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Committee Secretary
Senate Community Affairs References Committee
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Parliament House
Canberra ACT 2600

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Dear Committee Secretary,

The National Ethnic Disability Alliance (NEDA) firstly takes the opportunity to thank the Senate Community Affairs References Committee for providing the opportunity to contribute to the Hearing Health Inquiry.

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

Background to Inquiry

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 - a quarter of the total population of Australians with disability.

Yet the low uptake of government funded services by people from culturally diverse and NESB with disability and their family is widely reported. The 2009 Australian Government Productivity Commission *Report on Government Services revealed that people from NESB with disability* are approximately 4 times less likely to access a government funded disability support service than their peers born in an English speaking country. More examples are available in NEDA Facts Sheet 2 (Appendix 1).

This lack of participation is due largely to four key barriers – lack of information in alternative formats and languages, lack of cultural sensitivity by the majority of staff in the health service, poverty and cultural limitation.

lack of information in alternative formats and languages

Many important health messages are not accessible to people with disability from NESB and/or their carers. The messages are traditionally in English and are not produced in community languages or in alternative formats such as sign language. Furthermore, the TTY and National Relay Services are only available in English.

Where information is available in other languages, it is often only available in writing and presented in formal language that is difficult to comprehend. Many people from NESB who are deaf or have hearing impairment, and/or their carers (usually women), have little or no literacy skills and thus remain excluded and uninformed.

Some health practitioners, such as doctors, also refrain from using English language and sign language interpreters despite the fact that the interpreting service is available to them free of charge. Yet deaf migrants and refugees may not necesarily benefit from an English language or sign language interpreter if he/she lacks literacy skills and does not know Auslan.

In a report prepared by Dr Louisa Willoughby for the Victoria Deaf Society, a fairly recent method of communication with migrants and refugees – the Deaf Relay Interpreter service – was outlined.

The deaf relay interpreters are themselves deaf and convey their messages through mimes, gestures and exaggerated facial expressions. This service is being used in conjunction with sign language interpreters; so in a communication chain, the health professional will speak, the sign language interpreter will sign the message, the deaf relay interpreter will act it to the deaf migrant and visa versa. While the report presented the deaf relay interpreter system favourably, it also admits that more research needs to be done to gage its success. NEDA strongly supports further research into this method of communication as it may be highly useful when communicateing with migrants and refugees who do not have literacy skills, particularly in confidential and sensitive matters where a person may not wish to have a family member or friend present.

Other new technologies, such as the video relay system, must also be explored. In the UK, a video relay centre has been established since 2005 where sign language interpreters are connected to clients through video telephony via the internet (see http://news.soft32.com/the-first-ip-video-call-centre-for-deaf-people-in-uk_77.html
This allows people who are deaf or hard of hearing better access to sign language interpreters as travel time is reduced for the interpreters. While video calling is available in Australia, it is not widely used, particularly in the health service.

Any technology that improves communication and access to information for people who are deaf or hard of hearing will also benefit those from NESB backgrounds and their families.

Lack of Cultural Sensitivity by Health Professionals

Consultations with people from NESB with disability by NEDA and our member organizations repeatedly reveal a lack of cultural sensitivity of health professionals.

Muslim women with disability and female carers wearing Islamic attire report of being treated with disdain. Families discourage their family member who has a disability from social gatherings or consultations where food is provided, in fear that their loved-one would be fed food that is outlawed in their culture/religion. Patients in hospitals have not been permitted to pray and been examined by professionals of the opposite gender. Moreover, many negative assumptions are made by a patient's appearance and/or lack of English proficiency. These examples indicate that many health professionals have not received, or did not heed, cultural awareness courses.

Moreover, Dr Willoughby's report claims that NESB parents of deaf children have been advised by health professionals not to teach their child their mother tongue. This has resulted in the cultural and linguistic isolation of deaf children from their family and ethnic community. The report heavily emphasizes that NESB children who are deaf be taught their mother tongue as well as English.

NEDA strongly recommends that health professionals receive continual accredited, quality training in cultural difference and diversity and disability awareness.

The NSW Refugee Health Service provides training to GP's as part of its efforts to promote the wellbeing of refugees (see http://www.sswahs.nsw.gov.au/sswahs/refugee/). While the training is not provided by a person from a medical background, the project is reported to be successful. Yet anecdotal evidence indicates that some health professionals would value the training more if it were presented by someone in the medical field. If the Senate Community Affairs References Committee considers this option, NEDA advises that the training be undertaken by people from a medical background.

Poverty

Migrants with disability face systemic discrimination as they must live in Australia for 10 years in order to be eligible for the Disability Support Pension: a 10 year eligibility period is imposed on some migrants where they are unable to receive any allowances from CentreLink or any benefits associated with the DSP, including health services.

Those requiring medical attention or equipment (such as hearing aids) must rely on the family to provide the finances. This can often strain the family dynamic.

