THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

Organisation:

Royal Institute for Deaf & Blind Children

Alice Betteridge School

Name:

Suppressed

Date received:

1/09/2008





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PARLIAMENTARY INQUIRY INTO PADP

We are writing to inform you of our experiences with the NSW Provision of Appliances of Disabled Persons Program. This is an organizational response from the Royal Institute for Deaf and Blind Children. The therapy team that have collaborated in writing this response are occupational therapists, physiotherapists, and speech pathologists employed at the RIDBC Alice Betteridge School based in North Rocks NSW.

Client Group

The RIDBC Alice Betteridge School caters for students between the ages of 4 ½ to 18 years of age with hearing and or vision impairments and intellectual impairments. Many students also have an associated physical disability. These students have a permanent disability with ongoing complex needs requiring our intervention. The therapy team work within the school context to assist students to access and participate in the educational curriculum. The school's occupational therapists and physiotherapists often seek funding for their clients for necessary aids and appliances. Collectively, we have significant experience in assessing client's needs in the area of paediatrics and disability.

The students of RIDBC Alice Betteridge School live across Metropolitan Sydney and some even live as far as Newcastle and the Blue Mountains. We assist our families to seek funding for the appropriate aids and appliances through many PADP Lodgement Centres.

Common aids and appliances sought from PADP are:-

Wheelchair bases and seating systems, powered wheelchairs, continence products, commodes and shower/bath seats, walking frames, standing frames, inner shoe orthotics, ankle foot orthoses, specialised footwear, travel seats and sleep systems. Our speech pathologists prescribe communication devices for selected clients.

Disability equipment required for a student with complex physical needs can range from \$300 to many thousands of dollars. Although the Australian Market is growing, disability equipment suitable for our clients tends to be manufactured overseas which most likely contributes to the significant cost.

Improvements noted within the PADP System

Although we have a large number of issues that we feel require further improvement, as therapists we have noted some improvements with the process and system since its inception including

- Eliminating the means tested system where parents above a nominated salary were ineligible to receive PADP funding. It is unrealistic to expect parents with a child with a complex disability, to be able to finance the ongoing costs associated with the purchase of disability equipment on an average wage.
- The draft version of consistent documentation for PADP, made through working parties by the Lifetime Care Authority for NSW, made comment available to all stakeholders in 2007. However the progress with this draft is unclear.
- Some PADP centres have improved their communication to families and referees, regarding waiting lists and progress of applications

Current Issues

Inequity between the distribution of funds / wait times between different lodgement centres.
 Hornsby usually involves a wait of 3-4 months while Children's Hospital Westmead and Liverpool have waits of 1-2 years on larger items.

Lack of funding for sleep positioning systems

It is contradictory, funding a posturally supportive wheelchair when the child sleeps in a position promoting deformity at night.

· Lack of feedback re progress of applications

Some PADP centres do send a letter to parents but most don't. This appears to be an issue of reduced staff.

Criteria for clients who have received compensation

Approval continues for those with large compensation payments, while others with genuine financial hardship /no fund continue to wait.

Inconsistency with application criteria

Some lodgement centres request an additional letter from doctor/specialist to process the application e.g. Auburn, Calvary PADP.

Some PADP Lodgement Centres, notably Liverpool PADP, are extremely difficult to make contact by telephone or email

How PADP prioritize equipment needs for a large range of clients?

Priority should be given for children with a known disability so funding applications could be expedited.

Priority for items such as nappies, AFO's, and wheelchairs, which are required urgently.

PADP information available on NSW Health Web Site needs to be updated regularly
 Information regarding contact numbers and Lodgement Centres can be incorrect.

 Mt Victoria Hospital does not exist, yet it appears in the PADP circular!

The Paediatric Equipment Pool System could be improved

Returned equipment such as a child's Standing Frame and Walking Aid could be loaned from a central pool, instead of further funding being sought through for the same appliance through PADP.

Current difficulty with process of applications through Liverpool Hospital.

Several applications have been lost and some applications have been on waiting list for 3 years with no follow up on progress of application! Applications that have gone in more recently tend to get approved before these!

SPECIFIC EXAMPLES OF INCONSISTENCIES OF FUNDING THROUGH PADP

1. Limited Funds

A student at the RIDBC Alice Betteridge School diagnosed with severe cerebral palsy, hearing, intellectual impairment and scoliosis, having been assessed by their school occupational therapist, identified their need for new seating system due to growth. It was stated in the original application made to PADP, that due to future growth their current system would require continual adjustments to accommodate changes in this child's position.

A request was put in by the OT on the 1/4/2008, as an urgent need, for a new seating system at a cost of approximately \$5000 through Liverpool PADP.

Although the seating system has been approved, the item has been placed on a waiting list for an indefinite period.

This delay impacts on the student in question, as the current system is too small and causes discomfort. Furthermore the wheelchair is not maintaining the child in an ideal position, and therefore there is a risk that this poor posture leads to further deformity. However as the new seating system is not funded, there is no other alternative but to wait and face the potential consequences of pressure areas, pain and discomfort and further loss in range.

A student diagnosed with CP, vision, intellectual impairment and microcephaly has been assessed by their school PT and Visiting Orthotist and deemed they have outgrown their current pair of Ankle Foot Orthoses (AFO's). This student has been prescribed AFO's to continue to access a Standing Program regularly.

An application was made to PADP Liverpool in October 2007 to fund a new pair of customised AFO's at a cost of \$520.00. Later enquiry on the progress of this application in January 2008 led to information that this application had been "wait listed".

As of August 2008, the item has still not been provided and no further communication has been received.

This student continues to use their ill fitting AFO's to access their standing frame.

The AFO's have to be closely monitored as they cause pressure areas and are not suitable to be worn throughout the day, as would normally be expected. It is anticipated that the current AFO's will soon be too risky to wear, and this will mean we have to cease this student's standing program.

2. Poor administration and follow up

An application was made to Hornsby PADP in April 2007 for upper limb splints for a student with cerebral palsy. No correspondence was received, and in March 2008 a follow up phone call was made (almost 12 months after application). Told there was no funding available for current financial year for this application. A second phone call made in August 2008 and reported that funding had been approved last September (2007) and the fax to order these splints must have gone missing.

In summary, we appreciate the opportunity to submit our thoughts relating to the NSW PADP Program and hope that some measures can be implemented to assist all consumers requiring assistance from the PADP Program.

In our experience, the particular difficulties we face are with lack of funding to the Western Sydney PADP Lodgement Centres which experience the highest demand, and would benefit with a greater proportion of funding.

Due to the high number of persons with a disability accessing the service ranging from paediatrics to the elderly, the question often arises of how each centre prioritises the varying needs of the consumers.

The introduction of a consistent approach across all PADP Centres may help to streamline this wonderful service to the community.

Yours Sincerely,