OT however they really need more regular access to other therapy too.

The way therapy services are delivered is woefully inadequate and again, **chronically under-funded**, this will no doubt have negative long-term outcomes for our children. The possibility of a **self-directed funding model** such as InControl (a successful self-directed funding model operating in the UK) needs to be looked at as an alternative so parents can decide what best meets their child's needs - not bureaucrats. Many parents have had enough of being dictated to by **DADHC and PADP**, it's about time the **retrograde policies** of this government were dispensed with and a more progressive funding model were adopted, one where the parent has some **choice and control** in the services their child receives. Families have had enough of being told what they need and when they need it. **CUT THE BUREAUCRACY.**

PADP Efficiency

I used to call PADP and receive a response within a reasonable timeframe however since the merge - and if one employee in particular is involved - it can take much longer to receive a response. I called a few months ago for incontinence products and this particular employee had forgotten to order them, it became a rather frustrating process to have my phonecalls returned, it took **two and a half weeks for someone to return my call**, and this only when I called the hospital switchboard and asked if I should call the Health Minister's office and have the Minister order my children's incontinence products. I once called to order Jack and Ben's continence products a couple of days early (I was going to be busy later in the week with Hospital appointments), I was told to call back a couple of days later on the correct date as I was a couple of days too early. This is petty and the efficiency of PADP is questionable - at best - since the merge.

Access Issues

Ben is now facing the challenge of having a manual wheelchair funded, it is impossible for Ben to access certain places with a powerchair. Certain family outings will be inaccessible without a manual wheelchair, we have a couple of family members who have steps leading up to their homes, one family member we visit regularly lives in an apartment up three flights of stairs. According to others, PADP will be reluctant to fund a manual wheelchair as Ben will have a powerchair - my response to PADP should they refuse this request would be to ask them if they would carry a 30kg+ wheelchair up three flights of stairs. What is the alternative? That Ben miss out on visiting family who have stairs? Or that we injure ourselves whilst lifting a 30+ kilo chair? It is very important to us - and Ben - that he is able to participate socially.

Tax Deductibility

I have no doubt that there should be a well resourced, adequately funded public program of aids/equipment for those with disabilities however if in addition to this the government gave all equipment/aids 100% tax-deductible status it would allow for people who wanted to and were able to self-fund to do so, thus freeing up PADP funding for others.

Therapy and the need for an inquiry

The problem of provision of equipment is exacerbated by another government department - DADHC. DADHC no longer provide adequate access to therapists and Caseworkers as they once did, at the time of writing this Jack and Ben have not seen a Physiotherapist for over a year, they have no Caseworker or Speech Therapist. Jack was recently dumped from his Speech Therapy service - I voiced my concerns about Jack needing this service to continue however my opinion was completely disregarded and the service was promptly closed.

DADHC policy now allows for only short-term therapeutic intervention, it is woefully inadequate that one day a therapist or Caseworker - as was our experience - should just dump a child with high, ongoing needs from the service. The provision of therapy and other services to children with disabilities really needs close examination, preferably in a parliamentary inquiry. The need for an inquiry is perhaps more urgent following the recent "trespassing policy" (as it is referred to by carers) published by DADHC, I believe it highlights the attitude of this government towards those with disabilities. Recent policy and the behaviour of government departments towards those with disabilities warrants the setting up of a permanent, independent monitoring body to oversee and monitor disability services.

The Federal Government needs to introduce comprehensive disability rights legislation in line with other developed countries to prevent abuses such as these recent retrograde policies (that appear to have been written a couple of hundred years ago). Inclusion and self-determination should be legislated rights and then there would be no need for an inquiry such as this.

It is completely unacceptable that children should suffer lifelong pain and disfigurement because in NSW we do not have adequate access to disability aids, equipment and therapy. I have met parents of children whose internal organs have been adversely affected by severe scoliosis, respiratory and gastroenterological organs have been irreversibly affected - all exacerbated by inappropriate, ill-fitting equipment and lack of intervention. That this can happen in a relatively wealthy democracy with a multi-billion dollar budget surplus is absolutely unacceptable and a sad indictment on the priorities of both levels of government and their failure to respond to the needs - and more importantly the human rights - of people with disabilities. It concerns me how little DADHC and PADP (and hence the NSW Government) care about ethics in the area of disability.

