

Multicultural Disability Advocacy Association of NSW

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5 October 2010

Ms. Patricia Scott, Commissioner Productivity Commission GPO Box 1428 Canberra City ACT 2601

disability-support@pc.gov.au

Dear Ms Scott,

Submission to Long Term Disability Care and Support Scheme

Please find attached the Multicultural Disability Advocacy Association (MDAA) submission to the *Productivity Commission Inquiry into a Long Term Disability Care and Support Scheme.*

The submission does not contain any confidential information, and MDAA is happy for this submission to be made publicly available.

We appreciate the opportunity to contribute to the Inquiry's work and would be happy to discuss the issues with members of the Inquiry.

Thank you for the opportunity to comment.

Yours sincerely Lyn Lormer Assistant Director "A community where everyone regardless of background or disability, feels welcome, included and supported"

MDAA Submission to Productivity Commission Inquiry into Long Term Disability Care and Support Scheme



September 2010

Multicultural Disability Advocacy Association of NSW PO Box 9381 Harris Park 2150

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Contents

1. Executive Summary	4
2. Background	6
2.1 About MDAA 2.2 Defining NESB	
2.2 501111119 14205	
3. Introduction	7
4. Principles Underpinning the Scheme	8
4.1 UNCRPD	
4.2 Social Model of Disability	
4.3 Equity and Social Inclusion	
4.4 Substantive Equality	
4.5 Disability Discrimination & Service Coordination	
5. The Design of the Scheme	11
5.1 Cultural Competence	
5.2 Eligibility	
5.3 Guarantee of Service	
5.4 Independent Monitoring	
5.5 Investing in Research	
5.6 Independent Advocacy	
6. Strategies to Address Barriers	17
6.1 Access to Interpreters	
6.2 Industry Development	
6.3 Promotion Strategy	
7. Conclusion	19

1. Executive Summary

This submission is based on the advocacy work of the Multicultural Disability Advocacy Association of New South Wales (MDAA) and provides an overview of the experiences and issues of people from non-English speaking backgrounds (NESB) with disability, their families and carers.

MDAA welcomes the development of a national long term disability care and support scheme. It has been well documented that current support arrangements are inadequate and do not meet the needs of people with disability and their families. This inquiry presents a great opportunity to address the current inequity in service provision for people with disability and the lack of access to appropriate services for people from NESB.

MDAA envisages a culturally competent disability support system that meets people's needs and enables access by a diverse population.

MDAA makes the following recommendations, which will assist in improving the wellbeing of people from NESB with disability. The recommendations aim to improve the design and implementation of a national long term disability care and support scheme:

Principles

Recommendation: That the United Nations Convention on the Rights of Persons with Disability be the framework on which the long term disability care and support scheme is designed.

Recommendation: That equity, social inclusion and substantive equality be key principles underpinning the long term care and support scheme.

Recommendation: That the long term care and support scheme requires the Disability Discrimination Act 1992 to be applied to all policy areas including the *Migration Act 1958* and the *Social Security Act 1992*.

Design of the Scheme

Recommendation: The long term care and support scheme be delivered through a culturally competent service model.

Recommendation: That the disability care and support scheme be available to all people with disability regardless of:

- severity of disability
- citizenship or residency status, including recent migrants and asylum seekers

Recommendation: Incentives are available to ensure the supply of services/aids at an affordable price.

Recommendation: That an independent body is created to monitor the new scheme. As part of its work the independent body would monitor the responsiveness of the scheme to the cultural diversity of the population.

Recommendation: A Disability Research Institute be created and as part of its work develop a culturally competent disability assessment tool.

Recommendation: Funding for independent advocacy is guaranteed in the scheme. This includes funding for multicultural disability advocacy organisations.

Strategies to Address Barriers

Recommendation: Service providers and consumers have access to a nationally funded disability interpreting and translating service.

Recommendation: Service providers to be supported to transition to a new system through industry development.

Recommendation: A comprehensive promotion strategy targeting the NESB population is implemented.

2. Background

2.1 About MDAA

MDAA is the peak advocacy body in New South Wales (NSW) for people from NESB with disability, their families and carers. It is the *only* advocacy service in NSW available specifically to people from NESB with disability, their families and carers.

