

Submission
No 70

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

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The Honourable Robyn Parker MLC
Committee Chair
Legislative Council General Purpose Standing Committee No. 2
Parliament House
Macquarie Street
SYDNEY NSW 2000

Dear Chair:

INQUIRY INTO THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE

Thank you for the invitation to make a submission to your Committee's Inquiry into the Program of Appliances for Disabled People (PADP).

Equipment, aids and appliances available under the PADP are essential for the autonomy and independence of persons with disability, and for their safety, wellbeing and survival. They are necessary for comfort, mobility, communication, and personal development.

Although not typically identified as such by Aboriginal people, there is a much higher incidence of impairment and disability among Aboriginal people than for the general population. There are a number of social factors that contribute to this higher incidence, such as the lack of access to good quality healthcare (including health promotion and health prevention programs targeted at tobacco usage and obesity, for example), lack of access to appropriate housing and urban infrastructure (including clean water and sanitation), greater exposure to violence and abuse, the psycho-social impact colonisation, dispossession from land and the stolen generations, and substance dependence. Equitable access to the PADP is therefore a critical issue for our communities.

Aboriginal persons with disability experience multiple and aggravated forms of discrimination, disadvantage and neglect across all areas of life, including in the provision of equipment, aids and appliances under PADP. For Aboriginal people, the inability to obtain assistance, or adequate or timely assistance, from PADP, intensifies their impairment and disability, their social isolation, their inability to participate in education and the workforce, and it has a severe negative impact on their physical and psychosocial wellbeing.

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Lack of access to appropriate equipment, aids and appliances also contributes significantly to the disproportionately lower life expectancy of Aboriginal people, as compared with the general population. For example, the lack of equitable access to health monitoring equipment (such as blood glucose and blood pressure monitors) impacts very negatively on the survival of Aboriginal persons (there is a much higher incidence of diabetes and heart disease among Aboriginal people). Lack of access to essential aids and appliances, such as appropriately customised wheelchairs and pressure cushions can result in pressure sores that can mean prolonged periods of hospitalisation. If not appropriately treated, these pressure sores can result in life-threatening infection. Lack of access to customised mobility devices and posture supports can exacerbate skeletal and muscular conditions that compromise respiration and cause life-degrading discomfort and pain.

In this brief submission we would like to first draw the Committee's attention to a number of general issues we believe ought to be addressed in relation to PADP, and then focus in particular on specific access issues for Aboriginal persons with disability.

1. General comments about the provision of assistive technologies and devices, and PADP in particular

1.1 Under-funding of the PADP

While we acknowledge with appreciation recent State and Federal Government one-off financial contributions, and the increase to the funding base of the Program over the past 10 years, PADP remains significantly under funded relative to need. In this respect, it is essential to recognise that the 'need' we refer to includes both those persons who have registered a request for a PADP supplied item ('demand'), and those persons who would greatly benefit from PADP supplied items, but who have not registered a request because they are unaware of the program (which is the case with many Aboriginal persons with disability as we shall discuss later), or because they have become despairing and disaffected with PADP as a potential source of assistance and have given up applying. It is, of course, very difficult to estimate the number of people with disability who would benefit from, but have not requested, a PADP item. However, in our view it would not be unreasonable to suggest that for every person who has registered a request, there are two who have not.

The recurrent funding base for PADP in 2006-2007 is \$25.6million. In our view, this ought to be increased to at least \$40million recurrent per annum immediately and then progressively increased by 10% per annum over the next five years. In other words, the value of the one-off 'bail-outs' of the program in the past two years ought to be made recurrent, and there ought to be stable program growth to keep pace with increasing demand which will be, hopefully, associated with greater program visibility and penetration to its intended beneficiaries. Increased program demand will occur in any event as a result of the increased incidence of impairment and disability due to improved survival rates, and the ageing of the population.

1.2 Co-payment

The administration of PADP is beleaguered by a complex and confusing co-payment system that is difficult and inefficient to administer. This co-payment requirement also produces financial hardship and adds to the costs of disability in many instances. In particular, it is a major disincentive for Aboriginal people with disability to access the program. Many Aboriginal people with disability would lack sufficient disposable income to make the payment, often for a range of social reasons.

In our view, the co-payment system ought to be entirely abolished. The additional direct program costs that this would result in would, to a significant extent, be off-set by administrative savings. Abolishing the co-payment system would result in a greater program cost-benefit for the people of NSW. It would also result in improved penetration of PADP to its target group, including Aboriginal persons with disability.

1.3 Entitlement based program

PADP currently operates as a budget-capped discretionary program. In our view this is absolutely inappropriate. As we have noted, the equipment, aids and appliances provided under the PADP are essential for the autonomy and independence of persons with disability, and their health, wellbeing and survival.

This is so much the case that access to such equipment has been recognised as a fundamental human right, derivative of the right to liberty, in the recently formulated United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 20 of the CRPD requires States Parties to 'take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities including by ... (b) facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies ... including by making them available at affordable cost.' In international law the right to liberty is a civil and political right, and is therefore subject to the standard of immediate realisation. In other words, States Parties must immediately comply with their obligations under Article 20, rather than seek to realise these obligations progressively.

