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Submission No. 1110
(Inq into better support for carers)

NEDA
NATIONAL ETHNIC DISABILITY ALLIANCE

MDAA

"Addressing the needs of people with disability, by taking account of culture, community and family, also means addressing the needs of carers."

NEDA and MDAA submission to Standing Committee on Family, Community, Housing and Youth Inquiry into Better Support for Carers

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1. Executive Summary

This submission provides a summary of non English Speaking Background NESB carer issues, based on the work of the National Ethnic Disability Alliance (NEDA) and the Multicultural Advocacy Association of NSW (MDAA).

NEDA and MDAA acknowledge that NESB carers make an active and valued contribution to Australia, providing valuable support to people with disability to participate in their families, communities and broad social and economic life. NEDA and MDAA estimate that there are at least **640,000** carers from NESB in Australia.

NEDA and MDAA express two main concerns in this submission:

> a. There has been a failure to adequately acknowledge the relationship between the needs of carers and those being cared for in policy and program responses by governments. NEDA and MDAA strongly argue that addressing the needs of people with disability – by taking into consideration culture, community and family – necessarily entails addressing the needs of carers.
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> b. Carers from NESB are often unrecognised – by service providers, by statisticians and by governments – and face specific barriers to participation, including attitudes, inappropriate services and information, poverty and isolation.

NEDA and MDAA provide four simple recommendations, which if implemented will assist in improving the health and wellbeing of NESB carers in Australia. The recommendations aim to improve our understanding, provide better information and better support to NESB carers:

Recommendation 1

That the Australian Government develop a framework for meeting the needs of carers that also recognises the interdependence of the needs of people with disability, families, culture, community and the services system.

Recommendation 2

That the Australian Government improve the quality of data on NESB Carers and their needs in Australia.

Recommendation 3

That the Australian Government address language barriers by improving the availability and targeting of information to NESB carers on entitlements, support and services.

Recommendation 4

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

This report is based on research and policy development work by both NEDA and MDDA. The submission includes the MDAA Report “Culturally and Linguistically Diverse Carers in NSW: Strategies under the NSW Carers Action Plan 2007-2012” in Appendix A.

2. Background

2.1 About NEDA

The National Ethnic Disability Alliance (NEDA) is the national peak organisation representing the rights and interests of people from non-English speaking background (NESB) with disability, their families and carers throughout Australia. NEDA is funded by the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to provide policy advice to the Australian Government and other agencies on national issues affecting people from NESB with disability, their families and carers.

NEDA actively promotes the equal participation of people from NESB with disability in all aspects of Australian society. It manages a range of projects relating to NESB and disability communities and works closely with its state and territory members to ensure that its policy advice reflects the lived experiences of people from NESB with disability. In states and territories where no NESB-disability advocacy agency exists NEDA undertakes development work to establish a structure that can support people from NESB with disability, their families and carers.

NEDA estimates that one in every four people with disability is a person of either first or second generation NESB, representing approximately 1 million people across Australia.

2.3 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.

MDAA is funded by the NSW and Commonwealth governments to provide advocacy support to people from NESB with disability and their families and carers in NSW. We provide individual and systemic advocacy; advocacy development; industry development; research. We receive funding from the NSW Department of Ageing, Disability and Home Care (DADHC) 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 people with disability.

2.4 Defining NESB

NEDA and MDAA use 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. NEDA and MDAA contend 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.

NEDA and 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. Addressing the Needs of Carers? Or Addressing the Needs of People with Disability?

Informal care involves a relationship of support and interdependence between the person being cared for and a family member, friend, neighbour or other community member who provides support and assistance.

The support needs of those being supported are therefore closely related to the support role played by carers.

NEDA and MDAA emphasise that this is an ongoing issue in relation to considering the needs of NESB carers, where it is difficult to separate carer needs from those of the person with disability, family or networks of friends and neighbours. Addressing the needs of carers involves both addressing the needs of those being cared for, and taking into consideration broader context of family and culture.

3.1 The Needs of People with Disability

There has been growing concern in relation to the role of carers in Australian social life. While this focus is welcome in highlighting the important contribution of informal care in providing crucial forms of support, a disturbing climate has also emerged where the interests of people with disability are treated as unrelated – and on occasion opposed – to the interests of carers.

The terms of reference for this review reiterate this apparent split between carer interests and those of the person being cared for: nowhere in the terms of reference are people with disability mentioned, despite being linked very obviously to the role and contribution of carers.

Unfortunately, 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 upon the lives of people with disability.

NEDA and MDAA believe that it is impossible to address carer needs without understanding the context of this care, in particular the needs of those being cared for. NEDA and MDAA emphasise that addressing the needs of people with disability by taking into consideration their culture, community and family, necessarily entails addressing the needs of carers.

3.2 Who Cares?

A "carer" is normally understood as a family member, friend, neighbour or other community member who provides support and assistance to another person without payment other than in some cases a pension or a benefit.

However the definition of a carer will vary significantly as a result of cultural and linguistic factors. Carers from CALD backgrounds may not readily identify as 'carers' and they may comprise a significant proportion of the hidden carer population.[1] 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.[2]

Similarly, there may be 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. In an important NSW study:

> Ethno-cultural beliefs regarding the role of the family in providing care were more often articulated by CALD carers. By contrast, Anglo-Australian carers, while also perceiving care as a family responsibility, tended not to perceive their role as one shaped by their cultural background.[3]

A further issue relating to understanding NESB Carers is the difficulty associated 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

The above issues associated with understanding carer needs across different cultural backgrounds highlights the need to examine carer needs only in context of family, community and cultural considerations.

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

[2] Ethnic Disability Advocacy Centre, "Supporting CALD Carers: The service needs of culturally and linguistically diverse carers of people with disabilities." February 2003, p20.

[3] Ibid. p47.

3.3 Recognising Carers, Recognising People with Disability

NEDA and MDAA emphasise that respecting the rights, needs and choices of people with disability must be an integral part of any consideration of the needs of carers.

This commitment to meeting the needs of people with disability is important when designing support systems, particularly where those supports will impact on the lives of people with disability. We note that Article 3a of the UN Convention on the Rights of Persons with Disabilities emphasises as a principle the “respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.”

However, NEDA and MDAA acknowledge that the voices of carers, and their experiences remain important. It is further acknowledged that some NESB carers are unaware of entitlements and support, and experience social and economic isolation.