Our aim is to promote, protect and secure the rights of people from NESB with disability, their families and carers in NSW. We work to ensure fair access to services and fair policies in the government and non-government sectors.

We provide a range of advocacy services, including individual advocacy for over 400 people with disability each year; systemic advocacy through responding to enquiries and reviews and participating in government reference groups; industry development through providing resources, cultural competence training to service providers and cultural competence audits for disability organisations.

MDAA has advocacy services located throughout NSW, three in metropolitan Sydney, two in the regional centres of Newcastle and Wollongong and two in the rural towns of Bega and Griffith. We receive funding from the Ageing, Disability and Home Care, Department of Human Services (ADHC) and the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to provide these advocacy services.

MDAA is also a registered training organisation, providing support to government, non-government and private agencies to become more culturally competent in dealing with the diversity of the population.

2.2 Defining NESB

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.

3. Introduction

MDAA welcomes the Productivity Commission's (the Commission) inquiry into a long term disability care and support scheme.

It has been well documented that there is currently a significant unmet need in the disability services sector. Substantial investment is needed in the sector, as the population increases, to ensure that people with disability live meaningful lives and can exercise all their human rights.

MDAA supports the creation of a nationally funded and administered disability support scheme. The scheme would be long term and would provide appropriate support regardless of how the disability was acquired. Further, creation of a national scheme would result in consistency and consolidation of current Federal and various State/Territory Government schemes.

This inquiry presents a real opportunity to alleviate the current inequity in service access and disadvantage experienced by people from NESB with disability. Through our advocacy, we are aware that people from NESB with disability experience the following barriers:

- Limited knowledge and expertise in accessing information and/or services
- Limited availability of information in community languages and culturally sensitive education campaigns
- Stigma and discrimination within their community due to their disability
- Socioeconomic disadvantage
- Isolation and burn out of families and carers
- Service providers lack the skills to effectively target/reach the NESB population
- Services provided often do not reflect or cater for the cultural and linguistic needs of individuals and their families

MDAA encourages the Commission to include in its draft report (to be released in February 2011) and the design of the scheme , strategies to alleviate the current disadvantage experienced by special needs groups such as the culturally diverse population, Aboriginal and Torres Strait Islanders and those living in regional and rural areas.

4. Principles Underpinning the NDIS

We make the following comments on the principles that should underpin a new system.

4.1 United Nations Convention on the Rights of Persons with Disability MDAA strongly believes that a new scheme proposed by the Productivity Commission should be based on the principles and rights enshrined in the 2006 United Nations Convention on the Rights of Persons with Disability ("the Convention"). The Convention aims to ensure the 'full and equal enjoyment of all

human rights and fundamental freedoms by all persons with disabilities'.1

Australia ratified the Convention in 2008. In doing so, it became obligated to 'take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes'². The proposed scheme is a perfect opportunity for Australia to implement these obligations.

MDAA endorses the comments by the Australian Human Rights Commission³ in its submission to the inquiry in this regard.

4.2 Social Model of Disability

The Convention is a powerful document and presents a 'paradigm shift' in thinking about the rights of people with disability. It uses a social model of disability, which focuses on the physical, social and cultural environment in which people with disability live. The social model of disability argues that many of the difficulties people with disability and their families experience stem from how society is structured.

People with disability are often shut out of community activities and their right to participate fully in community life is ignored. Inaccessible buildings for people who use wheelchairs or other mobility aids, low expectations, assumptions and stereotypes about people with disability are some of the difficulties experienced because their needs are ignored.

By contrast, the Convention views persons with disability as 'subjects with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent...' Countries such as Australia that have ratified the Convention are obligated to remove societal structures that limit the participation of people with disability.

¹ United Nations Convention on the Rights of Persons with Disability, 2006, article 1

² United Nations Convention on the Rights of Persons with Disability, 2006, article 4(c)

³ Australian Human Rights Commission, Submission number 72, p.46

⁴ United Nations Convention on the Rights of Persons with Disability, 2006, preamble

Adopting a social model of disability would allow Australia to meets this obligation under the Convention. MDAA believes that this should be one of key principles underpinning the long term care and support scheme.

Recommendation: That the United Nations Convention on the Rights of Persons with Disability be the framework on which the long term disability care and support scheme is designed.

