



National Ethnic Disability Alliance

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Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

NEDA Submission to the Senate Inquiry into Planning Options and Services for People Ageing with a Disability

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.

This submission is based on previous research work done by NEDA. We believe that the points raised in this submission are critical for any consideration of planning options and services and hope that the Inquiry will give favourable attention to the recommendations.

If further information is required on this submission, please contact Sibylle Kaczorek on email office@neda.org.au.

Yours sincerely

Sibylle Kaczorek
Executive Officer

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This submission will address six discussion areas and conclude with a summary of recommendations.

1. **Special needs group**
2. **Definition of NESB**
3. **Inadequate data SDAC – NEDA estimates**
4. **Higher prevalence of impairment 45+ years for people from NESB**
5. **General issues**
6. **Previous research**
7. **Summary of Recommendations**

1. **Special needs group**

The Aged Care Act 1997 Section 11.3 identifies special needs group. NEDA welcomes that people from non-English speaking background are identified as a special needs group.¹

It is noted however that people with disability are not included as a special needs group. It would appear reasonable to argue that people with disability should be included as a special needs groups given that a large number of people develop disability at a later stage in life.

Recommendation:

To include people with disability as a special needs group in the Aged care Act 1997, Section 11.3.

2. **Definition of NESB**

NEDA argues that people from a non-English speaking background include people:

- Who were born overseas
- Where one or both parents were born overseas
- Who may be third or further generation to people born overseas but where cultural traditions whether through customs, language, religion, spirituality are upheld in their upbringing

It is believed that only such a broad definition of NESB can capture the differing needs of people and unless embraced will lead to misinterpretations, wrong assessments and ultimately will not meet the needs of people from NESB with disability.

Recommendation:

To define people from non-English speaking background including those born in a non-English speaking country and those with ancestry from a non-English speaking country.

¹ http://www.austlii.edu.au/au/legis/cth/consol_act/aca199757/s11.3.html

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3. Inadequate data SDAC – NEDA estimates

The Survey of Disability, Ageing and Carers is inadequate in accounting for people from NESB in regards to the ancestry question as discussed in the previous point.

The survey is also problematic in its sampling methodology as in the case of people from NESB with core activity restrictions a very small number is sampled to estimate figures for the whole population.

NEDA in its research report 'What does the data say' has discussed this issue in more detail.²

On the basis of utilizing a number of Australian data collections NEDA estimates that a true reflection of people from NESB with disability is 1 million; in addition it is estimated that 40% of the overall population of people with disability have some form of recent migration heritage.

These figures indicate that there needs to be a substantial improvement in data collection and reporting to reflect these estimates.

It is also noted that the large number of people from NESB with disability are under-represented in service provider usage.

Recommendation:

To alter the SDAC to include an ancestry question similar to the Census.

To alter the sampling methodology of the SDAC to make it more reflective of the overall NESB population in Australia.

4. Higher prevalence of impairment 45+ years for people from NESB

NEDA's above mentioned research report noted a higher prevalence of impairment for people born in a non English speaking country aged over 45 years of age, especially for 'first wave' non English speaking migrants, up to 3 times that of the Australian born population.

It is assumed that the causes for this higher rate of impairment is due in part to unsafe work practices for migrants. It is also assumed that a lack of knowledge of the health system leads to access issues and gaps in understanding.

The higher rate of impairment among people from NESB at a younger age compared to those from English speaking background has implications on the planning options and services.

In addition to general issues, people affected in such way have a lack of preparation time, have to learn the navigation of and access to the service system in a faster way.

² http://www.neda.org.au/files/what_does_the_data_say_final_report.pdf

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Recommendation:

To fund and conduct research on the incidence of higher rates of impairment for people from NESB with disability.

5. General issues

NEDA notes that some general points of consideration when considering the need of people from NESB with disability.

It is contended that cultural appropriateness of services providers is insufficient when it comes to accommodating needs such as language, written material, religious or customary events, gender and diet.

A key issue here is language regression of people with dementia.³

NEDA suggests that cross cultural understanding is critical to meet the needs of people from NESB with disability.

Recommendation:

To develop strategies, targets and outcomes for service providers to meet the needs of people from NESB, including bi-lingual staff.

To include cross cultural competence as a standard for all service providers and to fund cultural specific services in areas of high need.

6. Previous research

Consultations with people from NESB with disability conducted in 2004 highlighted the following;⁴

a) People from NESB with disability are almost exclusively dependent on their family members for support

Very few people with disability said they receive support from disability services. The support received includes home care for domestic tasks such as cleaning, and occasional respite care.

b) People from NESB with disability have no future plans

Most people expressed concern about the future, eg, who will pay the bills, manage their money and provide other support when parents or other family members cannot do it, but most people with disability had no plans for how to deal with this.

³ McMurtray A, Saito E, Nakamoto B. *Language preference and development of dementia among bilingual individuals*, Hawaii Med J. 2009 Oct; 68(9):223-6, University of Hawai'i, USA

⁴ <http://www.mdaa.org.au/service/systemic/topics/ageing.html>

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c) Family members/ carers of people from NESB with disability worry about the future for their family member with disability.

When asked about their hopes and dreams for the future, all family members/ carers expressed fears and concerns rather than positive hopes and dreams. The only real hopes expressed were that the family member with disability would learn to be independent. As the family members/ carers get older their focus is clearly on trying to make provision for the future support for their family member with disability. Some are focused on remaining strong for as long as possible because they do not see

NEDA notes that these consultations demonstrate the failure of the current service system to cater for the needs of people from NESB with disability.

Unpublished work by an Industry Group in NSW identified the need for State and Federal Governments to work collaboratively with the aged care, community care and disability services, consumers and carers to improve services and outcomes for people with disabilities who are ageing.

Among a range of suggestions the group noted the need to fund a project to identify and develop suitable service responses to the needs of people with disability who are ageing from NESB and their carers.

That such a project would need to be initiated and undertaken in conjunction with NESB communities to identify and develop suitable service responses to the needs of people from NESB with disability who are ageing.

Recommendation:

To fund a collaborate project with the NESB community to identify suitable service responses to the needs of people with disability who are ageing from NESB and their carers.

7. Summary of Recommendations

I. Recommendation:

To include people with disability as a special needs group in the Aged care Act 1997, Section 11.3.

II. Recommendation:

To define people from non-English speaking background including those born in a non-English speaking country and those with ancestry from a non-English speaking country.

III. Recommendation:

To alter the SDAC to include an ancestry question similar to the Census.
To alter the sampling methodology of the SDAC to make it more reflective of the overall NESB population in Australia.

IV. Recommendation:

To fund and conduct research on the incidence of higher rates of impairment for people from NESB with disability.

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V. Recommendation:

To develop strategies, targets and outcomes for service providers to meet the needs of people from NESB, including bi-lingual staff.

To include cross cultural competence as a standard for all service providers and to fund cultural specific services in areas of high need.

VI. Recommendation:

To fund a collaborate project with the NESB community to identify suitable service responses to the needs of people with disability who are ageing from NESB and their carers.