



NATIONAL ETHNIC DISABILITY ALLIANCE

**NEDA submission to the Senate Community  
Affairs Committee**

**Inquiry into the funding and operation of the  
Commonwealth State/Territory Disability  
Agreement**

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## 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, Community Services and Indigenous Affairs (FACSI) 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.

The NEDA network consists of the following state and territory peaks:

- ACT Multicultural Council (ACTMC)
- Amparo Advocacy Queensland
- Diversity and Disability VIC
- Ethnic Disability Advocacy Centre of WA (EDAC)
- Multicultural Disability Advocacy Association of NSW (MDAA)
- Multicultural Community Services of Central Australia
- Multicultural Council of Tasmania (MCOT)

## Defining NESB and Disability

NEDA uses the term *Non-English Speaking Background* in preference to *Culturally and Linguistically Diverse Background* as those from an English speaking background are encompassed by the latter term and they are not part of NEDA's constituency. NEDA contends that coming from a linguistic and cultural background other than Anglo-Australian can be a great social barrier and a source of discrimination in Australia. The intention of using NESB is not to define people by what they are not but to highlight the inequity people experience due to linguistic and cultural differences. NEDA 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.

NEDA maintains that disability is a social construct and arises when a society's infrastructure is not developed to ensure all individuals, regardless of capacity or impairment, can fully participate in society. Thus NEDA refers to *people with*

*disability* rather than *people with disabilities* to underline that disability is not a characteristic of an individual but a consequence of a society designed (whether consciously or inadvertently) to exclude many of its citizens from equal participation.

## **The intent and effect of the CSTDAs**

### *The Intent*

The CSTDAs have provided a contractual framework between the Commonwealth and State/Territory governments which distinguishes respective responsibilities in the funding and provision of services for people with disability.

The third and current CSTDA includes a preamble aimed to articulate a shared vision, some core beliefs that underpin the Agreement and five strategic policy priorities. It seems that the Agreement intends to promote “... *the rights, equality of opportunity, citizenship and dignity of people with disabilities...*”, “... *to remove all forms of discrimination*“ and “... *to build inclusive communities where people with disabilities, their families and carers are valued and are equal participants in all aspects of life*”. The Agreement also intends to recognise individual needs and acknowledges vulnerable groups such as people from culturally and linguistically diverse backgrounds.

The preamble places the CSTDA in a rights framework. It paints a moving picture where people with disability are valued citizens enjoying a good life and the Commonwealth, state and territory governments work hand in hand in the pursuit of a just and inclusive society. However, a further examination of what the CSTDA actually funds present a mismatch of objectives and delivery. The CSTDA only funds a limited range of programs based on a welfare/medical model of disability and many of the services continue to be delivered in segregated settings.

### *The Reality*

It's almost at the end of the third CSTDA the reality for people with disability, including those from NESB, is still far from being valued citizens living in a just and inclusive society. We encounter disadvantage, discrimination, racism and abuse on a daily basis. Many of us continue to be excluded from education, employment, generic services, healthcare, transport and social and cultural events. There is no whole of government and/or whole of life approach to meeting the needs of people with disability. Instead what we've seen is constant buck passing between departments or between the Commonwealth and state/territory governments.

The effect of CSTDA on the majority of people from NESB with disability is simple: there is none. Three out of four people from NESB with disability miss out on accessing disability services due to our cultural and linguistic backgrounds. The CSTDAs have been funding services accessible to Anglo-

Australians with disability and people from NESB are mostly excluded from those services due to cultural and linguistic barriers created by racism, lack of resources and lack of cultural competence.

According to the 2001 Census 24.5% of the total population are people from NESB. This includes people who were born in a non-English speaking country or who have at least one parent who was born in a non-English speaking country. The 2001 Census also indicated that 15.2% of Australians speak a language other than English at home.

NEDA estimated that 24.5% of the disability population are people from NESB with disability. Correlating the percentages of people from NESB and people with disability, the total population of people from NESB with disability is 5% of Australians.

The demographic picture in disability services is quite a contrast. The *Disability Support Services 2002 – National data on services provided under the Commonwealth/State Disability Agreement* published by Australian Institute of Health and Welfare (AIHW) shows that only 3.6% of service users are from non-English speaking countries and 1.3% received interpreters for spoken language other than English.

The recently released publication *Disability Support Services 2004-05* shows a very similar trend for the poor take up rate. Only 4.8% of service users are from non-English speaking countries and 1.5% requested for interpreting service.

People from NESB with disability experience grossly entrenched disability and racial discrimination within the disability and mainstream communities, as well as disability discrimination within their own cultural groups. Some of the major issues are noted below.

- Lack of information in community languages informing people of their rights, entitlements, essential services and support structures available. Access to information is often the first step towards people making meaningful choices and participating in the community. Access to information means, in effect, access to opportunities and therefore choice.
- Lack of culturally competent service provision in mainstream and specialist services.
- Lack of access to interpreters as the costs for language services to meet the needs are mostly unbudgeted.
- The prevalence of myth, misconceptions and negative stereotypes about disability and ethnicity.
- Lack of equity in income support. Migrants without disability have to wait two years before they can access income support, yet migrants with disability, including their carers, have to wait ten years before they are eligible for Disability Support Pension or Carers Pension.

