

Submission
No 35

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

Organisation: Multicultural Disability Advocacy Association
Name: Ms Diana Qian
Position: Executive Director
Date received: 2/09/2008



Multicultural Disability Advocacy Association of NSW

PO Box 9381, HARRIS PARK NSW 2150
40 Albion Street, Harris Park
Telephone: (02) 9891 6400
Toll Free: 1800 629 072
TTY: (02) 9687 6325
Facsimile: (02) 9635 5355
E-mail: mdaa@mdaa.org.au
ABN: 60 737 946 674

2 September 2008

The Director
General Purpose Standing Committee No. 2
Parliament House
Macquarie St
SYDNEY NSW 2000

Dear Director

Re: Parliamentary Inquiry into the Program of Appliances for Disabled People

Please find enclosed the Multicultural Disability Advocacy Association's response to the inquiry in to the Program of Appliances for Disabled People.

MDAA aims to promote, protect and secure the rights and interests of people from non-English speaking background (NESB) with disability and their families and carers. Our comments reflect this aim.

Thank you for the opportunity to comment on these issues. If you require further information about this submission, please contact me on (02) 9891 6400 or email diana.qian@mdaa.org.au

Yours faithfully

Ms Diana Qian
Executive Director

**MDAA response to the
Parliamentary Inquiry into the Program of
Appliances for Disabled People**



September 2008

**Multicultural Disability Advocacy Association of NSW
PO Box 9381 Harris Park 2150
Phone: 02-9891 6400 Email: mdaa@mdaa.org.au**

1. Introduction

1.1 About MDAA

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

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

MDAA's overriding objectives are:

- promoting and safeguarding the rights of people from NESB with disability and their family/carers;
- improving the quality of life for people from NESB with disability and their family/carers;
- increasing participation by people from NESB with disability and their family/ carers in community activities.

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

- Advocacy Development – provides community information days, training and information sessions for people from 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 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).

1.2 The Focus of the submission

This submission is based on our experience with people from NESB with disability through our work in individual and systemic advocacy. In 2006-2007 we provided individual advocacy support to 418 people with all types of disability (sensory, physical, intellectual, psychiatric, brain injury, etc). We also dealt with over 1,000 telephone enquiries from a wide range of people including people with disability and their families.

This submission addresses the following Terms of Reference of the Parliamentary Inquiry:

- Adequacy of funding for present and projected demand;

- Impact of client waiting lists;
- Effects of centralising PADP Lodgement Centres;
- Appropriateness and equity of eligibility requirements; and
- Other relevant issues.

The organisation's main focus is on the rights and interests of people from NESB with disability and this is central to the critique offered. Before beginning our comment it is thought advisable to clarify terminology and note the statistical significance of our constituency.

1.3 Identifying People from NESB with disability

MDAA uses the term *Non-English Speaking Background* in preference to *Culturally and Linguistically Diverse Background* as those from an English speaking background are encompassed by the latter term. MDAA contends that coming from a linguistic and cultural background other than Anglo-Australian can be a great social barrier and a source of discrimination in Australia. The intention of using NESB is not to define people by what they are not but to highlight the inequity people experience due to linguistic and cultural differences.

MDAA also uses the term *people from NESB with disability* rather than *people with disability from NESB* as we consider cultural background (not disability) an appropriate means of developing social identity.

MDAA estimates that people from NESB with disability equate to 25% of all people with disability living in NSW (those born in a non-English speaking country or one or both of their parents were born in a non-English speaking country).¹ 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 NESB.

2. Adequacy of funding for present and projected demand

To measure the adequacy of funding MDAA has considered the effectiveness of PADP in meeting the needs of all potential service users. It here addresses the shortfalls separately as the adequacy of funding, and the equity of its distribution, cannot currently be measured without adequate data.

The need for data

As indicated in the 2008 Productivity Commission Report on Government Service Provision², and reflected in the experiences of MDAA's consumers, people from NESB with disability are gravely under represented in accessing government funded services. The disparity in service usage reflects the current Anglo – Australian service provision model which inadequately caters for the cultural and linguistic needs of people from NESB.

In dollar terms this means that people from NESB are entitled to access 1/4 of the total PADP budget. The current NSW Government budgetary allocation for PADP is \$24.2 million per annum (2008/2009). People from NESB should ideally be able to access funding worth \$6 Million. However they are more likely to access only about 1/20 (e.g. \$1. million in 2008/2009) thus missing out on over \$5 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 cultural backgrounds of PADP users

¹ Multicultural Disability Advocacy Association of NSW, Factsheet No.1 'Number of People From Non-English Speaking Background With Disability'

² Productivity Commission, Report on Government Service Provision, 2008

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.

