

**Inquiry into the New South Wales Program of Appliances for Disabled People (PADP).**

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**Submission to the Inquiry into the Program of Appliances for Disabled People**

Thank you for giving me the opportunity to make this submission to the Inquiry into the NSW Program of Appliances Disabled People.

**Background:**

Spinal Cord Injuries Australia is Australia's leading Community organisation supporting people with traumatic and non-traumatic spinal cord injuries and similar conditions. Our organisation, currently in its 40<sup>th</sup> year, has a long history of providing services to our members and being a voice for their concerns both socially and to various levels of government.

## **NSW PADP INQUIRY TERMS OF REFERENCE**

That General Purpose Standing Committee No 2 inquire into and report on the Program of Appliances for Disabled People (PADP), and in particular:

- 1. Adequacy of funding for present and projected program demand*
- 2. Impact of client waiting lists on other health sectors*
- 3. Effects of centralising PADP Lodgement Centres and the methods for calculating and implementing financial savings from efficiency recommendations*
- 4. Appropriateness and equity of eligibility requirements*
- 5. Future departmental responsibility for the PADP*
- 6. Any other related matter.*

Submission:

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

There is a great deal of anecdotal evidence of issues around the funding levels for PADP. Often funding is discussed in terms of meeting equipment purchase needs and costs of the administration of the program. This is looking at the issue only in two dimensions when really we should be looking at the benefits that a recurrent increase in funding can give to the person with a disability, Australian society and direct savings to the NSW budget.

#### In two dimensions

If we look at recognised need as being an indicator of funding requirements there is an issue in itself. Trying to get an accurate snapshot of absolute demand for those who have a requirement for equipment under the PADP is virtually impossible. The NSW Department of Health (DOH) in May 2005 estimated that there was \$5,500,000 in equipment outstanding; this relates solely to the people who have applied for equipment. This figure was matched with an increase in funding in the 2005/06 budget of \$2 million ensuring that the program would continue to maintain a substantial waiting list.

The AIHW report in 2001 'Unmet Needs for Disability Services' estimates that within the Australian health system as few as one in ten people are successful in accessing programs. The figure of \$5,500,000 ignores or does not attempt to capture those who have 'unmet need' that is who:

- are deterred from applying for equipment owing to an understanding of the length of the waiting list;
- have been on the waiting list for a long time and simply dropped off it;
- are making do with inappropriate equipment;

- through severe need have sourced the equipment through a service provider or other arrangement; and
- who through language, cultural barriers or lack of understanding of the program have never applied.

In 2001 the Physical Disability Council of New South Wales (PDCN) investigated data capture at PADP Lodgement centres and found that of the 35 centres only 14 could provide any historical data and that was only for 12 months. How can funding thus be properly allocated if need isn't recognised?

Another way to get a real idea of how much to fund the program is to examine the applied increases in funding to PADP since it was first implemented. Funding for PADP has grown since 1982 with the biggest increases from 2001 to 2006:

2001	10,400,000
2003	17,900,000
2005	21,800,000
2006	22,300,000
2007	24,200,000

The large between 2006 and 2007 is owing to a \$2 million program specific boost by DADHC and does not represent a real terms NSW Health increase.

If, in treasury terms, there is recognised need for growth and the program maintains a waiting list with some people waiting up to four years for equipment (SCIA consumer survey, Freedom of Information released EnableNSW waiting lists please see appendix A.) then the present funding is insufficient ergo there is more need than the program is funded for.

A way of handling the recognised need that appears to have developed when working within a low budget/high need program seems to have been to create 'economic hurdles'. Both direct and indirect economic hurdles to stagger the need have been identified as:

- the \$100 co-payment;
- the tier structure for eligibility; essentially only those within Tier 1 will receive items of equipment;
- the application process itself - access to OTs and social workers in regional NSW is difficult;
- items under \$800 being automatically supplied whilst items over this threshold have to go to lodgement centre panels which may meet four times per year;
- long waiting times often requiring re-assessments and re-quoting on items; and
- poor invoice payment times for pieces of equipment by NSW Health leading to suppliers having difficulties in providing pieces of equipment (losing viability).

Only when a person has made it through all of these economic hurdles can they finally receive their piece of equipment.

Recently the NSW Government in conjunction with the Federal Labor Government announced, just as they had in Tasmania and the Northern Territory, a one-off burst of funding to clear the waiting list. This was \$11,000,000 and represented around 40% of the total program funding. Surely this is further evidence of how bad things have become. It is embarrassing for the NSW Government to formally recognise that a program is under funded within the 07/08 budget to the tune of around 40%.