NEDA and MDAA encourage the Australian Government to develop a framework that is able to offer recognition for both people with disability and carers; that is the recognition that the needs of carers are interdependent with the needs of people with disability, families, culture, community and the services system. NEDA and MDAA emphasise that addressing the needs of people with disability – by taking into consideration culture, community and family – necessarily entails addressing the needs of carers.

4. NESB Carers in Australia.

Carers provide assistance to others including frail older people, people with disability, people with mental illness, people with alcohol or other drug dependency, people with dementia, people living with HIV/AIDS, and people with chronic illness[4].

The role of carers in the lives of people from NESB with disability can be significant, as they are often exclusively dependent on their family members for support. Providing care and support to an ageing or relative with disability fulfils cultural and family expectations for many people from NESB. This expectation is understood as the responsibilities and duties of families' members towards each other[5]. Carers in NESB communities can be predominantly female family members who take on dual roles as sisters, mothers, wives, daughters etc. In many NESB communities, the caring role is almost exclusively the woman's responsibility.

4.1 How Many NESB Carers Are there?

NEDA and MDAA estimate that there are at least **640,000** carers from NESB in Australia.

This approximation is based on the estimated proportion of carers from a first or second generation NESB, taken as a portion of all carers as recorded by the 2003 Survey of Disability, Ageing and Carers.

Note that this figure includes both carers born overseas, and carers born in Australia but raised within a non English Speaking Background context, and thus captures important carer groups such as young Australian born NESB carers.

4.2 Problems with current NESB Carer data

A problem with much Australian data is the use of country of birth as the primary indicator of cultural and linguistic diversity. NEDA is concerned that the current use of country of birth as an indicator of NESB is problematic in that it fails to capture people who are born in Australia and are either raised or identify with a non English speaking cultural and linguistic context.

NESB may be defined as incorporating people:

- born overseas and whose language or culture is not English or Anglo-Celtic / Saxon

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[4] NSW Health, 2007.

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

- born here in Australia and the first language or culture of at least one parent is not English or Anglo-Celtic / Saxon
- born in Australia with linguistic or cultural background other than English or Anglo-Celtic / Saxon who wish to be identified as such.

This means that people may fall into the category of "Non English Speaking Background," even if their family has lived in Australia for several generations.

Table 1 provides a summary of current available data sources that indicate the NESB cultural diversity of carers in Australia, and also lists the associated problems with the data sources.

Estimate Proportion	Estimate Carers	Source	Notes
20%	**511,000**	Carers Australia, 2003	Estimate based on 20% Cultural and Linguistic Diversity. Appears to exclude 1st and 2nd generation NESB.
20.50%	**533,000**	Proportion of Australians who speak language other than English at home (ABS Census 2006), as a proportion of carers identified in SDAC 2003	Does not include English speaking carers in non English speaking cultural context households.
15.40%	**400,400**	Proportion of Australians born in non English Speaking Country (ABS Census 2006) as a proportion of carers identified SDAC 2003.	Does not include carers born in Australian NESB households
14%	**364,000**	AIHW 2004	Based on 1998 ABS SDAC country of birth only data.
ABS: Australian Bureau of Statistics *SDAC: Survey of Disability and Carers* *AIHW: Australian Institute of Health and Welfare*			

Table 1. Available estimates of NESB carers in Australia.

4.3 A Note on the ABS Survey of Disability Ageing and Carers

The Australian Bureau of Statistic conducts the Survey of Disability, Ageing and Carers (SDAC), a resource which has become a rich source of data on functioning and care needs for Australians. However, NEDA and MDAA express significant concerns in relation to the accuracy of data in the survey with respect to carers from NESB. Concerns include:

- problems with variability in answers to questions relating to 'disability,' 'severity of disability,' 'carers' and 'primary carers' as a result of the culture and language of the survey respondent.
- The need to improve survey collection and information processes to more accurately capture the views of culturally and linguistically diverse survey respondents – for example translation and interpreting for main community languages.
- The need to report on known cultural and linguistic factors that may affect the quality of reported results within releases of SDAC data, including for example, possible variations in answers to questions as a result or culture and language, and estimated non response or comparative partially complete rates for respondents from NESB.
- The need to include questions in relation to ancestry, and religion / spirituality in order to gain a more complete picture of NESB and culture issues for survey respondents.

NEDA and MDAA strongly recommend that the Australian Government work with agencies such as the Australian Bureau of Statistics and the Australian Institute of Health and Welfare to improve the quality of important data sources such as the SDAC.

5. Barriers and Issues experienced by NESB Carers

While caring can be a positive experience and provide a sense of satisfaction, it is well established that caring can have a negative impact on the carers' physical health, emotional wellbeing and financial security. The impact increases as the intensity of caring increases.

The experience of carers of culturally diverse people with disability is unique to that of the Anglo-Australian carer, in that they may face additional barriers to other carers such as language and communication barriers; lack of understanding of the health, community care, aged care and disability systems; cultural incompetence of those systems in dealing with carers from CALD backgrounds; high levels of stigma surrounding disability and mental illness; and fear of the lack of confidentiality, particularly in smaller communities[6].

5.1 '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. Whilst 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 communities[7].

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 female carers, especially those in communities where there is an enormous stigma attached to disability.

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[6] Multicultural Disability Advocacy Association (2007), Culturally and Linguistically Diverse Carers in NSW: Strategies under the NSW Carers Action Plan 2007 - 2012

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

5.2 Anglo 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, perpetuation of the 'they take care of their own' myth as aforementioned and limited efforts to target NESB communities by services.

As a consequence, carers and their families use services when there is a high level of need or when the level of need is at crisis point.[8]

In addition to the generally culturally incompetent service system, the main difficulties are the limited information and knowledge about these services, eligibility and assessment criteria; and the lack of bilingual/bicultural workers, and community health programs.

5.3 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 NESB carers 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.

5.4 Isolation/ Burn Out

Within their communities many carers from NESB experience isolation and stigmatisation, generally only seeking help when they reach a 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. The lack of support networks has

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

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

particularly adverse impacts on women caring for their children in communities where there is an enormous stigma attached to disability

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 for[10].