MDAA is not aware of any data currently being collected or available on the cultural diversity of PADP recipients. We can infer, however, that people from NESB with disability are under represented in accessing the PADP. This is due to a range of factors, including the lack of clear information available and the relatively obscure way in which one can access PADP.

We recommend that data be collected on the ethnicity of users of PADP. This data should not only focus on country of birth, as this is not an accurate reflection of diversity. Data collection on cultural and linguistic diversity should also capture those who were born in Australia and are either raised or identify with a NESB cultural and linguistic context. The outcome of this exercise would be to ascertain the correlation between the diversities of service users and inform any related policy/service provision areas such as membership of PADP Advisory committee and health promotion campaigns targeting specific communities.

The need for information

Access to information is often the first step towards people making meaningful choices to participate in the community.³ What has become apparent, through consultation with our consumers however, are the increased difficulties (and consequently limited choices) they face when accessing information about services. Many NESB carers have low levels of English language proficiency, and limited information is available in community languages, making it difficult for them to communicate with services.

The NSW official government policy states that anyone needing an interpreter can access one:

'NSW Government Agencies including Government Trading Enterprises are expected to ensure that contracts with private providers and funding agreements with non-government organisations identify a budget for interpreting and translating appropriate to the service provided and the needs of the clients of the service. In relation to state owned Corporations, I consider that this provision provides a sound approach when dealing with people from a non-English speaking background. Funding agencies are also expected to ensure through program monitoring that where such funding is made that language services are provided to clients who need them.' (Memo from the Premier (No.98/22).

MDAA has ample evidence to suggest that many service providers do not comply with this, with the main reason given by providers being a lack of resources.

While the money provided to PADP may not be adequate MDAA's main concern is that it is not equitably distributed, and due to this fact, PADP fails to deliver an adequate service to all members of the Australian disability community. There is a need to ensure such matters as information in community languages, data on ethnicity, equity of resources underpin both policy and funding for PADP.

The need for funds

The current allocated amounts for equipments and aids are for many of those consulted insufficient to meet their needs and contrastingly hindering their ability to participate in family and community activities⁴, though assisting such participation is a key objective of PADP. As a consequence, people from NESB with disability purchase appliances

³ Multicultural Disability Advocacy Association of NSW, 'Main Issues Facing People From a Non-English Speaking Background With Disability and Their Families and Carers

⁴ NSW Health, Program of Appliances for Disabled People Policy, 2005, page 3

themselves. This has a significant impact on their disposable incomes, as people from NESB rank lower on the socio-economic scale than their Anglo-Australian counterparts.

Whilst it is acknowledged that the PADP aims to effectively manage existing resources⁵, the experience of our consumers indicates that greater flexibility is required in the delivery of the program to meet the diverse needs of our consumers.

MDAA recommends a review of the allocated amounts for equipment and aids, and flexibility in the administration of allocated funds for equipment and aids to cater to the diverse needs of people with disability.

3. Impact of client waiting list

One of the key objectives of the PADP is to provide a timely and efficient service⁶. The experience of our consumers indicates that this is clearly not being achieved, resulting in extensive waiting lists.

Anecdotal evidence from MDAA consumers indicates that as time on waiting list lengthens, their health condition correspondingly deteriorates. This then requires reassessment, due to change in health conditions and possible aid/appliance required.

Further, with the amalgamation of some local lodgement centres, many consumers have indicated that they were not informed of the closure of the lodgement centre they previously accessed.

MDAA strongly urges NSW Health to take action to manage the unacceptably long waiting list. MDAA recommends interim staff to be employed to manage the current waiting list, and the transfer of consumers from closed lodgement centres.

Case study

Mr Ali is from the Middle East and has a physical disability which he sustained during the war in his country of birth. He receives Home Care Services – they also provide continence support products. Due to his disability, Mr Ali is bedridden, causing bed sores to develop. Although the bedsores were treated, Mr Ali's doctor recommended he purchase an ergonomic bed to alleviate their recurrence. In January 2008, Mr Ali applied for the bed through the PADP and was placed on the waiting list. In August 2008 with further assistance from MDAA, he was informed that the application was placed on a priority list. There was however no clarity as to the exact meaning of 'priority' from the PADP. Eight months later, Mr Ali is still on the waiting list, despite the priority listing.

What is most concerning is the relationship between financial status and waiting lists. It seems more likely that a person in gainful employment will wait less time for a service than those who are unemployed. This may have some bearing on the length of time Mr Ali has awaited assistance. The matter may be addressed by centralising the decision making process. As noted below, this would avoid the possibility of bias at the local level and reduce the anomaly.

