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29 July 2010

Mr. Mike Woods
Commissioner
Productivity Commission
PO Box 1428
Canberra City ACT 2600

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Dear Mr. Woods,

Submission to Inquiry in to Older Australians

The Multicultural Disability Advocacy Association of NSW (MDAA) is the peak advocacy organisation in New South Wales (NSW) for people from Non English Speaking Backgrounds (NESB) with disability, their families and carers.

MDAA aims to promote, protect and secure the rights and interests of people from NESB with disability, their families and carers. MDAA is funded by the NSW and Commonwealth Governments to provide individual and systemic advocacy, advocacy development, industry development and training.

We welcome the opportunity to submit comments on the *Productivity Commission Inquiry in to Older Australians*.

In June 2010, MDAA responded to the Federal Parliament *Senate Community Affairs References Committee Inquiry into Ageing Options of People with Disability*. In this submission we highlighted the experiences of people from NESB ageing with disability and their barriers to accessing relevant support. The submission also makes recommendations, which if implemented could assist in improving the situation for people from NESB ageing with disability.

We have appended this submission as the issues discussed and recommendations made in this submission are relevant to the Commission's current inquiry.

Thank you for the opportunity to comment.

Yours sincerely
Diana Qian
Executive Director

Appendix A

Submission to the Senate Community Affairs References Committee Inquiry into Planning Options and Services for People Ageing with a Disability



June 2010

**Multicultural Disability Advocacy Association of NSW
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1. Summary

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

Our comments are informed by our advocacy work with people from NESB with disability, their families and carers.

In our experience, people from NESB with disability, their families and carers face unique challenges and barriers in their daily lives. Moreover, there is currently a lack of recognition of the needs of NESB people with disability their families and their carers in policy, program design and delivery.

MDAA makes the following recommendations to the Senate Community Affairs References Committee Inquiry into Planning Options and Services for People Ageing with a Disability. If implemented, these recommendations would improve succession planning for NESB people with disability, their families and carers.

Recommendation 1: That the Australian Government develop a succession planning framework that meets the needs of people with disability and also recognises the interdependence of the needs of carers, families, culture, community and the services system.

Recommendation 2: That the Australian Government improves the quality of data on the needs of NESB people with disability, their families and carers in Australia.

Recommendation 3: That the Australian Government improve the cultural competence of disability and carer services, to ensure services meet the needs of both ageing people from NESB with disability and carers.

Recommendation 4: That the *Aged Care Act 1997* be amended to include people with disability as a special needs group and be eligible for aged care services before the age of 65.

Recommendation 5: That definition of family in the *Migration Act 1958* be amended to so extended family members can be granted Carers visas

Recommendation 6: A seamless transition process be developed from disability to aged care service system.

2. Background

2.1 About MDAA

The Multicultural Disability Advocacy Association of NSW (MDAA) is the peak advocacy body in New South Wales (NSW) for people from non-English speaking background (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 receive funding from 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 advocacy services.

MDAA is also a registered training organisation, providing support to government, non-government and private agencies to increase their cultural competence.

2.2 Identifying People from NESB with disability

MDAA uses the term *Non-English Speaking Background* (NESB) 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.

2.3 Summary of previous research and submissions

MDAA welcomes the opportunity to make this submission to the Inquiry. Our comments are based on advocacy work, and consultation with members and consumers. Their comments and recent case studies¹ are included throughout this submission.

¹ We changed some identifying details in the case studies to preserve individual privacy but the circumstances outlined are true.

MDAA is disappointed that this current inquiry predominantly focuses on the succession planning needs of carers. MDAA believes that addressing the needs of carers also requires addressing the needs of people with disability. These two things are interdependent. The focus should be on empowering people with disability to make their own decisions and plan for their future. This is the main principle that underlies the comments and recommendations of this submission.

The submission also draws on previous research and submissions relevant to the Inquiry which are available on our website

- MDAA and NEDA² joint submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth *Inquiry into Better Support for Carers* (July 2008)
(<http://www.mdaa.org.au/service/systemic/topics/carers.html>)
- Response to the then Department of Families, Community Services and Indigenous Affairs (FACSIA) Discussion Paper 'Succession Planning for Carers' (December 2006)
(<http://www.mdaa.org.au/service/systemic/topics/carers.html>)
- Research report on the impact aging has on the lives of NESB people with disability and their families - "*I like to go to Queensland*" *Growing older: Hopes and fears of people from a NESB with disability and their family members/carers* (2004)
(<http://www.mdaa.org.au/service/systemic/topics/ageing.html>)