5.5 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 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 immigrants without disability (except for those immigrating on humanitarian grounds) have to wait two years before they can access income support. However, immigrants with a disability, including their carers, have to wait ten years before being eligible for the Disability Support Pension (DSP) which is the usual entry criteria for essential disability services such as Post-School Options Programs, Home and Community Care (HACC), Program of Appliances for Disabled People (PADP) etc.

5.6 Ageing Carers

As with their Anglo-Australian counterparts, carers from NESB are ageing and experience increasing health problems and other health and caring related difficulties. Being increasingly unable to provide quality care, NESB family and carers are increasingly asking what would happen to the family member with disability when the primary informal carer could 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 care.

There is an increasing demand on NESB families – like on all families, for all adults in a household to be in paid employment. The financial pressures on families are similar on Anglo-Australian or NESB families. 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 might be an additional issue for NESB families who are generally poorer than their Anglo-Australian counterparts[11].

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[10] Multicultural Disability Advocacy Association, (2003), Less Talk More Action

[11] 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'

(For more information on Ageing carers, MDAA's research paper '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,' September 2004 and submission to the Department of Families, Community Services and Indigenous Affairs discussion paper 'Succession Planning for Carers,' December 2006).

5.7 Young Carers

As a result of different cultural factors in the structure and attitudes of families, as well as the poor access of people from NESB to disability services, it is likely that there are a significant number of young NESB carers in Australia. Recent consultations held by MDAA suggests that young NESB Carers often want more recognition for their caring role within their families, and need access to age appropriate recreational activities. However, NEDA and MDAA acknowledge there is a strong need for additional research in this area.

5.8 Access to Carer Payment and Carer Allowance Entitlements

NEDA is aware that a number of NESB Carers are not aware of their entitlements to carer payments and carer allowances. There is limited data available to indicate if there are carers in some communities who are not aware of their entitlement to a carers payment or allowance. Table 2, provides a summary of the limited available information on NESB carers based on country of birth of carer payment recipients. Again, as noted above, country of birth remains a poor indicator of the effectiveness of services and programs for NESB clients.

CHARACTERISTICS	MALE		FEMALE		TOTAL	
	NO.	%	NO.	%	NO.	%
Country of birth (top five countries)						
Australia	20,323	68.1	36,243	66.8	56,566	67.3
United Kingdom/Ireland/Eire	2,118	7.1	3,125	5.8	5,243	6.2
Lebanon	569	1.9	1,289	2.4	1,858	2.2
Italy	494	1.7	1,124	2.1	1,618	1.9
Vietnam	548	1.8	1,028	1.9	1,576	1.9
Other	5,786	19.4	11,435	21.1	17,221	20.5

Source: FaHCSIA Statistical Paper No.3

Table 2: Carer Payment customers, characteristics by sex, June 2004

NEDA and MDAA have the following concerns in relation to access to the carers allowance or payment:

1. The application process for entitlement to carers allowance is complex, and may prove more difficult for people who do not possess a strong English language proficiency to navigate. Some carers from NESB may be reluctant or not know who to use an interpreter to assist them to apply for carers allowance / carer payment, or may not call on friends or family – as a result of community status, attitudes or stigma – to assist them with an application.

2. Some carers may not understand the implications of answers in relation to their eligibility for carer payment / allowance, and may under-estimate or mis-describe the level of care that is provided. This will create inconsistency in equitable assessments for some carers from NESB.

3. Across the whole assessment process, information relating to needs, mobility, self care ability, cognitive function and behaviour will vary as a result of the social and cultural norms of carers, their relationship to the treating health professional, and the weightings provided by the assessment mechanisms of experiences (which are themselves product of social and cultural norms).

5.9 Access to Disability Services and NESB Carers

As stated above, there is a strong interaction between caring responsibility and the provision of support and services to people with disability.

People from NESB significantly underutilise government disability support services in Australia. A summary of available information (from Productivity Commission 2008) on the use of disability services gives a picture of current utilisation issues:

- Nationally, the proportion of people born in a non-English speaking country who use CSTDA funded accommodation support services in 2005-06 (0.5 service users per 1000 people aged 15-67 years) was lower than the proportion of people born in an English Speaking country who used these services (1.8 service users per 1000 people aged 15-64 years)." (p14.34)

- "Nationally, the proportion of people born in a non-English speaking country who use CSTDA funded employment services in 2005-06 (1.9 service users per 1000 people aged 15-67 years) was lower than the proportion of people born in an English Speaking country who used these services (5.6 service users per 1000 people aged 15-64 years)." (p14.34)

For supported accommodation services, this means that while approximately 1 in 5 people in Australia are born in a Non English Speaking Country, less than *1 in*

20 people from a Non English Speaking Country receive CSTDA funded supported accommodation services.[12]

Through consultations with NESB carers and people with disability, and as indicated in the 2008 Productivity Commission Report on Government Services, it is apparent that very few people with disability utilize support provided by disability services, and therefore there is likely to be an increased reliance on informal support for many people from NESB with disability.

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[12] Derived from Australian Institute of Health and Welfare, Users of CSTDA-Funded Services, 2004-05.

6. Conclusion and Recommendations

There are more than half a million carers from NESB in Australia, who play an important role within families and communities. Carers from NESB are often unrecognised – by service providers, by statisticians and by governments. Carers from NESB also face specific barriers to participation, including attitudes, inappropriate services and information, poverty and isolation.

However, as discussed in this submission, the role of carers can only be considered adequately by also considering the support needs of people with disability. The needs of carers are interdependent with other needs within the context of family, community and culture. Failure to consider the needs of people with disability when considering the needs of carers will not only lead to poor planning for supports

NEDA and MDAA make the following recommendations:

Recommendation 1

That the Australian Government develop a framework for meeting the needs of carers that also recognises the interdependence of the needs of people with disability, families, culture, community and the services system.

Recommendation 2

That the Australian Government improve the quality of data on NESB Carers and their needs in Australia.

Recommendation 3

That the Australian Government address language barriers by improving the availability and targeting of information to NESB carers on entitlements, support and services.

Recommendation 4

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

Appendix A - "Culturally and Linguistically Diverse Carers in NSW: Strategies under the NSW Carers Action Plan 2007-2012"

Culturally and Linguistically Diverse (CALD) Carers in NSW: Strategies under the NSW Carers Action Plan 2007-2012

Introduction

A carer is a family member, friend, neighbour, or other community member who provides support and assistance to another person, often in a regular and sustained manner, without payment other than in some cases a pension or benefit. Carers provide assistance to others including frail older people, people with disability, people with mental illness, people with alcohol or other drug dependency, people with dementia, people living with HIV/AIDS, and people with chronic illness[i].