Extensive waiting lists have two other severe consequences for clients that effectively waste both time and money.

The first relates to services provided to children. A child in need of an electric wheelchair may join a lengthy waiting list, awaiting assessment by an Occupational Therapist, then a decision on whether the service is justified, whether funds are available etc. By the time the child receives the chair s/he is likely to have outgrown it: and the process begins again.

⁵ NSW Health, Program of Appliances for Disabled People Policy, 2005, page 3

⁶ NSW Health, Program of Appliances for Disabled People Policy, 2005, page 3

The second relates to a failure to consider a wider picture when assessing clients. A person may wait in a hospital bed for many months (particularly in a rural setting) awaiting approval and/or assessment. The cost of the hospitalisation is not weighted against the cost of prompt service delivery, hence, PADP may cost the Government much more by its slow response than is observable in merely considering the PADP budget.

4. Effects of centralising PADP Lodgement Centres and calculating efficiency

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.

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.

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.

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.

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.

Case study

An MDAA client has a 3 year old child with disability. The child has high support needs and requires continence support during the day due to their disability. The parents are receiving support to purchase pads through PADP funding. The continence pads supplied through the PADP are not suitable for young children as they cause discomfort. The parents have identified a more suitable product, however, due to current purchasing arrangements the product falls outside the PADP suppliers list. This is a cause of concern for the parents, as they cannot afford to purchase the suitable products for their child.

5. Appropriateness and equity of eligibility requirements

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

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.

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.

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.

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.

6. Other Relevant issues

Consequences of isolation

Whilst there are differences in the perception of disability amongst different ethnic groups, the relative degree of stigma attached to disability appears similar across NESB and Anglo-Australian communities⁷.

⁷ Multicultural Disability Advocacy Association, (2003), Less Talk More Action

People from NESB with disability and their carers' are often stigmatised and isolated because of attitudes and misconceptions prevalent in their own communities and in the Anglo-Australian community. Many migrant families with a member with a disability tend to socialise less, and have fewer contacts and support networks with other people, often only with people who accept disability.

Consequently, the lack of support networks has particularly adverse impacts on the help seeking behaviour of people from NESB with disability and their families.

Improving service delivery

MDAA acknowledges that the PADP is undergoing a restructure. We do however believe the current quality of service delivery is not consumer focused.

Through our advocacy work with people from NESB with disability we have noticed a limited awareness of PADP, its referral process and eligibility criteria. This is despite the NSW Health Policy stating that PADP providers should be aware of the barriers to accessing service and take a proactive and collaborative approach to delivering services to multicultural communities⁸. MDAA recommends NSW Health develop a targeted strategy to promote PADP within NESB communities.

People from NESB with disability and Individual Advocates working at MDAA, have indicated that staff at PADP lodgement centres are difficult to contact. Calls are not returned, with many consumers indicating they were not informed of the closer of lodgement centres.

Many services centres seem unable to accommodate linguistic and cultural diversity of consumers. The most basic mechanisms for people from NESB such as the use of interpreters or the publication of material in languages other than English are often neglected. Moreover, in many instances the ability of staff to incorporate cultural difference, diversity and in particular the nature and reality of the persons' experience whilst delivering services is quite poor.

Moreover, the experience of MDAA consumers and advocates when trying to make complaints is that they are not informed of the internal and external compliments and complaints procedures. MDAA views this as being unacceptable. Particularly as people from NESB often fear the repercussions of complaining directly to a service provider.

Details of the mechanisms for complaints and compliments procedures should be readily available to all.

7. Conclusion and Recommendations

People from NESB with disability face many barriers when trying to access government funded services. The current funding levels are inadequate to meet the needs of people with disability. In addition, the management of the available funds is highly inequitable. Currently there is a lack of information and strategies to target culturally diverse communities which requires urgent attention.

MDAA makes the following recommendations:

Recommendation 1

MDAA recommends improved data collection on the cultural diversity of PADP consumers. This information would be used to inform relevant policy and service delivery areas.

⁸ NSW Health, Program of Appliances for Disabled People Policy, 2005

Recommendation 2

MDAA recommends a review of the allocated amounts for equipment and aids, and flexibility in the administration of allocated funds for equipment and aids to cater to the diverse needs of people with disability.

Recommendation 3

MDAA recommends interim staff to be employed to manage the current waiting list, and the transfer of applications from closed lodgement centres.

Recommendation 4

MDAA recommends NSW Health develop a targeted strategy to promote the PADP to NESB communities.