Within the recent PwC review of 2006 there were very clear recommendations on the adequacy of ongoing funding. Using the data supplied in the report it is recommended that total funding meet the present aims of the program \$35 to \$70 million per year. The large gap between the figures is owing to inconsistencies in the data supplied by the area health services which do not allow a 100% accurate figure to be calculated.

Recently released PADP waiting lists corroborate some of the periods that people have been waiting for items of equipment and the cash values of these items.

Based upon the information supplied through the PwC review and the NSW PADP waiting lists that corroborate anecdotal discussions with lodgement centres, Enable NSW staff and PADP consumers, a large recurrent increase in funding will provide for a successful program. We are calling for an increase of \$13.5 million indexed PADP funding.

### In three dimensions

This is best answered through the other terms of reference of the inquiry that look more holistically and socially at the impact that non-provision of equipment has on a person with a disability.

### **The Impact of client waiting lists on other health sectors**

When looking at a program that exists within a 'chain of need' (items that are essential to have a quality of life such as accessible housing, personal care etc and are all interdependent) you need to understand the knock on effect and impact that a lack of equipment can have upon the individual.

### Created health issues

Inappropriate or a lack of equipment items has been linked to pressure sores developing on the person with a disability. With estimated pressure sore treatment costs of between \$61,230 and \$100,000 (Queensland Health Journal May 2006 and we understand these figures do not record surgery and recovery costs that can take the total closer to \$500,000) the false economy of not providing equipment in a timely manner is very obvious, When we

further build in mortality issues around long established pressure sores the cost becomes highly significant.

Scoliosis may be a resulting condition prevalent in developing children that have either waited long periods for items of equipment or received inappropriate items. This curvature of the spine can lead to many ongoing health issues, as with pressure sores, resulting in surgery to correct the issue. On the recently released PADP waiting lists there is an incidence of a child in western Sydney waiting over 18 months for a back brace.

### Bed Block

A UK Study by the Audit Commission in 2002 called 'Fully equipped' stated that:

'Many acute services are struggling with the need to reduce waiting times and increase capacity. Yet they face increasing pressure from admissions and have, on average, around 6% of their beds occupied by patients who could be discharged if community services could be organised. Equipment services could, therefore, play a vital part in strategies to optimise capacity, prevent unnecessary admission to hospital and facilitate prompt discharge of patients.

There is little reason to believe that the situation is any different in NSW. The estimated costs to the DoH of acute hospitalisation is around \$864 per day (Hospital bed cost AIHW 2003/04) the cost of a typical motorised wheelchair (\$15,000) can be met in wasted costs in just 17 days stay in a spinal or acute care unit.

If you look at the emotional costs, lack of participation in the community and life, a feeling of isolation, loss of self-control, you have people paying a far higher cost for PADP.

### Carers

Often one of the overlooked groups of people to feel the effects of non provision of equipment are personal carers (Dr Samantha Bricknell AIHW 2003). They have increased workloads placing a greater strain on both themselves and on the family; if a family member. When it is a partner that is being cared for a carer can often be at great risk of physical injury and owing to the long term harshness of caring, may suffer premature ageing. In a family setting if there is no item of equipment you have to make do.

If using professional carers being provided under the Attendant Care Program, or Home Care Service, this can impact on the number of care hours a person is allocated. The initial assessment for care takes into account the person being in receipt of equipment and calculates the workload from that. If there is none or inappropriate equipment this can place undue stress on the Department of Ageing Disability and Home Care (DADHC). This department does not have a limitless bucket of care hours to distribute.

When looking at the Attendant Care Program and Home Care another issue that arises is OH&S. If the professional carer works in an environment that is unsafe for them, i.e. having to lift bodily a person into bed owing to no hoist being provided by PADP this can cause a serious problem both personally and legally.

Occupational Therapists (OT) needing to sign off the assessment application and the manufacturers or suppliers of equipment are two further involved groups.

An OT may use up resources and time in getting an application completed knowing full well that if a high cost item is requested they will end up redoing the script in 6 to 12 months time. Now part of this cost may find its way onto the PADP budget but if not it is still a large cost for NSW Health to have to shoulder. There is also the issue of access to an OT, especially acute in regional NSW that may have a further delaying action. Anecdotally we have become aware of an OT in New England needing to make 4 hour round trips to check a script.

The manufacturer or supplier using their sales person will need to spend time demonstrating, travelling and filing paperwork for a client with no sale as a prospect to cover the costs. This is understood to be a significant part of a working day with a single application script sometimes taking up to 7 hours to complete. Potential lead times for orders can be anywhere between 3 months and 2 years. This extended and unsure lead time can lead to a lack of viability in the supply sector and mean that there are less and less suppliers making it more difficult to source items.