4.3 Equity and Social Inclusion

Australia's population is increasingly diverse. MDAA estimates that in New South Wales, 6.4 percent of the population are people from NESB with disability⁵. This means that one in every three people with disability living in NSW is from a NESB.

MDAA strongly believes that cultural background, language, and religious beliefs should not compromise an individual's entitlement to receiving a government service. We envisage an NDIS that takes into consideration the multiple disadvantages experienced by people from NESB with disability. Adopting a principle of equity and social inclusion is required for this to occur.

MDAA draws the attention of the Productivity Commission to the Australian Multicultural Advisory Council (AMAC) statement on cultural diversity. Released in April 2010, the *'People of Australia'* details Australia's multicultural history and the rights and responsibilities of all citizens in maintaining a harmonious society. Further, the statement includes recommendations to the Government, which if implemented would promote an inclusive Australia.

Specifically, the AMAC recommendations include the following:

- A 'multicultural' Australia is presented as an important part of the national identity and expressed on more occasions than multicultural ones
- Protocols be established to consider migrant and cultural needs prior to implementation of policy and programs.
- An independent body is given the responsibility to monitor the responsiveness of Government and non-government services to cultural and linguistic diversity

MDAA encourages the Productivity Commission to incorporate these recommendations when designing the long term care and support scheme.

⁵ Multicultural Disability Advocacy Association of NSW, *Number of People From non-English Speaking Background with Disability in NSW*, 2010 (unpublished)

⁶ Australian Multicultural Advisory Council, *The People of Australia*, 2010

4.4 Substantive Equality

MDAA recommends that 'substantive equality' be a principle underpinning the scheme. This approach recognises that the same application of policies or rules to groups of unequal status can have unequal results'⁷. Introduced by the Western Australian Equal Opportunity Commission in 2004, it recognizes that in order to treat people equally, it is necessary to treat people differently, as their needs differ.

Substantive equality when applied to people with disability would involve supporting people to maintain their dignity, independence and ensure opportunities for social participation and contribution.

The focus of substantive equality is on outcomes, recognising that a person with disability might require various forms of support (e.g. aids, appliances) in order to fully participate in the community.

The substantive equality approach, MDAA argues is comparable to cultural competence, as it focuses on equality of outcomes and is responsive to the needs of the individual.

Recommendation: That equity, social inclusion and substantive equality be key principles underpinning the long term care and support scheme

4.5 Disability Discrimination and Service Coordination

The Commission in its discussion paper highlighted the need for of a new scheme to provide a coordinated package of services. The services would include accommodation support, aids and equipment, respite, transport and a range of community participation programs over a person's life time.⁸

MDAA supports this approach. We also believe that it is important for the long term care and support scheme to be linked with other social policy areas (such as health, ageing, youth, education, housing and employment). This would reflect the current reality of people with disability accessing a range of services from both disability specific and mainstream providers.

More specifically, MDAA recommends that the long term care and support schemes ensures the *Disability Discrimination Act 1992*, is applied to the following policy areas:

 Migration Act 1958 (Cth) which currently discriminates against potential migrants and refugees with disability

Western Australian Equal Opportunity Commission, (2004), 'The Policy Framework for Substantive Policy'
 Productivity Commission, 2010, *Disability Care and Support*, p.28

 Social Security Act 1991(Cth) – which excludes migrants with disability from being eligible for social security payments/benefits until after ten years in Australia

This would result in greater access of the NESB population to essential services.

Recommendation: That the long term care and support scheme requires the Disability Discrimination Act 1992 to be applied to all policy areas including the *Migration Act 1958* and the *Social*

5. Design of the Scheme

5.1 Cultural Competence

Through our advocacy experience we are aware that many services poorly respond to the linguistic, religious and cultural diversity of service users. The provision of culturally inappropriate services often results in NESB consumers having significantly lower service usage rates in comparison to their Anglo-Australian counterparts.

This is also reflected in consecutive reports on government funded disability services released by the Productivity Commission⁹.

MDAA argues that this 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. As a consequence, carers and their families use services when there is a high level of need or when they are at crisis point.¹⁰

MDAA envisages a new disability support sector that is culturally competent. Cultural competence refers to the capacity, skills and knowledge of individuals, agencies and systems to respond to the needs of a diverse community.