The following points, made by MDAA in these submissions and research reports focus on the empowerment of people with disability to make their own choices:

- The right for a person with disability to live an independent life is enshrined in the United Nations Convention on the Rights of Persons with Disability³. This means that Governments that have ratified the Convention are obligated to respect the rights, needs and choices of people with disability.
- There has been a failure to adequately acknowledge the interdependent relationship between the needs of carers and those being cared for in policy and program responses by governments. The focus on the needs of carers in exclusion from the needs of people with disability has meant that in many cases people with disability have been excluded from input into the design and delivery of support systems that will inevitably impact their lives.

² National Ethnic Disability Alliance (NEDA). For more information go to <http://www.neda.org.au/>

³ Article 19 at <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

- It is impossible to address carer needs without understanding the context of this care, in particular the needs of people with disability. Addressing the needs of people with disability requires taking into consideration culture, community and family which entails addressing the needs of carers.
- Carers from NESB are often unrecognised by service providers, by statisticians and by governments. They face specific barriers to participation, including attitudes, inappropriate services and information, poverty and isolation.
- The definition of a carer will vary significantly as a result of cultural and linguistic factors. Carers from NESB may not readily identify as 'carers' and they may comprise a significant proportion of the hidden carer population.⁴ A closely related factor is the cultural variance in understandings of 'disability' within NESB communities, as noted by a Western Australian Study:

CALD carers reported problems with understanding the unfamiliar western notions of disability and care as promoted by generic services. Most participants regarded the term 'carer' as foreign to them. The role of carer was most commonly regarded as a 'natural duty,' as of a mother caring for her children, children caring for her parents, brother or sister caring for their siblings and so on.⁵

- Similarly, there may be a variance in caring roles – for example difficulty in identifying a 'primary carer' because of perceived sharing of caring responsibilities, or because of different perceptions of the role of family, culture and caring responsibilities. Some NESB Carers find it difficult to identify with using a Western model of care to describe non Anglo-Australian care relationships. For example, Australian government programs tend to focus on the concept of a 'primary carer,' even though some family structures may not clearly support the concept of a single resident caregiver: for example families that share care responsibilities between resident family members, with non resident family members or friends.
- Previous research and consultations with MDAA members and consumers indicates that there is very little succession planning among people with disability and carers from NESB. For some, the idea can be daunting as it

⁴ Centre for Cultural Research (2006) Diverse Strategies for Diverse Carers: The Cultural Context of Family Carers in NSW. University of Western Sydney.

⁵ Ethnic Disability Advocacy Centre, "Supporting CALD Carers: The service needs of culturally and linguistically diverse carers of people with disabilities," February 2003, p20.
MDAA Submission to Productivity Commission Inquiry into Older Australians

requires them to come to terms with their own mortality. Further, NESB families have expressed their limited knowledge of how to access support services that will assist them to make suitable arrangements for the future.

3. Barriers and Issues Experienced by People from NESB with Disability and Carers that are Ageing

3.1 Data

At present, there is little available data on the number of people from NESB with disability. As the diversity of Australia's population increases there is a need for high quality demographic data on this group. The little information that is currently available often only includes country of birth data, ignoring second or third generation Australians from NESB. This needs to be improved to build a more informed picture of Australia's population.

MDAA recommends a review of data collection methodologies, including Minimum Data Set and Census, to ensure better capturing of the intersection of cultural backgrounds and disability. In doing this, the Australian Government would work with agencies such as the Australian Bureau of Statistics and the Australian Institute of Health and Welfare to improve the quality of data sources.

This information, once available would allow for improved planning of both aged and disability policies, programs and services.

3.2 Myth: 'They take care of their own'

An often falsely perpetuated myth of culturally diverse communities is that '*they take care of own*', i.e. the support provided by the family and community is sufficient and external support particularly from service providers is not required. It is true that some ethnic communities are well resourced and can provide excellent support to individuals and families. The reality for many people from NESB with disability is that they and their families face discrimination from their own communities. The prejudicial attitudes and misconceptions regarding disability present in Anglo-Australian communities are equally evident in NESB communities.

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 communities⁶.

People from NESB with disability and their carers are often stigmatised and isolated. Migrant families with a member with disability tend to socialise less. They have fewer contacts and support networks with other people and often only with people who accept disability. The lack of support networks has an adverse impact on women as they make up the majority of carers for people with disability in NESB communities. This is especially so for those in communities where there is an enormous stigma attached to disability.