In the 2006 Census[ii] 546,600 people said they provide unpaid assistance to a person with a disability. For NSW we can estimate that 25%, or 136,000 are from a CALD background (taking into account first and second generation data).

According to the ABS Survey of Ageing, Disability and Carers (2003)[iii], there are 748,000 carers living in NSW (11%). Although specific data on CALD carers is not available from this Survey, again with CALD figures of about 25%, we can estimate that there are 186,000 Carers from CALD background living in NSW.

Background

While caring can be a positive experience and provide a sense of satisfaction it is well established that caring can have a negative impact on carers' physical health, emotional wellbeing and financial security. The impact increases as the intensity of caring increases.

Carers from CALD backgrounds may face additional barriers to other carers such as language and communication barriers; lack of understanding of the health, community care, aged care and disability systems; cultural incompetence of those systems in dealing with carers from CALD backgrounds; high levels of stigma surrounding disability and mental illness; and fear of the lack of confidentiality, particularly in smaller communities[iv].

Furthermore, research currently underway highlights that many carers from CALD backgrounds may not readily identify as 'carers' and they may comprise a significant proportion of the hidden carer population[v].

NSW carers receive support from family, friends, other carers, volunteers, and formal services provided through non-government agencies. Some services directly support carers, while others benefit carers indirectly through support given to the person cared for. The majority of services and support specifically designed for and targeting CALD carers are funded through the NSW Department of Ageing, Disability and Home Care (DADHC) and the NSW Department of Health. These include[vi]:

- Culturally appropriate programs to educate and inform carers, e.g. the Multicultural Disability Advocacy Association ran workshops in five community languages.
- Local CALD carer support groups, e.g. Ethnic Child Care Family and Community Services provide carer support networks for CALD carers.
- Translated information available in community languages, e.g. the Macedonian Australian Welfare Association provides information for Macedonian carers.
- Advocacy support provided by bilingual workers, e.g. St George Migrant Resource Centre assists older carers to manage issues with Centrelink and other services[13].
- Carer events aimed at specific groups of CALD carers, e.g. the Down Syndrome Association of NSW supports families from CALD backgrounds through networking and social support.

Strategies in the NSW Carers Action Plan

The NSW Carers Action Plan lists five priorities for action that are fundamental to improving the quality of life for carers and the people they support. Below each priority for action we have included what carers have told us about the priority for action, some current or previous projects that have been shown to be effective for CALD carers and what carers tell us they need.

An important theme across the different action areas is the need for collaboration across government departments and between government and non-government agencies. Governments, as policy makers, funding and service providers, need to incorporate the vision of the Carers Action Plan into their programs, and allocate resources that support the continuous development of CALD carer support services. Service providers need to be given the impetus, opportunities and support to work together, to achieve better outcomes for CALD carers.

Priority for Action 1: Carers are recognised, respected and valued

What carers say/ What we know

- Providing care and support to a relative is part of what many families from CALD backgrounds expect to do[vii]. While carers from CALD backgrounds

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[13] Although most organisations are not funded specifically to provide advocacy support, it has been identified as one of the most important and under-resourced components of holistic carer support (Carers NSW, 2003-2006).

may not accept that there is a need to 'label' themselves as carers, they do want others to recognise, respect and value their role as a carer, not only because they are contributing to the care provided in NSW, but also because of the impact caring has on their own life[viii].

- Carers from CALD backgrounds often report a lack of recognition, understanding and respect by governments, service organisations, society, their communities and families for their contribution and their decision to care. This is a major contributor to the stress levels, dissatisfaction, and isolation[ix] of CALD carers.

- Carers have reported that the provision of practical services through government and non-government organisations is the best way to recognise and value their contributions[x].

Strategies for CALD carers:

- Organisations and communities regard **Carers Week** as a fantastic opportunity to increase awareness in CALD communities about carers and their issues. The focus of celebration in the past few years on the abilities and contributions of carers has also resulted in carers reporting a sense of being recognised and valued[xi].

  In 2002-2004, the State Carers Week Launches focused on targeting carers from CALD backgrounds. These included a seminar style launch in Parramatta in 2002, an outdoor launch in Belmore Park, Sydney in 2003, and a luncheon style launch in Cabramatta in 2004[xii]. It is important to note that while the NSW Government provided extra resources for the 2003 launch, local governments, organisations and businesses also provided funding to make these events possible. Moreover, the organisation of these events relied heavily on 'a responsible person' and 'a reliable network'[xiii]. These events are often not specified in job or service descriptions. Where there is a specific CALD carer project officer to organise these events, there is usually no continuity after the completion of these short term projects, such as the ones funded through the NSW Carer Program.

- **Carers NSW** is the peak body representing all carers in NSW. Its vision states that 'Governments and communities recognise, value and support carers'. As regards carers from CALD backgrounds it develops and delivers education and training for health, mental health, and community care providers; convenes and supports the Multicultural Carers Alliance; supports and resources other organisations in developing CALD carer support; and carries out a range of community development activities to raise awareness among carers and CALD communities in general.

While the lack of state based translated materials has for a long time been regarded as a weakness, with funding from DADHC five resources are being developed to enhance the awareness of carers in 16 language groups. The Multicultural Carer Alliance has highlighted, however, that this is the first of many steps required to address the needs and issues of carers and caring in CALD communities.

- **Social housing:** While there is no quantitative evidence available about the need for social housing in CALD communities, numerous studies and projects have discussed the housing needs of people from CALD backgrounds with disability and mental illness and their desire to live with their carers, and the benefits of such arrangements. Carers from CALD backgrounds, however, often report cultural insensitivity and incompetent practices in the housing system. In particular, carers believe that government departments are not listening to them or valuing their views about their housing needs[xiv], and that the types of housing available do not suit their particular needs.