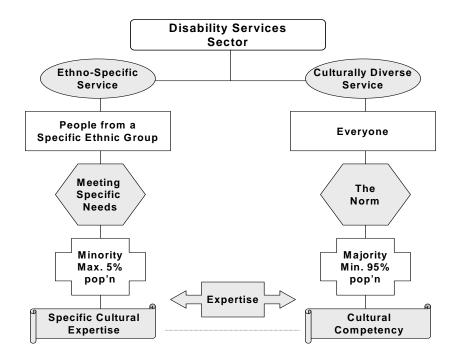
Cultural competence is defined as a set of values, behaviours, attitudes, and practices within a system, organisation, program or among individuals. It enables them to work effectively cross culturally. Further, it refers to the ability to honour and respect the beliefs, language, interpersonal styles and behaviours of individuals and families receiving services, as well as staff who are providing such services. Striving to

⁹ Report on Government Services 2010, 2009, 2008, 2007, 2006, 2005, 2004, 2003, 2002, 2001, 2000, 1999, 1997.

¹⁰ Centre for Cultural Research, (2006) *Diverse Strategies for Diverse Carers: The Cultural Context of Family Carers in NSW*, University of Western Sydney.

achieve cultural competence is a dynamic, ongoing, developmental process that requires a long-term commitment.¹¹

A culturally competent service delivery model would look like this 12:



The above model, developed to meet the needs of a culturally diverse community, is made up of two components:

1. Culturally Diverse Services

This would be the standard model of operation with services providing for all people in the target group (for example people with disability), regardless of their cultural, religious and linguistic background. Given the diversity of the community, every service must become culturally diverse. Culturally diverse services would:

have a high level of cultural competence; and

run in accordance with a culturally competent service delivery model.

These services would work with all members of the community and purchase culturally specific expertise from ethno-specific services when needed.

¹¹ Denboba MCHB, 1993 http://www.nccccurricula.info/culturalcompetence.html

¹² MDAA, 2004, Fact Sheet 3: Towards a Culturally Diverse Disability Sector

2. Ethno-Specific Services

This would be the exceptional way of service provision. An ethno-specific service would need to justify why it needs to be ethno-specific. Thus, mainstream services would need to justify why they only cater for Anglo-Australians.

There are reasons why a service might be allowed to operate as an ethnospecific service. For instance:

- 2.1 to provide to a particular cultural or linguistic group only, where specific cultural or linguistic needs and requirements can be demonstrated; and
- 2.2 where a particular service model is demonstrated to be more appropriate for delivering services to a particular cultural group only.

Recommendation: The long term care and support scheme be delivered through a culturally competent service model

5.2 Eligibility

MDAA strongly believes that eligibility for the new scheme should be based on the impact a person's condition has on their capacity to undertake daily activities.

In addition, MDAA supports an entitlements approach- a guarantee of access to services at a level that meets the needs of the individual, their family and carers.

No other restrictions or waiting periods should apply.

Severity of disability

It was indicated in the discussion paper released by the Commission that only people with severe and profound disability would be eligible for the NDIS. MDAA does not support this. It is our view that a social model of disability would allow for a broader range of people to be included in the proposed NDIS.

The Convention defines disability as 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.¹³ MDAA also recommends that this definition of disability be utilised in the long term care and support scheme.

MDAA's analysis of the 2006 Australian Bureau of Statistics Census of Population and Housing indicates that people with mild disability equate to 5.3

¹³ United Nations Convention on the Rights of Persons with Disability,2006

per cent of the NSW population¹⁴. The rates are comparable at a national level. Excluding people with mild disability will result in higher support needs (and costs) in the future, as in some cases the lack of support will worsen the condition.

Further, this would be a direct contradiction of the social model of disability and the rights enshrined in the Convention, which assures that individuals with disability have '..access to support services necessary to support living and inclusion in the community and to prevent isolation...'

MDAA is also concerned about what support would be available to people who are not eligible for the long term care and support scheme.

Migrants and asylum seekers with disability

In Australia all migrants without disability (except for those migrating on humanitarian grounds) have to wait two years before they can access income support (e.g. Carer payment, Mobility Allowance, Newstart Allowance). However, migrants with a disability, including their carers, have to wait ten years before being eligible for social security payments such as the Disability Support Pension (DSP) 16.