### **The Effects of centralising PADP lodgement centres and the methods for calculating and implementing financial savings from efficiency recommendations.**

One of the recommendations within the PwC review was to centralise the PADP administration, essentially closing down local lodgement centres and divorcing responsibility and control to EnableNSW from the area health services. There are many advantages and some disadvantages of doing this.

#### **Monetary savings**

The potential for \$1.4 million savings that could be generated by centralisation could be a welcome funding boost. This figure although optimistic, as far as we are aware doesn't take into account legacy wages of displaced health staff who will remain on the NSW Health books for up to 3 years awaiting reassignment consequently savings will be much lower.

#### **Local interpretation**

A UK Study by the Audit Commission in 2002 called 'Fully Equipped' found that the smaller distribution centres often misinterpreted direct governance policy on eligibility and made decisions based upon what they could afford. Basically 'eligibility criteria were generally set by provider organisations with a view to their meeting the available annual budget'. This same situation occurring in NSW was outlined in the PwC review.

The interpretation of how to use clinical PADP indicator scores also seems to vary. This has been demonstrated through the recently released NSW PADP waiting list. An example of this can be seen through Sydney West Area Health Service that seems to operate an indicator scale of 1-9 with the majority of their applications on a 9. As I understand it 9 is low priority and contains instances of high cost items such as wheelchairs, hoists, beds and manual wheelchairs for children. Hunter New England seems to operate a 1-54 ranking.

There seems little consistency throughout all of the area health services as to how to operate, evaluate and what makes someone eligible. This variance leads to differing outcomes for PADP applicants with some reporting an excellent service and many saying otherwise.

#### Service levels after efficiency savings

Many people have indicated to our organisation their worries that PADP will become a faceless entity with long waits to call centres in Mumbai. This may be the case as all of the recommendations within the PwC being enacted are not yet finished but it's too soon to draw any conclusions. We would like to hope and certainly the conversations coming out of EnableNSW are encouraging that an applicant centred approach will be taken.

As lodgement centres have never operated as shop fronts the actual contact that an individual applicant has with their lodgement centre will not change if centralisation occurs.

As with all rationalisation there is a potential for the loss of individual expertise that instigated best practice at their local lodgement centres. This should be stopped at all cost and these people involved in the changes to the PADP under the PwC review.

Anecdotal conversation with some lodgement centre managers informed us that PADP lodgement centre work is very much a sink and swim task.

In relation to training lodgement centre staff told us that you are given very little guidance from above. There is little to no formal training and what there is, or was, can often be delivered second hand by the previous manager or staff. They also indicated that those staff members may equally have received it second hand themselves from other former staff members. This would certainly seem to corroborate the wide variety in experiences people have talked about with lodgement centres. The PwC review says:

*'It was unclear how the members of the advisory committee for this lodgement centre were appointed, for how long they served, on what basis they were appointed and to whom within the AHS executive the committee reported.'* P114 PwC review

In light of this, centralisation seems a positive thing if done with a pure focus on positive client outcomes.

### **Appropriateness and equity of eligibility requirements**

There is very little argument in what is a clear black and white position around eligibility. PADP should look at becoming an entitlement program. If a person requires an ambulance and the NSW ambulance budget is over its limit does that person wait 3 months, 6 months, 12 months for that ambulance? If a person requires oxygen to be able to breathe do they receive it with no wait? The same should equally occur under PADP. If a person has a clinical requirement for an item of equipment it should be instantly sourced and supplied as fast as it can be delivered. It would appear that it is the decision of NSW Health that it is more financially prudent to allow people to use expensive hospital beds or care, respite or rehab facilities rather than produce what would work out to be very cheap items of equipment.

### **The Co-payment**

When looking at eligibility, as the PwC review did, it grouped co-payments in with eligibility.

The co-payment of \$100 per year for items of equipment is one that albeit small in size can have great impact on the budget of people on a Disability Support Pension. In the PwC review it states that PADP makes around \$1.5 million in revenue for the PADP. Anecdotally there is a belief that the co-payment costs more to administer than it gives to the program.

The co-payment can often break the bank of a person who may be left with as little as \$20 per fortnight in their pocket after other life and disability related expenses (A Survey of the Unavoidable Cost of Disability –AQA 1999). This research showed that as the level of disability increases so logically do the associated costs.

In the PwC report it discusses the inequity between someone applying for high cost items paying \$100 and someone applying for low cost items also paying \$100. What this review failed to report on is that often high cost items are going to people with more acute disabilities and this group of people are often pensioners, unable to either gain employment or manage other income streams. The people with less acute disabilities often do have more income options available to them.

We would like to see the co-payment completely dropped as essentially this is a non voluntary payment that has no precedence in the health system. It's a tax on those that most need items of equipment and can often least afford it. This is morally wrong.