⁶ Multicultural Disability Advocacy Association, (2003), Less Talk More Action
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3.3 Anglo-Australian Service Provision

Many services 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.

The provision of culturally inappropriate services often results in NESB consumers having lower service usage rates in comparison to their Anglo-Australian counterparts. As indicated in the 2010 Productivity Commission's Report on Government Service Provision, and reflected in the experiences of MDAA's consumers, people from NESB with disability are gravely under represented in accessing government funded disability services.

'I get support from disability service. They have taught me how to use public transport. I also got cooking classes from this organisation. The classes were in my home and were helpful to a point. The skills they taught me did not reflect my cultural background. There was a lot of microwave cooking – we don't use this in my culture when we cook. So the skills I was taught were not very helpful. My mother is now teaching me how to cook' (MDAA consultation, April 2010)

For example in 2007-08, when identifying service users per head of population, people from NESB with disability, equated to 1.9 service users per 1000 (under 65 years) accessing Commonwealth State/Territory Disability Agreement (CSTDA) funded community support services. This is significantly lower than the 5.9 service users per 1000 (under 65 years) born in an English speaking country⁷. This disproportion could be higher, as the report only uses 'country of birth' as an indicator of cultural and linguistic diversity.

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.

Effectively, this means that there is little opportunity for succession planning by people from NESB, their families and carers as services are often only accessed when there is a high level of need.

MDAA in its 2007 response to the Department of Families, Community Services and Indigenous Affairs (FACSI) Discussion Paper 'Succession Planning for

⁷ Productivity Commission, Report on Government Services, 2010, page 14.43
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*Carers*⁸ recommended the following strategies to address poor succession planning in NESB communities.

- Education and training campaigns targeting specific NESB communities in which complex succession planning concepts and options (e.g. 'Setting up a Trust', 'What is and how to appoint an Enduring Power of Attorney', 'Enduring guardianship', safeguards, legal and financial advice or the role of the Guardianship Tribunal) are explained and discussed.
- Work intensively with several communities to develop more culturally appropriate planning.
- Explore opportunities to pay carers a wage rather than a Carer's Pension. This would enable other family members (i.e. next generation siblings, etc.) to take on some of the caring role.
- Ensure engagement with carers from NESB in a range of caring programs to ensure input from and consultation with carers from NESB.

3.4 Lack of accessible information and familiarity with services

Access to information is often the first step towards people making meaningful choices to participate in the community.⁹ What has become apparent, through consultation with consumers and members however, are the increased difficulties (and consequently limited choices) they face when accessing information about services. Many NESB people with disability/carers have low levels of English language proficiency. As limited information is available in community languages, it is difficult for them to communicate with services.

Despite this, services do not incorporate language services in their budgets and funding bodies do not encourage them to do so. This results in:

- a reduction in community services available to people from NESB with disability;
- lack of information;
- the provision of inappropriate information; and
- an overall increase in the use of family members and other relatives as interpreters, a clear violation of Standard 4 of the National Standards for Disability Services.

Further, many people with disability, their families and carers from NESB have only limited knowledge and expertise in accessing planning information. They don't know what options are available or don't want to think about future service planning because many services are regarded as culturally inaccessible.

⁸ A copy of this submission is available on MDAA's website (<http://www.mdaa.org.au/service/systemic/topics/carers.html>)

⁹ Multicultural Disability Advocacy Association of NSW, 'Main Issues Facing People From a Non-English Speaking Background With Disability and Their Families and Carers' MDAA Submission to Productivity Commission Inquiry into Older Australians

'Our own churches or clubs are often not accessible - even though they say yes when you ask them about it. You feel embarrassed when you get there and it isn't. Then you don't want to go. People really don't understand disability'. (MDAA consultation, April 2010)

To improve access to practical information about succession planning, distribution strategies must be developed that specifically focus on the NESB population. For example, creative new information strategies should include promoting succession planning through Migrant Resource Centres, TV channels, ethnic community radio and various ethnic community websites and newspapers. Information booklets that explain possible planning choices and care options should also be produced and translated into community languages.

Further, cultural competence training with mainstream service providers, including Home and Community Services (HACC), should be continued and extended.

Information on succession planning should be presented in a way that is accessible to all. Thus, translation and distribution strategies for resources, like the 'Planning Ahead Kit'¹⁰, must be sensitive to Australia's cultural, linguistic and religious diversity.