The family is further steeped into poverty if the person with disability requires a high level of care as the carer, often female, must forego employment in order to provide the care. Caring for a deaf migrant/refugee can also include attending medical appointments to help communicate messages to the deaf person, to compliment the English language interpreter.

Legal advice released by NEDA in July 2008 suggests that the ten year qualifying period for the Disability Support Pension is at odds with the obligations of the recently ratified United Nations Convention on the Rights of Persons with Disabilities. In NEDA's view, the ten year qualifying period for the DSP is both unfair and discriminatory.

Because many health and community services require eligibility to the DSP, NEDA remains concerned that migrants affected by the 10 year eligibility period are also missing out on crucial support services including free hearing tests administered by Hearing Australia. NEDA urges that the Australian Government provide health care to migrants with disability regardless of the 10-year waiting period if it is serious about improving hearing health of deaf immigrants.

Cultural limitations

The shame and guilt that is associated with a disability is not unique to people from non-English speaking backgrounds, however, their concept of disability can vary markedly. In Western cultures, disability is explained and treated medically. In some non-Western cultures, religion is often used to make sense of disability, and in some cases impairment might be seen as a punishment from God, a test, etc. The shame and stigma produced by such beliefs can isolate a person from their ethnic community, and often also his/her family. Only when religious solutions are exploited without the anticipated full recovery do most people from NESB begin to accept the person with the disability. By then however, the person with disability may have been deprived from education, health and other important services.

Medical advancements, such as cocklear implants can be seen by NESB families to be an 'instant fix'. Dr Willoughby argues in her report that more NESB families choose to have cocklear implants in relation to those from English speaking backgrounds.

One way to get around cultural isolation is to fund ethno-specific social forums where people from NESB with disability and their family can gather to learn, share ideas and receive peer support. It would be more beneficial for people from some cultures and religions if these gatherings were also gender-specific as some women may not be able to attend events where males are also present.

The funding for such events must include finances for English language interpreters, sign language interpreters and transport. Currently, most grant programs do not include these components, and this is a major factor in the lack of participation in the community by people from NESB with disability and their families.

Ethhno-specific, gender-specific and, where possible, disability-specific gatherings can reduce the embarrassment many NESB people who are def or hard of hearing and their family members report to experience when they are among people who speak only English. Only when they gain confidence through engaging with people whith whom they can identify, can we expect them to become involved in the wider Australian communities.

Further research

There is very little research on the health of people from NESB who are deaf or hard of hearing. While Dr Willoughby's report was comprehensive, it only focused on people in Victoria and there was no specific section on health.

Dr Willoughby's report, along with brochures published by the Deafness forum, lament the absence of research of the mental health of people who are deaf and hard of hearing, particularly those who have other disabilities including mental illness.

Article 25 of the United Nations Convention on the Rights of Persons with Disability (UNCRPD) asserts that all people with disability have the right to good health. For a long time people with disability in Australia, particularly those with multiple disabilities and perhaps from NESB, have been devalued in the Australian system. With Australia's ratification of the UNCRPD in July 2008, it is now time to investigate into the health of Australian citizens who are deaf and hard of hearing, as well as those with other disabilities. NEDA cautions that in the studies, those with a disability who are further disadvantaged through factors including culture, race, unidentified disabilities, gender, sexual preference etc, are not excluded.

Conclusion

While bringing to light the disadvantages of people from NESB with disability (particularly those who are deaf or hard of hearing), NEDA will conclude our comments with a summary of our suggestions to improve the health of people from NESB who are deaf and hard of hearing.

We urge the Committee to:

- investigate into technologies that will improve communications and access to information for people from NESB who are deaf or hard of hearing, including the deaf relay interpreter system outlined in Dr Willoughby's report to the Victoria Deaf Society.

- Provide continual accredited, quality training in cultural difference and diversity and disability awareness to all health professionals and service providers.

- Permit new and temporary migrants with disability access to the Australian health system.

- Provide forums for people from NESB with disability and their family to socialize and learn about the disability services in Australia, and include the components of language and transport in the funding that would facilitate the attendance of these families and individuals. Where possible, these forums should be ethno-specific, gender-specific and disability-specific.

For further information about any of the issues covered in this submission, please contact Zeliha Iscel, Senior Policy Officer at zel@neda.org.au.

NEDA hopes to work with the committee in the near future to improve the hearing health of people from NESB.

Yours faithfully

Dinesh Wadiwel
Executive officer

References:

Dr Louisa Willoughby and the Victoria Deaf Society 'Catering to a Diverse Community: a Report on the Situation and Needs of Deaf People from Migrant Backgrounds Living in Victoria: http://www.aussiedeafkids.org.au/deaf-and-migrant.html

'The First IP Video Call Centre for Deaf People in UK':
http://news.soft32.com/the-first-ip-video-call-centre-for-deaf-people-in-uk_77.html

NSW Refugee Health Service: http://www.sswahs.nsw.gov.au

NEDA 'Refugees and Migrants with Disability and the United Nations Convention on the Rights of Persons with Disabilities': www.neda.org.au