- **Local Area Health Service Initiatives:** The appointment of Carer Support Officers has provided an opportunity for capacity building within Area Health Services and has also allowed the development of localised CALD carer specific services (see also Priority 3). Different areas have adopted different strategies to enhance service responsiveness to CALD carers. These include providing education and training to health and community care professionals in conjunction with the Education and Training Team from Carers NSW[14] and developing resources and tools[15]. For these strategies to be effective, however, there are some associated issues that need to be addressed, including the lack of appropriate policies, networks and links within and across services and areas, as well as an overloaded workforce. These service and resource problems make it difficult to support carers, particularly carers from CALD backgrounds[xv].

- **Current policies and programs**: Although carers from CALD backgrounds have had increased participation and input into the development of policies and programs in recent years, many policies and programs do not yet reflect or meet the specific needs of CALD carers.

  A number of support programs targeting carers from CALD backgrounds are funded by Governments through a range of programs. These include carer support group projects, respite programs, various education and

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[14] Examples include Hunter AHS at Newcastle Hospital, Illawarra AHS at Shoalhaven and Wollongong Hospitals, Sydney South West (Eastern Zone) AHS at Canterbury Hospital, and Sydney West AHS at Auburn Hospital.

[15] Examples include Sydney South West (Eastern and Western Zones) AHS, and Greater Southern AHS.

training programs, and the SBS Homereach Series[16]. The impact and specific issues associated with these programs are discussed under Priority 3.

Priority for Action 2: Hidden carers are identified and supported

What carers say/ What we know

- The majority of carers from CALD communities remain hidden even though their care needs are well established[xvi]. Most large scale studies[17] do not include carers from CALD backgrounds at a representative level, for various reasons. Most importantly the service system (including policy making, service planning and development, research and service delivery) remains largely culturally incompetent[18] and therefore unable to meet the needs of carers from CALD backgrounds[xvii]. Other reasons include the unavailability of translated materials[xviii] and the use of the term 'carer', which cannot be translated (literally or conceptually) into some languages[xix].

- The lack of culturally and linguistically appropriate information for carers is one of the main reasons for the low self-identification of carers in CALD communities[xx].

- It is also impossible to talk about hidden carers without talking about the stigma within many communities that exists for people with disability and their carers.

- The 2006 Census included a question about providing unpaid assistance to a person with disability. While the data for the general population and Aboriginal and Torres Strait Islanders is readily accessible, specific data for CALD communities is currently unavailable[xxi]. For governments the lack of reliable statistical data continues to be a major challenge, but many CALD communities perceive data collection as secondary, wanting governments to take action now to plan and develop service systems that are culturally competent.

- Research conducted by MDAA in 2004[xxii] identified that many carers of people with disability from CALD backgrounds have little or no understanding of the service system. Many carers said they were proud that the person they cared for had never needed to use a public service.

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[16] The value of the Homereach Series was highlighted particularly in regional and rural areas (Ethnic Communities Council et al, 2002 & Quaglio, 2001).

[17] Including the Ageing, Disability and Carer Survey, Time Use Survey, etc.

[18] Cultural competence generally refers to the ability of individuals, programs and service systems to respond to the diversity of the community. For a detailed discussion about cultural competence go to http://www.mdaa.org.au/publications/index.html

Few people with disability had made any plans for the future, including what would happen when their main carer could no longer provide the care and support they need.

- Two studies conducted by Carers NSW also confirmed that ageing carers from CALD backgrounds rely mostly on other family members rather than formal respite services. This is partly due to the lack of suitable respite options, and partly due to the stigma attached to disability[xxiii].

- A number of smaller scale CALD carer studies indicate that their practical support needs are similar to those of other carers. These studies also highlight the negative experiences of CALD carers due to the cultural incompetence of the service systems[xxiv].

- The lack of post-research feedback or reporting to the communities has put some carers off from participating in research[xxv].

- The positive role of ethno-specific and local multicultural organisations in research is undeniable. A number of studies[19] were able to include sufficient inputs from CALD carers because of the assistance and support provided by these organisations.

- Three out of ten state-wide projects funded through the NSW Carer Program have specific CALD components. Other projects with no specific CALD focus also identified the need to develop culturally sensitive services and materials for carers from CALD backgrounds[xxvi]. This funding has provided some opportunities for organisations to share experiences and resources and to work with other organisations to support carers from CALD backgrounds.

- Carers may come into contact with services in other ways. The Community Settlement Support (CSS) officers[xxvii] located across NSW, funded by the Department of Immigration and Citizenship, are often their first point of contact. Because their positions are well known in communities they are often the only people who can address language and cultural needs. While working with CSS officers is an obvious form of partnership, there is a huge communication gap between the CSS and other services supporting CALD communities.

- The significant role of young carers in CALD families is well recognised, although little literature is available. The proportion of young people from CALD communities with an identified caring responsibility is probably much higher than in the general population[xxviii], because the lack of

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[19] Such as the Respite Reconsidered study conducted by Carers NSW with assistance from Newtown Neighbourhood Centre and May Murray Community Centre, and the Cancer Carer Survey conducted by the Sydney Cancer Institute with assistance from CanRevive.

culturally competent health and community services results in people from CALD communities depending more on their children.

- There are various difficulties with most intake systems used by both State and Commonwealth run and funded programs. These include the difficulties in working out how to get access to the service[20] and in participating in needs assessments where the assessment tools may not be valid across cultures and may therefore not measure the needs of carers from CALD backgrounds accurately.

- There is little evidence of the importance of culturally competent assessment and intake tools in the Home and Community Care Program (HACC) and community care sectors. This is despite evidence from the mental health sector and dementia care generally which stresses the importance of such tools and skills[21]. Intake and assessment could also provide a good introduction into the service system. A rare study of the impact of a needs assessment on carers from CALD backgrounds reported that the assessment process can itself be a form of support and deliver therapeutic outcomes[xxix].

- Although caring is seen as a predominantly female role, the roles of male carers in CALD communities are complex and they are likely to be providing some levels of care without realising the impact of this[xxx]. The needs of male carers and ways to support them are different from female carers[xxxi]. When targeting hidden carers it is important to include male carers.

- A description of caring roles and tasks would help carers from CALD backgrounds to identify themselves[xxxii].

- A Multicultural Carers Alliance workshop[xxxiii] suggests the need for basic information for carers in all CALD communities about caring and the services[22] available. This would support organisations working with CALD communities to help carers identify themselves. The workshop highlighted another critical issue, namely the diverse needs of different CALD communities. One size does not fit all. Some communities, for example, need information on carer support groups and residential care in order to encourage uptake of services and support, whereas other communities do not need such information because the services and support they need

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[20] That is, the whole concept of intake and waiting lists may not be understood culturally by many communities.

