

**MDAA response to the
PricewaterhouseCoopers
Discussion Paper on:
Program of Appliances for Disabled
People**



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About MDAA

The Multicultural Disability Advocacy Association of NSW (MDAA) is the peak agency for people from a non-English speaking background (NESB) with disability and their families/carers in NSW.

MDAA aims to promote, protect and secure the rights and interests of people from a NESB with disability and their families and carers in NSW.

MDAA's overriding objectives are:

- Promoting and safeguarding the rights of people from a NESB with disability and their family/ carers
- Improving the quality of life for people from a NESB with disability and their family/ carers
- Increasing participation by people from a NESB with disability and their family/ carers in community activities

We provide a range of advocacy services and initiatives for people from a NESB with disability, their families/ carers and service providers in NSW.

- Advocacy Development – provides community information days, training and information sessions for people from a NESB with disability.
- Advocacy in Action Project - provides advocacy development for people with disability living in rural and remote NSW.
- Community Voices – develops and uses the skills and expertise of people from a NESB with disability and their families/ carers to educate and raise awareness about the diversity of the community.
- Individual Advocacy - helps people to stand up for their rights, for example, when people have problems with housing, immigration, school, work and disability services.
- Industry Development - assists disability services across NSW to become more culturally competent.
- Systemic Advocacy - works towards positive change in policies, procedures, practices and service delivery in government and non-government agencies.

In addition, we operate mdaa cultural abilities, providing support to government, non-government and private agencies to become more culturally competent. As a registered training organisation (RTO), mdaa cultural abilities offers a comprehensive training program including nationally recognised qualifications and/ or statements of attainment under the Australian Qualifications Framework (AQF).

Key issue for people from a non-English speaking background with disability

At the outset we would like to articulate one important issue relevant to people from a non-English speaking background (NESB) with disability which is not addressed in the discussion paper and which appears not to have been included as an issue in the current debate. It relates to access to the program and data collection to ensure more equitable access for people from a NESB.

People from a NESB with disability make up about 25% of all people with a disability. As the incidence of disability appears to be roughly the same across ethnic communities, including the Anglo-Australian community, one in every fourth user of a PADP service ought to be from a NESB. We are unaware of any data currently being collected or available on the ethnic background of PADP recipients. We are certain, however, that people from a NESB miss out on PADP services simply because of their ethnicity. This is due to a range of factors, such as the lack of clear information available and the relatively obscure way in which one can access the program, as well as the overall under-representation of people from a NESB with disability in disability services.

In dollar terms this means that while people from a NESB are entitled to access 1/4 of the total PADP budget (e.g. \$5.45 million in 2004/2005), they are more likely to access only about 1/20 (e.g. \$1.1 million in 2004/2005) thus missing out on over \$ 4 million annually.

To ensure that the program is accessible to all people who are eligible and to measure that, we strongly urge that data be collected on the ethnicity of PADP users each year, to ascertain year by year the correlation between the diversity of the community in an area and the diversity of the service users in that area.

Key Issues as identified in the discussion paper

1. Access

It is as crucial for this program as it is to for all other taxpayer funded programs to be available for all those who are eligible. As outlined above, the program has been designed to be available to all who are eligible, but in reality it is only accessible to those savvy enough to find the program by themselves or lucky enough to have access to disability and health professionals who know about the program and how to access it.

It is absolutely unacceptable to run a program funded by taxpayers that is, in effect, accessible to only a few and to those who are lucky enough to know how to work the system. The way PADP funds are currently allocated has little to do with need and all to do with know-how and luck.

The fact that there is more demand for the PADP program than there are resources cannot be used as an argument to 'hide' the program in the current bureaucratic maze, in the hope that only as many people as there is money will be able to find out about it. Information about the program needs to be made available widely in community languages, including to ethno-specific community based organisations. Information needs to be clear and consistent and the information needs to be 'true' across all Area Health Services.