The CRPD has been ratified by the Australian Government and it entered into force with respect to Australia on 16 August 2008. Under Article 4(5) of the CRPD its provisions are binding upon all parts of federated States such as Australia. Consequently, NSW programs such as PADP must give effect to the human rights recognised by the CRPD, including Article 20.

In our view, because PADP is a principal means by which the fundamental human rights and freedoms set out in Article 20 may be realised, it ought to operate as an uncapped entitlement program, under which equipment, aids and appliances are made available to all eligible persons.

1.4 Multiplicity of equipment programs

There is a multiplicity of programs that provide equipment, aids and appliances for persons with disability operating at the State and Territory and Commonwealth levels across Australia. Each program has its own distinctive administrative arrangements (and usually also infrastructure), target group, and rules. In our view there is great inefficiency and injustice associated with the maze created by this multiplicity of programs. It is essential that these programs are integrated and harmonised so as to eliminate administrative inefficiency, ensure that the maximum possible resources are deployed to service delivery, and improve visibility and access.

We note that some steps are currently being taken by the New South Wales Government to integrate a number of equipment programs under its administration. We support this effort, but see it only as a starting point for what should be much wider reform.

1.5 Lack of portability/ownership

One of the key problems with the PADP rules is the requirement that the equipment, aids and appliances it supplies remain the property of the New South Wales Government. In effect, this means that if a beneficiary under the program wishes to move interstate or overseas for any length of time they must relinquish these items. In our view, this is unreasonable and unjust. It results in the violation of fundamental human rights, including the right of liberty of movement (Article 18 of the CRPD).

Equipment supplied under the PADP ought to become the property of the beneficiary. In our view, conferring ownership of an item of equipment on its beneficiary would have little or no impact on the likelihood of that item being returned to a central pool for reallocation when it is no longer required. However, it would eliminate the unnecessary and inefficient administration associated with the ongoing accounting for such items.

At the very least, equipment, aids and appliances ought to be 'portable' across State and Territory borders on the basis of a mutual recognition scheme that also provides for maintenance and repair of 'imported' items.

1.6 Strategic program development

We are concerned that PADP operates essentially as a static equipment delivery system, as do all other equipment programs around Australia. Currently, very little research and development is undertaken in relation to mobility and other aids and appliances and assistive technologies. The result is that new assistive technologies and aids are slow to emerge, and inefficiently produced.

Additionally, many people who would benefit from available technologies and aids do not know about them, or don't know how to use them with maximum effectiveness. There is a highly variable level of expertise among

professionals involved in 'prescribing' (or advising) in relation to assistive technologies and aids about the availability and use of these items. Paid support staff and family members have a particularly important role in encouraging and facilitating the mobility and communication of children with disability, and adults with cognitive disability. They may also have limited knowledge of relevant technologies and aids and their use.

This situation is now contrary to Australia's international obligations. The CRPD requires a much more active approach to promoting autonomy and independence through personal mobility and communication. For example, it requires States Parties:

- To undertake or promote research and development of universally designed goods, services, equipment and facilities ... which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines (Article 4(1)(f) of the CRPD).
- To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost (Article 4(1)(g) of the CRPD).
- To promote accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, ... (Article 4(1)(h) of the CRPD).
- To promote access for persons with disabilities to new information and communications technologies and systems, including the internet (Article 9(1)(g) of the CRPD).
- To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost (Article 9(1)(h) of the CRPD).
- Provide training in mobility skills to persons with disabilities and to specialist staff working with persons with disability (Article 20(c) of the CRPD).
- Encourage entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disability (Article 20(d) of the CRPD).

In our view these obligations require the Commonwealth and the States and Territories to work together to reposition service delivery systems for equipment aids and appliances. Essentially, the service delivery system for equipment, aids and appliances ought to become strategic and activist in

nature, promoting the development of new and improved assistive devices, and ensuring their production at minimum cost.

1.7 Social model of disability

Equipment, aids and appliances have, historically, been provided through health services because the impairment and disability related needs of persons with disability have been conceptualised according to a medical model which locates the problem of disability in the individual and which, consequently, seeks to treat (or “cure”) the person so that they may adapt to society as it presently exists. This approach has been oppressive of disabled people.

Contemporary disability policy ought to be based on a social model of disability. The social model locates the problem of disability in the social environment and carries the action implication of changing the environment to remove barriers to inclusion and participation by persons with disability.

Although the current PADP policy substantially embraces a social model approach, the program’s service delivery system is still tied to health professionals, health structures and health culture. It is therefore inevitable that decision-making, particularly about resource allocations, will be influenced (even if unconsciously) by a static ‘treatment’ mentality, rather than by an emancipatory approach. Equipment related to participation (for example, higher cost mobility devices) is therefore susceptible to being viewed as a lesser priority, or even unnecessary, as compared with items that treat physical conditions (surgical stockings, continence aids etc).

For this reason, we believe it would be preferable for all programs providing assistive technologies and devices, and aids and appliances, to be situated outside health systems.