3.5 Isolation and Carer/Family 'Burn Out'

Within their communities many carers from NESB experience isolation and stigmatization. They generally only seek help when they reach crisis point.

Due to limited familiarity of support services, they manage several responsibilities and may experience multiple layers of disadvantage – disability, poverty, disruption to the family as a result of migration, diminished support networks and lack of sufficient and culturally appropriate services.

In general, carers from NESB have a 'grin and bear it' attitude to an even greater extent than their Anglo-Australian counterparts. Asking for support is seen as failing, not only in one's caring role but also in the family, the community and most importantly the person they are caring for¹¹.

Furthermore, people with disability have indicated that carers are in many cases their main link to the wider community and social activities. Participants in MDAA's consultations were quite concerned that as their carers age, their ability to support and link them with social activities will reduce. This will further add to the isolation and 'burn out' of families with a member with disability.

¹⁰ DADHC (May 2006): *Planning Ahead Kit: Resources for managing financial, health and lifestyle decisions into the future*. See <http://www.dadhc.nsw.gov.au/NR/rdonlyres/E0B88110-78E2-4626-B6D8-A2B3601E353B/1901/PlanningAheadKitMay1.pdf>

¹¹ Multicultural Disability Advocacy Association, (2003), *Less Talk More Action*
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3.6 Financial Vulnerability

In general, people from NESB can rank lower on the socio-economic scale than their Anglo-Australian counterparts, particularly some migrant groups such as refugee and humanitarian visa holders. This is often explained by proficiency in English, the levels and recognition of educational qualifications and the levels and recognition of work skills and experience.

In Australia, all migrants without disability (except for those immigrating on humanitarian grounds) have to wait two years before they can access income support. However, migrants with a disability, including their carers, have to wait ten years before being eligible for social security payments such as the age and disability support pensions¹².

In addition, those who *are* eligible for pensions, other support payments or services are frequently not aware of their entitlements because successive Government information strategies have failed to communicate new initiatives and programs to people with low English proficiency.

When asked, about their concerns for the future, participants in MDAA's consultation on ageing with disability (held in April 2010) raised their financial status as a key concern. Their future standard of living was seen as crucial to their independence. Some of their concerns are included below:

'The Disability Support Pension is not enough because everything is expensive – food, rent, water and electricity. I need more money so I can live!'

'If you don't have a job, how are you going to live alone? Where do you get the money from? And the DSP isn't enough to support you'.

'Sometimes, living alone or independently is not realistic. We have to be reasonable with our expectations'.

'I go to the movies on Tuesdays 'cause it is only \$5 a movie. I do this maybe once a month. I can't afford to go to the movies any other time – it is too expensive'

Rising costs for rent, food, utilities and other health related expenses continue to make it difficult for people to maintain a decent standard of living or live independently. In addition, the low levels of personal savings and superannuation amongst this population group will mean that the main source of income will be

¹² <http://www.immi.gov.au/living-in-australia/settle-in-australia/everyday-life/work/whatsupport.htm>
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from Government pensions. As mentioned earlier, pensions barely cover the costs of providing personal care, domestic chores, shopping and transport.

In addition, MDAA is aware that Special Disability Trusts are available to assist families with members with a disability plan for the future. This succession planning tool, will have limited effect for the NESB population. The reason for this is that many NESB people with disability are on low to moderate incomes. Special Disability Trusts are generally most effective for people on higher incomes. There is a need for an option for people with low-moderate incomes.

3.7 Ageing Carers

In MDAA's experience, caring for family members with disability or health conditions is a shared family responsibility. Parents (most often mothers), have a key role in providing this support. But as parents age, they also have increasing health problems and might themselves need support from carers.

Being increasingly unable to provide quality care, NESB people with disability and their families are asking 'what would happen when the primary informal carer can no longer provide the level of support required?' Ageing NESB carers find that the caring role becomes more difficult with time and wish to see alternative arrangements put in place for the future care¹³. They must make the difficult decision of when to stop providing care for their family member with disability.

'I am afraid I will not be strong enough to take care of him in the future. I worry for him when I'll not be around any more that he'll not be taken care of the way I used to because all my children are working - besides they have their own families.' (MDAA NESB carer consultation, September 2004)

Research also suggests that failing to plan may provoke ongoing anxiety in older family carers and the person being supported.

Moreover, there is an increasing demand on NESB families – like on all families, for all adults in a household to be in paid employment. Thus while it may have been possible at some stage in the past for an adult to take on a caring role, this seems increasingly impossible. This may be an additional issue for NESB families who rank lower on the socioeconomic scale than their Anglo Australian counterparts¹⁴.