[21] For mental health see: http://www.mmha.org.au/mmha-products/books-and-resources/cultural-awareness-tool-cat; for general health see: http://www.mdaa.org.au/publications/CulturallyCompetentDisabilitySupport.pdf; pg 51 onwards.

[22] Carers from CALD communities may be more willing to identify with the term 'carer' as a strategic way to link in with services and support (Centre for Cultural Research, 2006; Sutherland Shire Community Care Network, 2005).

are not available or are culturally inappropriate. What is required in those circumstances is increased resources and capacity building to improve the cultural competence of existing services.

Strategies for CALD carers:

- The latest initiatives[23] from both the Commonwealth and NSW governments targeting older parent carers, including **respite,** may help older parent carers from CALD backgrounds to link in to the service system and plan for the future. The effectiveness and outcomes of these initiatives are yet to be seen as they are just starting to be implemented.

- The experiences of funded **State-wide projects** illustrate that support methods and strategies vary depending on the specific characteristics of different communities[xxxiv].

- **Young carers** from CALD backgrounds will benefit from better recognition and support from schools and other educational institutions. To improve our understanding of their particular issues, however, there is also a need to collect better data, conduct further research and find ways for governments and service providers to listen to young carers from CALD backgrounds and hear what they want to say.

- More systematic **research** would assist services to plan and develop appropriate services and support for CALD carers.

- Improved, culturally competent **intake systems** and better coordination of information and services would greatly benefit carers from CALD backgrounds.

- Work needs to be done to undertake extensive community education and development to address the stigma experienced by people with disability and their carers[xxxv]. It is important to work with the communities and partner with ethno-specific and multicultural organisations, including CSS officers, in developing and delivering CALD carer support.

Priority 3: Services for carers and the people they care for are improved

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[23] These include the Transition Support Service where Centrelink social workers will visit parent carers aged 65+ who receive the Carers Allowance to assist their transition to the future; and the ageing parent support program across NSW, in which two programs target CALD parent carers specifically. In addition, all general projects are required to demonstrate their ability to support CALD carers.

What carers say/ What we know

- While many carers from CALD backgrounds are reluctant to use **community, disability, mental health, health and respite services**, people from CALD backgrounds are generally under-represented across generic aged care, disability, mental health and carer services.

  While only limited data is available, MDAA estimates that service utilisation rates are between 5%-15% depending on service type. Under-representation appears to be greatest in prevention and early intervention services, whereas crisis services appear to provide services more equitably.

  Under-representation appears even greater in residential aged care facilities (with the exception of ethno-specific aged care) and residential disability and mental health facilities. Approximately 10% of permanent and respite aged care residents identify a language other than English as a preferred language, and between 10-15% were born overseas in a non-English speaking country[xxxvi]. The 2007 Report by the Productivity Commission[xxxvii] on government services identifies that NSW reported a lower than national average proportion of Commonwealth, State and Territories Disability Agreement (CSTDA) service users born in a non-English speaking country for accommodation support services for people with disability. NSW reported 0.2 service users born in a non-English speaking country per 1,000 people, whereas the national average was 0.5. People from CALD backgrounds with disability and their families see many of those services as culturally inappropriate.

  By contrast, services delivered in the home are seen as much more appropriate and utilisation rates are generally much higher[xxxviii]. Examples are Community Aged Care Packages (CACP) and Extended Aged Care in the Home (EACH). Both of these programs when delivered through ethnic community organisations have proven to be very successful in many CALD communities. 22% of CACP packages in 2004 -2005 were being used by people from CALD backgrounds. Although the general number of participants in the EACH program is much lower, an even higher percentage of people using that program are from CALD backgrounds, especially people aged 75 years and over[xxxix].

- In addition to the generally culturally incompetent service system, the main difficulties are the limited information and knowledge about these services, eligibility and assessment criteria; the limited availability of local and geographically accessible language or culturally specific services; and the lack of bilingual/bicultural workers[xl]. Programs such as intensive family support, Provision of Appliances for Disabled People (PADP), many community health programs and others are not known in many CALD communities.

- Any additional funding for community, disability, mental health, health and respite services must be linked to achieving fair results for people from CALD backgrounds and the results must be monitored.

- Information about programs and services needs to be made available to all eligible members of the community.

- The priorities for CALD carer services include a more active role for GPs and other health practitioners in linking carers to services; a stronger partnership between the social work department in hospitals and community services; ongoing language and culture-specific carer support groups; mental health promotion and services for carers (including counselling services by bilingual counsellors); development of translated materials to address the particular needs of different communities; training for mainstream service providers to support carers from CALD backgrounds; CALD carer-specific services including respite; and more and better coordinated community education about carers and their issues[xli].

- The importance of the partnership between specialist organisations and ethno-specific or multicultural organisations is obvious from the experience of various programs. Without the support of these organisations, specialist organisations often experience difficulties attracting CALD carers to their services. Ethno-specific organisations can often express the needs of their communities that can be addressed by specialist organisations[24].

- Advocacy and support agencies identify difficulties such as the unavailability and inaccessibility of interpreters and translators, the level of understanding and expectation in relation to advocacy and support, and the limited number of culturally sensitive and appropriate support and services[xlii].

Strategies for CALD carers:

- The **Family and Carer Mental Health Program** has enabled organisations to deliver education and training to carers of people with a mental illness, to enhance their ability to care and participate in the mental health system. Much of the training is not readily accessible for carers from CALD backgrounds due to the unavailability of translated materials and trained, experienced bilingual workers. The different learning needs

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[24] This is particularly true for more common disability conditions such as Autism, Down Syndrome, Diabetes, Alzheimer's Disease.

and styles of carers from CALD backgrounds mean that direct translation of materials and programs is not suitable for some communities[xliii].

The NESB Carer Support Project at the Transcultural Mental Health Centre of NSW is also funded through this Program. Mostly[25] bilingual group leaders provide support to carers through language specific carer support groups and raise carer awareness in their communities through community development activities. Some difficulties experienced include capacity to retain the bilingual group leaders due to the project's sessional and short term nature, the complexity of carer issues that causes burnout among the workers, and the unpaid additional time required to keep the group going. The need to recruit and train new workers also creates additional work for the coordinator[xliv].