2. Specific comments about access to PADP by Aboriginal persons

2.1 Lack of program visibility

PADP lacks visibility to Aboriginal people with disability. Information about the program is not available in culturally sensitive and accessible formats. Program access is intake and application based, rather than outreach based. This impacts negatively on Aboriginal people who may have limited volition for psycho-social reasons. Intake points operate within general health services, rather than through Aboriginal specific services. Aboriginal persons with disability are more likely to experience discrimination in general health services, and in any event, are less likely to trust and relate to generalist services.

In this respect we are very disappointed that the current centralising reforms to the PADP (the establishment of *Enable*NSW within Health Support and its 1800 line) appear likely to exacerbate these problems. In particular, the

1800 line will do nothing to improve access to the program by Aboriginal people – many of whom would not have ready access to a phone in any event.

There ought to be specific culturally sensitive and accessible information available to Aboriginal persons about PADP. There ought also to be specific Aboriginal PADP workers facilitating the delivery of the program to Aboriginal people with disability on an outreach basis across NSW.

2.2 Permanent resident of Area Health Service

The requirement that an applicant for PADP be a permanent resident of an Area Health Service (PADP policy 4.1) impacts very negatively on Aboriginal people with disability, many of whom move regularly across the borders of Area Health Services. We cannot identify any programmatic justification for this policy, and it amounts to indirect discrimination against Aboriginal people with disability. The policy ought to be repealed.

2.3 Corrections/community interface

The PADP policy also appears to require that items provided to persons with disability by Corrections Health during a period of imprisonment be left with the Corrections system upon release (Policy 33.1). We have been unable to clarify if this is how the program is administered in fact. If it is, it would clearly disproportionately impact on Aboriginal people, who are incarcerated at a higher rate than any other group in the community. In any event, once the person is released they must apply again for assistance from their Area Health Service. The policy is therefore more likely to result in complete discontinuity of services for the reasons we have already outlined. We cannot see why the person's service arrangements cannot be simply transferred from Corrections Health to a relevant Area Health Service.

2.4 Repairs and maintenance

There are very significant problems with repair and maintenance of PADP provided equipment. Funds are often not available for such repair and maintenance, and even where repairs and maintenance are to be arranged, there may be a very substantial wait. Depending on the seriousness of the equipment damage or malfunction it may be impossible to use, and the person may be rendered immobile or unable to communicate as a result.

General problems with PADP repairs and maintenance are amplified for Aboriginal persons with disability, who will typically require a greater number of instances of repair and maintenance of equipment than others, due to the conditions in which many are forced to live (for example, dirt roads without paths, and inaccessible housing may result in more frequent damage and breakdown of an electric wheelchair), and a range of other social factors (interpersonal violence in Aboriginal communities, communal use of equipment etc).

The PADP policy requirements to the effect that equipment repairs and maintenance be infrequent and reasonable does not adequately take into account the social circumstances of Aboriginal people with disability, and is indirectly discriminatory.

PADP's repair and maintenance functions require a major overhaul to improve the timeliness, and to eliminate discrimination against Aboriginal people.

2.5 Lack of individual advocacy support

Aboriginal persons with disability have very limited access to individual advocacy support to assist them to make applications for equipment, aids and appliances, and to deal with problems when they arise (for example, by raising complaints and appeals). In the absence of such support Aboriginal persons with disability are very poorly equipped to work the system to ensure that their needs are met.

Although the NSW Government committed to improving access to individual advocacy for Aboriginal people with disability nearly ten years ago, and it has done so through several policy iterations, nothing substantial has been achieved towards this goal.

This situation must be urgently addressed.

2.6 Lack of systemic advocacy and participation in advisory structures

Aboriginal persons with disability also have very limited access to systemic advocacy.

The PADP is supported by a State Advisory Committee, which is convened by the Department of Health, and by Local Advisory Committees, which are convened by Area Health Services. Few, if any participants in these Advisory Committees are Aboriginal persons with disability, or persons with experience and expertise in the provision of equipment, aids and appliances to Aboriginal persons. This lack of effective program participation by Aboriginal persons perpetuates and entrenches the structural discrimination we face in gaining equitable access to program resources at the service outlet level. It means that there is little pressure to adapt program delivery strategies to ensure equitable access for Aboriginal persons. Moreover, the absence of such representation, and the presence of advocates for other population groups in these advisory structures, has a negative distributive impact on Aboriginal persons with disability. That is, it results in a *progressive distortion away from* Aboriginal people with disability.

Even if such participation were offered Aboriginal people with disability and their representative groups, such as ourselves, it would be very difficult or impossible for us to serve on such Committees due to the lack of infrastructure support for such participation. Despite heavy demand to serve on numerous State Government advisory structures to assist in improving program and service access for Aboriginal persons with disability, our requests for recurrent

funding to support such participation have been repeatedly denied by the Department of Ageing, Disability and Home Care. This situation is grossly discriminatory and unjust.

We would welcome the opportunity to elaborate on our submission, and to clarify any points of interest and concern, in oral evidence to your inquiry.

Thank you for the opportunity to contribute our views in relation to this important inquiry.

Yours sincerely



DAMIAN GRIFFIS
Executive Officer