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

The PADP operates with two stages of governance. The Department for ageing and Disability and Home Care (DADHC) has an over-arching role of ensuring that as a disability program its aims are compliant with its commitment to ensuring that older people, people with disabilities and their carers are valued, lead independent lives and have the opportunity to participate fully in community life.

This relationship is historical and was quoted in the PwC review:

*The MOU makes clear that this funding was provided to NSW Health under the Disability Services Act (NSW) 1993 (See appendix B) and that both departments are required to ensure that the use of the funds confirms with the Act. The MOU provides for ADD (Now called DADHC) to have a responsibility to review the PADP guidelines to ensure that the guidelines comply with the Services Act. Should ADD determine following a review that the funding of PADP is not compliant with the Services Act, NSW Health 'must ensure that (any) non-compliance is rectified as soon as possible' (Clause 6.4). Under the MOU, the role of ADD is to provide notice in writing in order to require NSW Health to rectify any non-compliance and to withdraw the funding."*

If we apply the Disability Services Act 1993 onto PADP it becomes very easy to interpret the PADP as not being compliant in a number of areas.

NSW Health and DADHC are two very separate government departments. The approach that NSW Health will take will be largely clinical in relation to issues around equipment. This is borne out through a PADP clinical indicator score that is built around risk of injury or readmission to hospital. It is our feeling that although valid this isn't the whole picture. DADHC will look at this from a person centred approach as they do across all of their disability services. This approach will look at contribution to society and their community. Ease of access to shops and employment. A person with a disability does not necessarily have an illness it's a situation they live with. Items of equipment provide life opportunities. This aim is better served under a disability program (DADHC) than it is under a NSW Health one.

### **Other related issues.**

#### **Maintenance of equipment**

A common issue raised by people with disabilities in relation to PADP is maintenance and troubles with repairs to items of equipment. According to the PwC review the costs to the program at the delivery end for maintenance is around 12% of average lodgement centre costs.

To the user of the item of equipment certain themes were prevalent:

There was a lack of 24/7 assistance. This was highlighted with the story of a gentleman whose batteries ceased working on Good Friday and was unable to leave the house until the following Tuesday when his batteries were replaced. In this instance the lodgement centre was helpful although all they could do was leave a phone message for their sub-contracted repairer to pick up when they returned to work on Tuesday.

There was a recognised lack of local repairers resulting in a small number of repairers servicing large areas consisting of many people leading to a virtual maintenance lottery.

The long lead times for the complete repair of items of equipment was very telling on some clients with one person waiting almost 18 months to get elements of their chair corrected. These elements made the chair unusable in a wheelchair accessible taxi and greatly inhibited her movement.

## **Summary**

In summarising our submission to this inquiry there is a lot more to be done with PADP to make it into a program that meets the needs of people with a disability:

- adequate ongoing funding of around \$35 million per year;
- restructured governance bringing the program under DADHC control;
- eligibility criteria to be dropped and the program to be one of entitlement;
- more effective data capture of applicants so that future planning can be accurate;
- a person centred approach to equipment delivery and prescription.
- The program to be unequivocally in line with the Disability services act 1993;
- innovative new ways to be explored to deliver ongoing rapid maintenance of existing items of equipment; and
- the co-payment to cease.

Again, thank you for providing the opportunity to make a submission to the Inquiry into the NSW PADP; I trust that these issues above will be given serious consideration and that the inquiry results in a positive outcome.

Yours sincerely,

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*Appendix A.*

PADP supplied waiting lists provided under a freedom of information request submitted by the NSW Greens. Information supplied was tested for validity by running two very obvious PADP applications through the data. We found these applications to be missing and thus question the wholeness of this data.

Please see attached PDF's that represent Appendix A.

Appendix B.

**DISABILITY SERVICES ACT 1993 - SECT 3**

**Objects**

**3 Objects**

*The objects of this Act are:*

*(a) to ensure the provision of services necessary to enable persons with disabilities to achieve their maximum potential as members of the community, and*

*(b) to ensure the provision of services that:*

*(i) further the integration of persons with disabilities in the community and complement services available generally to such persons in the community, and*

*(ii) enable persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community, and*

*(iii) are provided in ways that promote in the community a positive image of persons with disabilities and enhance their self-esteem, and*

*(c) to ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account in the granting of financial assistance for the provision of such services, and*

*(d) to encourage innovation in the provision of services for persons with disabilities, and*

*(e) to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community, for persons with disabilities, and*

*(f) to ensure that designated services for persons with disabilities are developed and reviewed on a periodic basis through the use of forward plans.*

All of these are aims that DADHC and all programs with an aim of empowering people with disabilities are supposed to be commensurate with.