- **Carer specific projects:** As well as the specific services and supports[26] offered by the state-wide and local/regional carer projects funded through the NSW Carer Program, these projects also deliver information and education to carers from CALD backgrounds and their communities. Some of the projects have been able to engage and raise awareness about carers, their issues and support needs through ethnic media as well as local and regional communities[xlv].
- **Social Housing:** Carers from CALD backgrounds are often unfamiliar with the system for accessing social housing in Australia. Some carers experience difficulties filling in the forms and providing evidence because of language and communication issues. Some carers have also raised lack of cultural competence of the system and service structure in which their need for and values about co-residence are not respected. This places tremendous pressures on carers, for example, where some carers need to travel every day to provide care to their relatives and some carers have to cover the high cost of housing in the private market.

Priority 4: Carers are partners in care

What carers say/ What we know

- Involving carers from CALD backgrounds as partners in care is challenging for various reasons. Language and communication difficulties prevent some carers from having their say and contributing to care decisions and arrangements. Carers from some cultures also believe that only the professionals know what is best for their relatives, hence their own ideas and inputs are irrelevant. It is particularly evident in decision

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[25] The bilingual support group model did not work for the Spanish community despite two attempts (Var, 2004).

[26] These services and supports include face-to-face or telephone practical and emotional support, education and training, advocacy and referral services to individual carers and in groups.

making about medical treatment that carers from some cultures believe firmly that they are not supposed to ask questions or challenge the decisions of medical professionals [xlvi].

- Many people from CALD backgrounds are not familiar with a system which emphasises inclusion of their views and experience; hence they are not always confident about voicing their issues and concerns with professionals. This is particularly evident from comments by some Chinese carers of cancer patients and carers of people with mental illness.

- Another factor that restricts carers from CALD backgrounds from becoming partners in care is the unavailability of information on different health, medical, community and other care and service options[xlvii]. This not only affects carers' confidence in contributing to decision making about care, but also prevents carers from making real informed choices and planning for the future.

- The vast majority of educational programs offered by the state-wide and local/regional projects targeting carers from CALD backgrounds focus on information about the health condition/disability, services, self-care strategies, and provide an opportunity for carers to meet others in similar circumstances.

- Some Carer Support Officers have produced good practice guidelines and other resources to reinforce and assist health professionals to treat carers from CALD backgrounds as partners.

- Many carers from CALD backgrounds have expressed their willingness to work with professionals to achieve better outcomes for their relatives. Carers have also explicitly indicated their training needs in order to become more effective in working with health and community care professionals. This contradicts some views that carers from CALD backgrounds are not interested in being partners in care. It is important that services listen to carers from CALD backgrounds and value their contributions.

- More education on service users' and carers' rights and responsibilities would help carers to be more comfortable and confident in making decisions about the care and support they provide.

- Service providers should be guided by the following[xlviii]:

    - Communicate to CALD carers the latest information about what is going on without using jargon or difficult words;
    - Take the time to listen to CALD carers – no-one wants to have to repeat themselves over and over;

- Where possible provide things such as transport support, equipment, etc, as carers lack financial resources;
- Explain the service and any criteria, including waiting lists;
- Train workers in 'cultural competence' so they know how to respond effectively to the needs of CALD carers;
- Ensure staff are aware that discrimination is unlawful;
- Ensure that staff providing attendant care undergo stringent police checks and do not employ former offenders;
- Identify issues in families and address them before they reach crisis point;
- Include people from CALD backgrounds and encourage community participation in service planning and development;
- CALD specific local/regional projects can also support carers as partners in care by providing important information and training, to enable carers to make informed choices and empower them to advocate for themselves and the person they care for. (Refer to Priority 2)

Strategies for CALD carers:

- **Family and Carer Mental Health Program:** similar to other carer population groups, carers of people with a mental illness from CALD backgrounds will benefit from a more carer friendly and responsive mental health service system.

- **Information Sessions, Seminars, Workshops and Training Programs:** Carers say that to be effective partners in care they need training about practical skills such as assertiveness, communication, advocacy, note-taking, and English[xlix]. This type of training is not readily accessible for people from CALD backgrounds.

Priority 5: Carers are supported to combine caring and work

What carers say/ What we know

- There is no evidence specifically about CALD carers and workplace participation. We know, however, that carers participate in the workforce at lower levels than others. Research demonstrates the ongoing financial and social impact of low workforce participation, including lack of superannuation and career advancement. Carers who work in paid jobs also report that lack of flexibility and assistance from their employers do not help them to balance caring and work[l].
- These issues are likely to compound the difficulties for people from CALD backgrounds, particularly newer migrant carers. Anecdotal evidence suggests that new migrants often experience difficulties getting and keeping a job relevant to their qualifications, and often fall into the lowest

income groups. This has adverse impacts on their health and wellbeing. Comments from CALD carers of people with a mental illness certainly highlight the relationship between self image and employment[li].

- Inflexible and unsupportive practices in the workplace impact on all carers but carers from CALD backgrounds may be less willing to discuss their caring responsibilities and the impacts on their work with their employers due to the stigma attached to ageing, disability, mental illness, and caring. Many CALD carers, particularly those with limited English, may not be aware of the *Carers' Responsibilities Act* 2000.

- Carers from CALD backgrounds also experience additional financial difficulties as a result of government policies and legislation. Some carers are not eligible for income support, including carers who have a Carer (Temporary) Visa, carers who have been in Australia for less than two years, and carers who care for a person who is not eligible for income support (Age Pension or Disability Support Pension) because of their residence status or the ten year waiting period. These policies have a huge impact on decisions about work arrangements for carers.

- Some service structures also disadvantage carers from CALD backgrounds. A carer caring for a frail elderly parent who does not receive the Age Pension, for example, may not be able to use day care to allow the carer to participate in the workforce because of the financial costs. Similarly, a carer may choose not to work because the costs far outweigh the benefits. Some carers may, however, be forced to work longer hours in order to provide for the family because the person requiring care has no other income support.

- Working Carers Gateway: web based information and support is increasingly important. While some carers from CALD backgrounds are familiar with the internet, there are many who do not use computers. The availability and currency of online translated materials can also be a challenge. Moreover, there is often a gap between information about services to support carers who are in the workforce and the availability and accessibility of those services.