¹³ MDAA and NEDA joint submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth *Inquiry into Better Support for Carers* (July 2008)

¹⁴ Multicultural Disability Advocacy Association (2004), 'I'd like to go to Queensland...I have no other future plans: Hopes and fears of people from NESB with disability and their family members/ carers'

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3.8 Living Independently

Whilst some people with disability are able to live independently, some require the support from their families, carers and/or support services. As detailed in article 19 of the United Nations Convention on the Rights of Persons with Disability, people with disability have the right to live an independent life.

NESB people with disability have expressed concern in developing and maintaining their independence. For many, the support provided by informal carers limits their opportunities to gain independent living skills.

For example, some consumers have indicated that currently, families and carers manage their money. They do most of the shopping and pay the bills, with little discussion with the person with disability. Consumers with disability raised concerns about their ability to manage their own finances, without the support of their families or carers. They expressed interest in taking part in a budgeting course to gain these skills. Money management needs to be a key feature of future succession planning programs.

In contrast, the case study of Mikhail below highlights the importance of teaching independent living skills.

Mikhail aged 71

Mikhail migrated to Australia during the 1980's at the age of 40 from Hungary. He came to join his younger siblings and parents who had migrated earlier. Mikhail has polio and as a result, uses an electronic wheel chair.

He talks of his independence

'...my parents gave me support to live independently even when I was still staying with them. All throughout my life I like to be independent and not rely on others - if I can still do it myself. I have to paddle my own canoe. I do the cooking, shopping and washing. The bottom line is, I still do it even though I'm already 71 years old..... I don't rely on someone's help. I am happy living independently'

A young person with disability expressed his wish to live a life similar to his friends without disability.

Joseph, aged 26

'I would like to get a full time job, buy a home and move out of my parents house,... do my own cooking, cleaning.....have a relationship'

A further hindrance to independence is access to transport. Participants in MDAA's consultations noted that their families and carers provided transport assistance. This assistance included driving them to appointments or social events, assisting them to catch the bus or train. The accessibility of public transport was a concern, as this would be the main form of transportation.

'You have to ring up the train station before you get on the train to let them know you will be coming– it is our responsibility. You also have to let them know if you have to stop over somewhere when you are going home.

What if the train station is not accessible? I can't afford to take a taxi!'

A general shift from crisis management to long-term planning needs to occur. People with disability and their carers need to be engaged much earlier in the succession planning process. This should not only be when carers can no longer provide informal support.

MDAA believes that succession planning should build on and further strengthen the capacities of the person with disability. Many of the current services are based on deficit models that focus more on what a person cannot do, rather than strengthening the capacities, skills and knowledge that people with disability already have.

3.9 Early Onset Ageing

Research indicates that the process of ageing can occur much earlier in people with disability than other population groups. People with early onset ageing may need the same services as the general ageing population, but at an earlier age. Their support requirements may also need to be reassessed as they get older.

As a consequence, people who are ageing with disability may require access to both disability and aged care services. Due to eligibility restrictions however, aged care services can usually only be accessed by people aged 65¹⁵ years and over. Except for Aboriginal and Torres Strait Islanders, who are eligible for aged care services at the age of 50.

The Commonwealth *Aged Care Act 1997* is legislation that allows funding to be provided for aged care services. The Act details service standards, eligibility criteria and funding allocation. As detailed in the Act, one of the factors in the distribution of funding to service providers is the proportion of 'people with special needs' in an area.

¹⁵ Aged Care Act 1997

The Act defines Aboriginal and Torres Strait Islanders, people living in rural or remote areas, financially or socially disadvantaged individuals and people from non-English speaking backgrounds as having 'special needs'¹⁶. An important omission is people with disability.

Similarly, the Productivity Commission classifies people from a non-English Speaking Background with disability as belonging to the 'special needs group'. This classification reflects the governments' objective that access to services should be equitable for all members of the community.¹⁷ Further, it is also an acknowledgement of the current inequity in service access and utilization by the NESB population.

In recognition of this, MDAA recommends a review and subsequent amendment of the *Aged Care Act 1997* to include people with disability as a 'special needs group'. Their eligibility for aged care services should be permitted before the age of 65.

These changes would ensure that funding allocation, program development and delivery includes people with disability that are ageing.

3.10 Support from Carers

Currently people with disability or health conditions can apply for their relatives living outside of Australia to come to Australia and be their carers. They can do this through the Carer Visa (Offshore) subclass 116.