We would encourage an investigation into whether the program would be fairer and more accessible if it were administered and processed centrally, but delivered locally. The functions of policy making, funding, processing of applications and information development and distribution could be administered centrally. Distribution and repairs of equipment and aids could continue to be delivered through local service centres. If the program funds were managed centrally this should ensure greater equity across the state and would also open the possibility for services other than hospital and health related services to deliver and repair equipment and aids. Those services could include non-government disability providers. Through centralised administration of the program, single state-wide application forms could be developed and distributed through various means, including the internet.

Professional prescribers should be qualified to prescribe the best equipment for their client, irrespective of whether they have had a long term or short term relationship with the client. Advice on equipment needs to be sought by the prescriber so that they are well informed and prescribe the most appropriate equipment for a client. In a centralised application process it should be assumed that the prescription made for a client is the prescription which best meets the needs of the client. A list of prescribers should be readily available for eligible PADP clients.

2. Eligibility

First, as outlined above, it is critical that those eligible for the program have the opportunity to know about the program.

While we generally do not support universal access regardless of income, we understand that the number of children needing equipment from families whose incomes are higher than those outlined in the bands is at present not so great as to warrant the cost of means-testing families. If this were to change in the future, however, we would support a generous means-test, taking into account the high costs and need for high turnover of equipment for children.

If all applications are to be assessed centrally, the need for the local advisory committee is superseded. For a centralised assessment process, we believe clear criteria for priority allocation of equipment must be developed, including the urgency with which equipment is needed to facilitate daily living. A centralised

assessment system also needs to ensure that no information is collated which would value some applicants over others (e.g. anecdotal evidence suggests that people needing equipment who work in paid employment get their equipment faster than people who do not). Such value judgments are unrelated to the need for equipment and may be more readily avoided in a more centralised decision making system.

The policy and guidelines should be consistent about whether the program is about participation or simply meeting medical needs. Circular 2004/53 states that the program “is only required to meet the cost of the most economically clinically appropriate item”. However, one of the stated aims of the program is about enhancing independence and quality of life. The aim and the circular appear contradictory and this doesn’t provide any clarity at the implementation level when some products that support a positive lifestyle are not the cheapest. A product that is the “most economical and clinically appropriate” may not achieve the best participation outcomes. Some PADP centres restrict the purchase of some items to those only available from government selected contractors. There is a lack of clarity in terms of balancing value for money and enhancing individuals’ quality of life.

The current bands should be maintained but should also be indexed. Band 1 particularly needs to be carefully monitored in light of increases in the cost of equipment exceeding the growth in a person’s income.

It is our view that users of incontinence aids should not be excluded or quarantined in the program, and we urge the NSW Government to seek funds from the Commonwealth to pay for the costs of equipment and aids used by people over the age of 65 whose need for equipment and aids arises from ageing rather than a congenital or acquired disability.

3. Management and Administration

Policy decisions about maintenance and repairs should be made centrally and if this can save significant costs such decisions should be undertaken through a centrally developed system that is delivered locally. Such a system would then not be limited by local boundaries.

We are unsure why there is a co-payment, as there must be significant costs in administering it and it appears not to be well implemented anyway. In addition, we would argue that most people in Band 1 do not readily have \$100 and if the aim is to get revenue and reduce costs it would be more equitable to raise the bands or to reduce funds to the value of the money recovered from the co-payment after the costs are taken into account. Alternatively, we would prefer the Bands to be indexed and perhaps the introduction of indexation could be delayed until the costs for the co-payments are recovered.

A more centralised system would provide greater opportunities for bulk buying through both private and government contracts. A major concern about bulk buying, however, is that those decisions about contracts are made by public servants who may not know about specific disability needs. Currently items appear to vary from one purchasing period to the next because of apparently arbitrary decisions. We therefore recommend a process by which users of PADP are actively encouraged to participate in getting the best, most effective and efficient products for PADP users.