- Many carers have expressed their willingness to gain paid or voluntary work and study opportunities[lii] provided that support is available.

- Carers from CALD backgrounds have the right and should be encouraged to participate fully in society. The uptake of language and culture-specific aged day care and dementia day care services demonstrates the needs in CALD communities. Carers who are not currently in the paid workforce but who are willing to take up work may not obtain the benefits from these services.

Conclusions

Previous experiences of the NSW Carer Program and other programs demonstrate that carers from CALD backgrounds will benefit from the NSW Carer Action Plan. Achieving such benefits depends on:

- Government departments and programs recognising CALD carers as a specific target group.
- Government funding and monitoring non-CALD specific programs to include output and outcome measures to demonstrate fair access and outcomes for carers from CALD background.
- Specific projects targeting CALD carers being available.
- Opportunities and resources for different organisations to work together being available.

Continuity and a continuum of services and support in CALD

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[i] NSW Health, 2007.

[ii] Australian Bureau of Statistics, 2007.

[iii] Australian Bureau of Statistics, 2003.

[iv] ARAFMI, 2005; Carers NSW, 2003.

[v] Centre for Cultural Research, 2006.

[vi] NSW Health, 2005.

[vii] Carers Victoria, 2001; Centre for Cultural Research, 2006; Cole and Gucciardo-Masci, 2003; St George Migrant Resource Centre, 2004; Sutherland Shire Community Care Network Inc., 2005; Sydney Multicultural Community Services, 2007.

[viii] Carers NSW, 2004; Multicultural Mental Health Australia, 2004; St George Migrant Resource Centre, 2002; Sutherland Shire Community Care Network Inc. 2005.

[ix] Centre for Cultural Research, 2006; Multicultural Mental Health Australia, 2004; Pagnini, 2005.

[x] Centre for Cultural Research, 2006; Multicultural Mental Health Australia, 2004; St George Migrant Resource Centre, 2002.

[xi] Carers NSW, 2003-2006.

[xii] Carers NSW, 2003-2006.

[xiii] Carers NSW, 2003-2006; Multicultural Mental Health Australia, 2004.

[xiv] Carers NSW, 2003-2006.

[xv] Carers NSW, 2003-2006.

[xvi] Carers NSW, 2003-2006; 2004-2005; 2007; Cleary et al, 2005; Kingshott, 2003; Multicultural Carers Alliance, 2006; Multicultural Carers Alliance, May 2007; 2004; Multicultural Disability Advocacy Association, 2007; St George Migrant Resource Centre, 2002.

[xvii] Carers NSW, 2003-2004; Disability Council of NSW, 2005; Hudgson et al, 2002; St George Migrant Resource Centre, 2002.

[xviii] Social Policy Research Centre, 2003.

[xix] Carers NSW, 2006; 2007.

[xx] Carers NSW 2006.

[xxi] ABS Carer data, 2006 Census.

[xxii] Multicultural Disability Advocacy Association, 2004.

[xxiii] Carers NSW, 2006; Disability Council of NSW, 2005.

[xxiv] Carers NSW 2003-2006; Disability Council of NSW, 2005; Multicultural Mental Health Australia, 2004; St George Migrant Resource Centre, 2002.

[xxv] Carers NSW, 2003-2006; National Health and Medical Research Centre, 2005; Multicultural Mental Health Australia, 2004.

[xxvi] Carers NSW, 2004-2007.

[xxvii] Carers NSW, 2003-2006; Ethnic Communities Council, Carers NSW & Ethnic Child Care, Family and Community Services Co-op, 2002.

[xxviii] Schofield, 1998.

[xxix] Multicultural Mental Health Australia, 2004.

[xxx] Schofield, 1998.

[xxxi] Payne, 2005; Rothwell, 2005; Ussher & Sandoval, 2005.

[xxxii] Carers NSW, 2007; Multicultural Carers Alliance, 2006.

[xxxiii] Multicultural Carers Alliance, 2006.

[xxxiv] Johnson et al, 2007; Multicultural Mental Health Australia, 2004; Newtown Neighbourhood Centre, 2007.

[xxxv] Carers NSW, 2003-2006; Carers Victoria, 2001; Centre for Cultural Research, 2006; Multicultural Mental Health Australia, 2004; St George Migrant Resource Centre, 2002; Sutherland Shire Community Care Network Inc. 2005

[xxxvi] Australian Institute of Health and Welfare, 2007.

[xxxvii] Productivity Commission, 2007.

[xxxviii] National Centre for Social and Economic Modelling, 2004

[xxxix] Australian Institute of Health and Welfare, 2006; 2007.

[xl] Carers NSW, 2003-2006; Disability Council of NSW, 2005.

[xli] Multicultural Carers Alliance, 2007; St George Migrant Resource Centre, 2002; Sutherland Shire Community Care Network Inc. 2005.

[xlii] St George Migrant Resource Centre, 2002; Sutherland Shire Community Care Network Inc. 2005.

[xliii] Carers NSW, 2004-2005.

[xliv] Var, 2004.

[xlv] Johnson et al, 2007; Newtown Neighbourhood Centre, 2007.

[xlvi] Carers NSW, 2003-2006.

[xlvii] Cleary et al, 2005; St George Migrant Resource Centre, 2002.

[xlviii] NSW Department of Ageing, Disability and Home Care, 2003; 2004.

[xlix] Carers NSW, 2004-2005; Pagnini, 2005; Sutherland Shire Community Care Network Inc. 2005

[l] Roshier-Taks et al, 2005.

[li] Berrutti & Suos, 2007; Carers NSW, 2004-2005.

[lii] Carers NSW 2003-2006.

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NEDA

MDAA

11 July 2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600
AUSTRALIA

Dear Committee Secretary

Please find attached the joint National Ethnic Disability Alliance (NEDA) and Multicultural Disability Advocacy Association of NSW (MDAA) submission to the Standing Committee on Family, Community, Housing and Youth inquiry into Better Support for Carers. The submission does not contain any confidential information, and NEDA and MDAA are happy for this submission to be made publicly available.

If you require further information about this submission, please contact Dinesh Wadiwel on 02 9687 8933 or email office@neda.org.au or Diana Qian on 02 9891 6400 or email mdaa@mdaa.org.au.

Yours sincerely

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