



PDCN News

Volume 4 Number 6 December 1998



PRESIDENT'S MESSAGE

On behalf of the Committee and staff, I wish all our members a Merry Christmas and a Happy New Year.

As I look back over the year, I have a mixed sense of pluses and minuses.

At this time last year we had expected that the Transport Standards would now have been passed, and that the disability amendments of the Building Code of Australia would have gone through. More delay!

We had expected that there would be some reform of PADP. Nothing!.

Backsliding on attendant care and home care, possible introduction of a poorly designed GST, marginalisation of human rights as an issue, political correctness as a term of abuse are all minuses. Too many minuses!

However, the positive side of the ledger is the consolidation of PDCN's submissions, our consultations and our policy development.

We have made strong submissions on Transport, Building, Taxis and the GST. These submissions have argued for access on economic as well as social justice grounds, and have been used as a valuable resource to the whole disability sector.

We have pursued strategic alliances with other groups who are better placed than us to take the running on issues such as Education, Services, Accommodation, and Ageing.

We have produced a Complaints Kit, Position Papers '99, and six newsletters.

Over the next twelve months we will be revamping our consultations. Rural consultations will continue to introduce the idea of advocacy and training people to lobby. In Sydney, we will have evening consultations which will have an issues orientation rather than a training orientation.

We will continue to develop our media presence and we hope to undertake some exciting joint research projects.

In disability advocacy, we have to think long-term as well as fighting fires. PDCN is beginning to do this, and in my mind this is a big plus.

1999 is shaping up as a great year for PDCN - make sure you are along for the ride.

Regards John Moxon

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PADP PROTEST RALLY

Wednesday 20th January 1999

11.00 am

Outside Premier Carr's Office

Governor Macquarie Tower, 1 Farrer
Place, Sydney

PADP ISSUES

What is PADP?

PADP is the NSW Government's Program for Appliances for Disabled Persons.

It is meant to provide the funds for the vital equipment necessary for maximum independence and dignity for people with disabilities to enable them to continue to live in the community (avoiding institutionalisation) and to reduce their dependency on others at home and at work.

The PADP annual budget of \$13 million is managed by Local Area Health Services for the NSW Health Department. The program is meant to assist adults and children with such disabilities as cerebral palsy, spina bifida, muscular dystrophies, multiple sclerosis, spinal cord injury, and post polio. The program is meant to provide a range of mobility aids ranging from expensive items such as electric wheelchairs through to custom made shoes.



The Problems:

There is not enough money allocated to the program. This has led to highly restrictive means testing.

PADP funding has been seriously eroded because:

- ▶ medical items such as oxygen and CPAP machines (for sleep apnoea) have been introduced into the program and now take up more than 30% of the PADP budget;
- ▶ the pressure on hospital beds and lack of hospital funding has meant that more people are being discharged with supportive equipment taken from PADP funding;
- ▶ the incidence of disability has increased due to a lower mortality rate;
- ▶ developments in technology and design have resulted in more sophisticated equipment, providing more opportunities and a greater demand;
- ▶ funding for the program has never been based on need but simply an arbitrary allocation which has never been enough.

In some cases people are told the waiting list can be as long as 4 years.

Families already struggling financially cannot cope with additional expenses for necessary equipment and are forced to beg from charities, service clubs and their local community. Families' resources are depleted by the costs associated with a disability, and many families are forced into poverty because of these costs.

There is confusion over:

- ▶ eligibility criteria for assistance;
- ▶ probability of assistance (and time frame);
- ▶ ownership of equipment;
- ▶ why legitimate concerns have been constantly ignored over the last 12 years.

Lack of funding, fragmented management and unclear guidelines have particularly disadvantaged:

- ▶ people requiring complex mobility aids and higher priced items such as wheelchairs;
- ▶ children who are growing and in need of continuing modifications; and
- ▶ people in high population growth areas.