It is the responsibility of governments to remove barriers to inclusion and create equality, currently people with disabilities and their parents/carers are disempowered by the system, a system where they have no say and very few rights. The aim of all disability policy should be to maximise potential and enhance quality of life. The system as it currently stands requires a drastic overhaul.

Regards,

Faye Galbraith.

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Mr Cohen to the Attorney General, and Minister for Justice representing the Minister for Health

1. In relation to the PADP program why is it much faster to have equipment paid for by a charity, such as the Variety Club, than by the Government Department funded to fulfil this role and meet this need?
2. Has the agreement that PADP would be responsible for maintaining and repairing any equipment for children supplied and paid for by Variety Club now ceased?
 1. If so, why?
3. Is PADP so chronically under-funded that they can no longer honour this agreement?
4. Do you think it is fair that parents and unpaid Carers are now made to foot the bill for this - especially considering that The Variety Club is providing for the unmet need that your Department is responsible for?
5. Are you aware that children (such as the 5 year old son of a constituent) are developing further problems and deformities such as severe Scoliosis and experiencing chronic pain because of inappropriate seating due to the long wait for appropriate equipment such as wheelchairs?
6. Do you think that children who already face many challenges in life due to their disability should be further disadvantaged in this way?
7. What does your Government plan to do about the shortfall in funding to PADP?

Answer

I am advised that:

1. As we do not have access to data related to waiting times and application processes for people who apply to charities for equipment we do not know what the differences in waiting times are.
PADP is only required to meet the cost of the most economically clinically appropriate item. Charities (such as the Variety Club) are sometimes approached by clients and prescribers when the items being requested exceed the cost of the most clinically appropriate item.
Reforms currently being undertaken to PADP will result in more equitable access to PADP regardless of where a client may live.
2. This agreement has not ceased. PADP policy remains that PADP may assist with the costs of maintaining and repairing an item supplied by another organisation. In situations where this occurs, the client may be asked to consider returning the item to PADP for recycling if and when the item was no longer required.

3. This agreement continues to be honoured. The PADP budget in 2007/08 is \$24.2M. A further \$0.8M is allocated for the Spinal Setup Fund to provide for the equipment setup costs of people with traumatic spinal cord injuries. This represents a doubling of the budget since 2000/2001.
4. Parents and unpaid carers can apply to PADP for assistance with the costs of maintaining and repairing this equipment under the current PADP policy.
5. If the Hon. Member would like to provide the details of the 5 year old he was referring to, NSW Health will investigate this issue further.
6. The NSW Government is committed to supporting children with long term disabilities and ensuring that services are responsive to their needs. The NSW Government recently released its response to a comprehensive independent review of the Program of Appliances for Disabled People (PADP) by Pricewaterhouse Coopers (PWC). The recommendations of the review provide an opportunity to develop an integrated, consistent, cost-effective and equitable approach to the delivery of all NSW Health disability support services.
7. The independent PADP Review recommended that the Government implement major reforms to improve the program's efficiency, consistency and quality. The Government has endorsed the key recommendation in the Review of PADP "that all PADP functions be transferred from the existing Lodgement Centres across NSW to one statewide administration".

This reform, along with key initiatives such as:

- Progressive extension of new procurement arrangements to PADP centres across NSW following positive evaluation of procurement pilots
- Establishment of statewide advisors to provide better support for clinicians making complex equipment prescriptions
- A statewide 1800 number to provide clients and clinicians information about the program
- Enhancement of the existing spinal setup fund to include children and adults with acquired brain injury
- Development of standardised application processes and guidance for prescribing clinicians through the Common Equipment Prescriber Guidelines Project and development of a web based information system (which will improve the program efficiency and administrative processes and provide support for consumers and prescribers) will mean that the delivery of disability equipment support services will be integrated, consistent, cost-effective and equitable.

All savings achieved through program reforms will be redirected back into the program and used to purchase equipment for people with disabilities.

Once these reforms have been implemented, the Government will review demand for equipment support services.