Their difficulties are compounded as these pensions are prerequisites for entry to essential Government funded disability services such as, Home and Community Care (HACC), Enable (NSW program for aids and equipment), job search assistance through the Disability Employment Network, transport concessions such as the NSW Taxi Transport Subsidy Scheme (NSW) and Vision Impaired Person's (VIP) Pass.

This is a clear contradiction of article 4(e) of the Convention which obliges parties to '...eliminate discrimination on the basis of disability 17.

This current inequity in eligibility for services must be rectified in the new long term care and support scheme. The adoption of a social model of disability requires the removal of societal barriers (such as waiting periods) and provision of support that enables social participation. MDAA strongly believes that the current exclusions and waiting periods should not exist in the proposed long term disability and support scheme.

¹⁴ MDAA, 2010, Fact Sheet 1: Number of People from non-English Speaking Backgrounds with Disability in NSW, unpublished

Article 19, United Nations Convention on the Rights of Persons with Disability, 2006

¹⁶ For more information, refer to MDAA's submission to the Joint Standing Committee on Migration Inquiry into the Migration Treatment of Disability, available on MDAA's website

www.mdaa.org.au/service/systemic/topics/immigration.html

17 United Nations Convention on the Rights of Persons with Disability

Recommendation: That the disability care and support scheme be available to all people with disability regardless of:

- severity of disability
- citizenship or residency status, including recent migrants and asylum seekers

5.3 Guarantee of service

MDAA is concerned that the support needs of people with disability might not be met if a market/supply and demand approach is adopted in the scheme. The market approach focuses on providing services/items that can attract a profit. Generally this means the higher the demand for an item the lower the costs are to supply it.

MDAA is concerned that the price for a service or product could be high if there is a low demand, despite it being essential to the daily life of the consumer.

For example, the price of a bicycle used for recreational purposes is significantly lower when compared to the cost of a wheelchair.

MDAA strongly recommends that incentives should be offered to ensure supply of essential services/support at an affordable price. This is particularly relevant in regional and rural areas where, due to population size, there could be smaller demand for a service.

Recommendation: Incentives are available to ensure the supply of services/aids at an affordable price.

5.4 Independent Monitoring

MDAA supports the AMAC's recommendation for an independent monitoring body and believes that one should be created to oversee the long term care and support scheme. A monitoring framework would include outcome measures as well as performance indicators.

We envisage a monitoring body to have the following features:

- Independence from funding body and Government
- A governing body which would be made up of a majority of people with disability and relevant representative organisations. Representation must to take into account the unique perspectives of women, Aboriginal and

Torres Strait Islanders, people from culturally diverse backgrounds, rural and regional areas

• The monitoring body would also evaluate the responsiveness of the scheme to the diversity of the population. For this to occur, performance and measures must include culturally competent practices. Auditors must also be trained and familiar with cultural competence best practices.

Recommendation: That an independent body is created to monitor the new scheme. As part of its work the independent body would monitor the responsiveness of the scheme to the cultural diversity of

5.5 Investing in Research

At present, the quality of information available on the NESB with disability population is quite poor. As the diversity of Australia's population increases there is a need for high quality demographic information and data on this group.

The little information that is currently available often only refers to country of birth data, ignoring second or third generation Australians from NESB. Further, the lived experiences of this population group are often ignored by researchers. This needs to be rectified to build a more informed picture of Australia's population. This information would contribute to policy and program development.

MDAA endorses the recommendation of the Disability Investment Group¹⁸ for the creation of a National Disability Research Institute.

MDAA recommends that a research agenda be created which includes:

 Review and enhancement of data collection methodologies, including Minimum Data Set and Census, to ensure better capturing of the intersection of cultural diversity and disability.

MDAA also recommends that one of its first tasks is to develop a culturally competent disability assessment tool. Assessments will have an important role in the proposed long term care and support scheme. The outcomes of assessments will determine an individual (and their family's) eligibility for support, the nature and frequency of support and so on. In short, the outcomes of assessments can have significant implications for people with disability, their families and carers. As a consequence, it is paramount that assessment tools be culturally competent.