The (Mis)management:

In addition to inadequate funding, the program is restricted by:

- ▶ lack of a centralised policy which results in crisis allocation and no clear rational rationing and assessment procedures. High need areas do not have the budgets to support their demand;
- ▶ fragmented management and discrepancy of the Program's management between different regions;
- ▶ outdated and inappropriate guidelines e.g. where a family has one working adult they are ineligible for PADP irrespective of other disability-related expenses or the number of children in the family – this is inequitable;
- ▶ lack of accountability – for money, equipment or returned equipment (which is often left in storage);
- ▶ areas with small budgets are reluctant to spend on expensive items i.e. wheelchairs;
- ▶ no consumer involvement in policy development;
- ▶ difficulties in accessing the program for disadvantaged persons e.g. poor literacy skills, people from NESB;
- ▶ inadequate information for people with a newly acquired disability, and parents of children with a disability;
- ▶ no independent complaints mechanism available.

Essential Equipment for People with Physical Disabilities

Needs vary according to age and disability. For independence, some people may need a range of equipment such as a motorised wheelchair (which can cost up to \$12,000), a manual wheelchair (approx. \$1250), a hoist, voice synthesiser, computer, crutches, splints, calipers, a shower chair (\$1,000), custom made shoes or incontinence products.

PADP guidelines allow for most of these items (if funds are available in the local area) with the exception of communication devices and environmental control units.

Effects of Inappropriate Equipment:

Aids and equipment require construction or modifications to suit individual needs. Inappropriate or ill-fitting equipment can cause serious medical complications (poor breathing & circulation, pressure sores, curvature of the spine, pain, and contractures of muscles) which can lead to hospitalisation and increased disability.

As children continue to develop until about 18years, they require continuous minor modifications and adjustments to equipment such as wheelchairs and standing frames with annual refits for calipers, braces, splints.

People with a degenerative condition will also require regular modifications as their condition progresses.

WHAT NEEDS TO BE DONE WITH PADP?

In consultation with the disability sector, the scheme:

- ▶ **needs to be restructured with a view to introducing centralised management and accountability, clear eligibility, prioritisation of funds and a proper complaints and appeals mechanism.**
- ▶ **needs to have its budget doubled immediately with funding requirements to be reviewed annually on an on-going basis.**

**CONCILIATION CONFERENCE
RE SYDNEY CITY COUNCIL CITY
REDEVELOPMENT**

John Moxon and Mark Relf from PDCN, Wendy Potter and Phillip French from PwD, representatives of Sydney City Council and lawyers from both sides met on 14th December at a HREOC conciliation conference relating to the kerbs, kerb ramps and footpath redevelopments in the CBD. Progress was made, and the parties will meet again in January.

We are not at liberty to divulge results of a conciliation conference, but suffice it to say that progress was made.

BUS TIMETABLES

There are now a number of low-floor wheelchair accessible bus routes, but there are still teething problems with getting information about times and routes. At this stage, the best bet to get information is by ringing the relevant local depot:

Brookvale	9941 5816
Mona Vale	9997 1257
Willoughby	9941 9214
North Sydney	9245 5267
Botany	9582 6715
Randwick	9298 6711
Waverley	9298 6625
Burwood	9582 4444
Kingsgrove	9582 3015
Leichhardt	9582 5950
Ryde	9941 6814

PDCN 1999 COMMUNITY CONSULTATIONS

DATE	PLACE	TIME	ISSUE
Wednesday 10 th February	Blacktown	5.30 - 8.00pm	State election issues and access to transport.
Monday 22 nd February	Wollongong	10.00 - 3.30pm	Introducing PDCN, State election issues and training in lobbying.
Monday 29 th March	Albury	10.00 - 3.30pm	Introducing PDCN, training in lobbying.
Wednesday 5 th May	Hornsby	5.30 - 8.00pm	Access to buildings.
Friday 30 th July	Grafton	10.00 - 3.30pm	Introducing PDCN, training in lobbying.
Wednesday 11 th August	Bankstown	5.30 - 8.00pm	Care and support - home care, attendant care and supported accommodation.
Monday 13 th Sept.	Griffith	10.00 - 3.30pm	Introducing PDCN, training in lobbying.
Sunday 31 st October	Chatswood	1.30 - 4.00pm	1.30pm - 2.30 pm PDCN Annual General Meeting. 2.30pm - 4.00pm PDCN Open Meeting. The issue will be citizenship.

Physical Disability Council of NSW provides a statewide representative voice by being the communication link between people with a physical disability and service providers, decision makers in government, the community and the business world.

For information on membership telephone 1800 688 831

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Contributions Welcome. NEXT EDITION DEADLINE: February 12th