The *Migration Act 1958* defines eligible relatives as 'spouses, parents, children, brothers, sisters, aunts, uncles, nieces, nephews, grandchildren and grandparents as well as half brothers and half sisters.'¹⁸

This definition reflects an Anglo/Western perception of family. In many cultures, there is no distinction between immediate and extended family members. By limiting the relationship between the carer and the person being cared for, the pool of potential carers is also limited. This has important flow on effects, as in the absence of family and informal carers, paid carers and support services are required. It has been well documented that there is a significant unmet need in disability services.

When asked what his concern for the future was, a participant in MDAA's consultation responded with the following:

¹⁶ Aged Care Act 1997

¹⁷ Productivity Commission Report on Government Services 2010, p.14.33

¹⁸ Immigration Advice and Rights Centre, 'The Immigration Kit', J. Burn & S. Reich, The Federation Press, 2007, Seventh Edition p.255

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'The main problem I am worried about is that the Immigration Department does not like to get someone from my country as my carer – unless they are immediate family. I want the daughter of my first cousin (to be my carer) – the rest of my family have their own families, or are working – how can they come to Australia to be my carer?'

*'I paid \$275 for a medical assessment to prove I need a carer. I don't have a lot of money so it is difficult to pay for the application fees. I applied in 2007 and have not had any response yet I do not know what I will do'.
(April 2010)*

MDAA recommends an amendment to the definition of family within the *Migration Act 1958*, so extended family members can be granted Carers Visas.

3.11 Transition to Aged Care Services

While there are similarities between the current disability and aged care service systems in broad service philosophies and policy directions, the two systems differ in their program focus, service types, main target groups and trained personnel. In particular, aged care services are geared to the needs of frail older people, while disability services generally focus on people under age 65.

Aged care services focus more on health needs, broad personal care and self maintenance, while disability support services emphasise non-health needs and address a broader range of life domains, including employment.

When attempting to access these services, consumers can encounter bureaucratic barriers. The links between aged care and disability service providers and Government policies are often weak or absent, resulting in service gaps and inflexibility. These service gaps place increased pressure on carers at the very time in their lives when their capacity to meet such demands is reduced. It also adds to the isolation of NESB people with disability and their carers.

Moreover, MDAA is concerned that the Federal Government's decision to split the responsibility for disability and aged care services will have a negative impact on the lives of people with disability.¹⁹ MDAA believes that people should not be disadvantaged by the transition from disability support programs to aged care programs. A seamless transition from disability services and aged care services/packages is required.

¹⁹ These changes were announced in the Council of Australian Government Communiqué 'National Health and Hospitals Agreement, p.25
http://www.coag.gov.au/coag_meeting_outcomes/2010-04-19/docs/NHHN_Agreement.pdf

There is a need for flexibility in services and programs. For example, a framework for planning individual services, and possibly mixing aged care and disability service programs, could be useful.

There is also a need for developing the skills of staff in the disability, aged and community care sectors to work with this population group.

For example, some people ageing with an intellectual disability may acquire dementia relatively early in life. They may become frail and need health and medical care more than help with other activities. These people might be more appropriately assisted by aged care services, because of their early ageing and deteriorating health. There is however a lack of work force expertise in providing care/services to individuals ageing with disability.

4. Conclusion and Recommendations

In summary, MDAA strongly believes that the needs of carers can not be discussed without considering the needs of those being cared for (people with disability). Responding to the needs of carers, in effect means responding to the needs of people with disability.

Succession planning frameworks must consider a person's individual needs and their cultural heritage.

MDAA makes the following recommendations which, if implemented would respond to the cultural diversity of people with disability, their families and carers in Australia.

Recommendation 1: That the Australian Government develop a succession planning framework that meets the needs of people with disability and also recognises the interdependence of the needs of carers, families, culture, community and the services system.

Recommendation 2: That the Australian Government improves the quality of data on the needs of NESB people with disability and carers in Australia.

Recommendation 3: That the Australian Government improve the cultural competence of disability and carer services, to ensure services meet the needs of both ageing people from NESB with disability and carers.

Recommendation 4: That the *Aged Care Act 1997* be amended to include people with disability as a special needs group and be eligible for aged care services before the age of 65.

Recommendation 5: That definition of family in the *Migration Act 1958* be amended to so extended family members can be granted Carers visas.

Recommendation 6: A seamless transition process be developed from disability to aged care service system.