¹⁸ Disability Investment Group, *The Way Forward: A New Disability Policy Framework for Australia*, 2009, p.49

MDAA argues that currently, assessments of disability/need for assistance/ or functionality are based on competencies of the dominant culture or society within which they are developed.

Using culturally competent assessment tools is essential in reducing the current inequity in service access and disadvantage experienced by culturally diverse people with disability.

Recommendation: A Disability Research Institute be created and as part of its work develop a culturally competent disability

5.6 Independent advocacy

Independent advocacy aims to protect and secure the rights of people with disability. It is important for a variety of advocacy models to be adequately funded, for example individual, systemic and advocacy development.

It is our view that the advocacy sector does not adequately cater for the needs of the NESB population. We envisage a disability sector which is culturally competent and can respond to the diversity of the population, eliminating the need for specialist advocacy organisations such as MDAA. However, until this occurs, it is important that funding for multicultural advocacy organisations continue as they cater for the unique needs of the NESB population.

Recommendation: Funding for independent advocacy is guaranteed in the scheme. This includes funding for multicultural disability advocacy organisations

6. Strategies to Address Barriers

The following strategies would improve the outcomes for the NESB population:

6.1 Access to interpreters

Ensuring that Government funded translating and interpreting services are available to services and all people with disability who require them. We are aware that poor access to accredited interpreters and translators continues to be a key issue for both service providers and users.

MDAA anticipates that this issue will be rectified in the proposed scheme by providing access to interpreting and translating services for both service providers and service users. An example of a current service is the New South Wales Health Care Interpreting Service (HCIS). It is funded by the Department of

Health and provide translating and interpreting services for health providers within the NSW health system. The interpreters are accredited and receive regular training in medical terminology. The HCIS is free for organisations within the NSW health system.

MDAA recommends a similar service for the long term disability care and support scheme, with interpreters receiving training on disability terminology. We are aware through our advocacy work with NESB communities that words associated with disability are culturally defined and have a range of meanings.

MDAA also recommends that service providers undergo training on how to effectively use interpreters.

Recommendation: Service providers and consumers have access to a nationally funded disability interpreting and translating service.

6.2 Industry development

The term 'industry development' refers to the support provided to assist disability services to better respond to the diversity of the population. This support can be in the form of resources, mentoring and training.

The new scheme will involve a significant shift from the current support model. MDAA believes that industry development should have a key role in the transition from the current service system to the proposed long term care and support scheme. Through industry development the organisation and individual workers capacity to work with diversity is enhanced.

Recommendation: Service providers to be supported to transition to a new system through industry development.

6.3 Promotion strategy

MDAA recommends that a targeted promotion strategy aimed at people from NESB with disability is needed to ensure that awareness of available support and programs is increased. This is particularly necessary when the new scheme is introduced.

It is important to note that a 'one size fits all' approach is not appropriate, as not all communication styles are suitable for all NESB communities. Research is required into the most appropriate and effective communication style for the various communities.

Further, information should be in accessible formats including audio (translated into community languages), Braille, large print format, texts written in plain English, and electronic format.

Recommendation: A comprehensive promotion strategy targeting the NESB population is implemented.

7. Conclusion

In summary, MDAA envisages a community in which everyone, regardless of background or disability is welcomed, included and supported.

Regrettably, the experience of people from NESB with disability is that they face significant barriers in accessing appropriate services and being included in the community.

The proposed long term care and support scheme is a chance to ensure that people from NESB with disability enjoy their fundamental human rights.

MDAA makes the following recommendations to the Productivity Commission:

Principles

Recommendation: That the United Nations Convention on the Rights of Persons with Disability be the framework on which the long term disability care and support scheme is designed.

Recommendation: That equity, social inclusion and substantive equality be key principles underpinning the long term care and support scheme.

Recommendation: That the long term care and support scheme requires the Disability Discrimination Act 1992 to be applied to all policy areas including the *Migration Act 1958* and the *Social Security Act 1992*.

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- citizenship or residency status, including recent migrants and asylum seekers

Recommendation: Incentives are available to ensure the supply of services/aids at an affordable price.

Recommendation: That an independent body is created to monitor the new scheme. As part of its work the independent body would monitor the responsiveness of the scheme to the cultural diversity of the population.

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Recommendation: Service providers and consumers have access to a nationally funded disability interpreting and translating service.

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