- Lack of effective legislative and policy direction and government intervention.

The impacts on people from NESB with disability, our families and carers include:

- extreme isolation and marginalisation;
- financial vulnerability and fewer opportunities to reach our full potential through education and employment;
- inability to participate fully in social, economical, political and cultural life; and
- dependence on families and carers. This can often lead to carer burnout and relationship breakdown due to lack of appropriate support.

### *Data collection and performance indicators*

The following table shows typical performance indicators specified in each of six categories of services - accommodation support, community support, community access, respite, open employment and supported employment:

<p>Must include number of consumers versus number of services.</p> <ul style="list-style-type: none"> <li>• Average cost per unit of service.</li> <li>• Average cost per service user.</li> <li>• Proportion of total service users by: <ul style="list-style-type: none"> <li>▪ -primary disability type;</li> <li>▪ - location;</li> <li>▪ -culturally and linguistically diverse;</li> <li>▪ -Aboriginal and Torres Strait Islander; and</li> <li>▪ -age.</li> </ul> </li> <li>• Total service user numbers / time by: <ul style="list-style-type: none"> <li>▪ -proportion per 1000 of total jurisdiction population/location; and</li> <li>▪ -proportion of total jurisdictional target group population/location.</li> </ul> </li> </ul>
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The proportion of service users from culturally and linguistically diverse backgrounds is listed as one of the performance indicators. However, the National Minimum Data Set (MDS) collects very little data in relation to this target group. Only two questions in the MDS relates to cultural backgrounds, one on country of birth and the other on the use of interpreters, both provide insufficient understanding of the exact numbers of people from NESB. Furthermore, the collection of MDS is inconsistent and incomplete.

Setting aside the issue of highly problematic data collection there has been no monitoring in relation to the lack of equity and poor outcomes for people from NESB with disability. In the Audit Report released last year the Australian National Audit Office (ANAO) has criticized the failure of the CSTDA to contain measures of outcomes, effectiveness, quality and unmet need. Although the preamble states the importance of meeting individual needs and recognises the high vulnerability of people from culturally and linguistically diverse backgrounds evidence of extremely low service access rates and poor outcomes continue to

be ignored by governments. No action has been taken to address the access barriers experienced by people from NESB with disability, our families and carers.

The first recommendation of the Audit Report seeks:

*“To improve monitoring of the performance of specialist disability services provided under the CSTDA, which the States and Territories are either wholly or partly responsible for administering, the ANAO recommends that the Department of Family and Community Services work with the other National Disability Administrators, and consult the Australian Institute of Health and Welfare and other agencies where appropriate, to:*

*(a) continue improving measures of equity and efficiency, and include them in any future CSTDA, or related multilateral agreements;*

NEDA supports the recommendation and would like to stress the importance of ensuring equitable distribution of resources and a basic benchmark is that the representation of people from NESB with disability in disability services is comparable to the general population.

### *Research and development*

One of the components of the CSTDAs is joint contribution to research and development for service improvements and innovations. No research has been conducted that specifically addresses the needs of people from NESB with disability, for example, research into culturally competent service models.

People with disability should be a key stakeholder in the development of the research agenda and priority should be given to disadvantaged groups that are currently receiving poor service outcomes.

### *Advocacy enhancement*

As documented above the expressed intent of the CSTDA is to remove discrimination and promote full participation. These objectives can't be achieved without changing the system and one of the effective ways to create systemic changes is advocacy. Ironically, the expenditure on advocacy is less than 3% of the total CSTDA funds and the lack of focus on advocacy inhibits the fulfilment of those objectives.

In the negotiation of the next CSTDA funds for advocacy should be dramatically enhanced in order to realise the rights of people with disability.

## **Current Commonwealth/State/Territory joint funding arrangements, and levels of unmet needs**

NEDA believes that Commonwealth and state/territory joint responsibilities in funding and providing disability services should be maintained for better accountability and Commonwealth/state coordination.

As stated above, majority of people from NESB with disability do not have access to disability services and this is in addition to the levels of unmet needs estimated by the AIHW in its 2002 publication: *Unmet Need for Disability Services*.

It should also be noted that work with what we know is a good starting point when addressing unmet need. There is no need to know exactly how many people require accommodation support. For example: we have known for a long time that there are thousands still living in institutions and six thousand young people with disability in aged care facilities. Immediate action should be taken to remedy those who are already in the system but inappropriately placed.

It should be noted that there is a lack of clarity and delineation of responsibilities in relation to mental health and psychiatric services. Currently funding arrangements are split between departments which results in varied quality of outcomes between states and territories. For example, people from NESB with psychiatric disability living in NSW often fall through the gaps between NSW Health and the Department of Ageing Disability and Home Care (DADHC) with no-one taking overarching responsibility. This is also the case for people with dual diagnosis who require disability support as well as mental health services. Psychiatric services in NSW are highly medicalised where funds are mostly absorbed into the health system. This creates a high level of unmet need for community based mental health services and psychiatric rehabilitation services.

### **The ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency;**

There is currently no coordinated whole of life approach to disability. Disability services are simply just about disability and we fall through the gaps when we try to access generic services. People with disability experience significant barriers when accessing health services, particularly preventative and primary healthcare.

Research show that people with disability are living longer with their disability and therefore better coordination and flexibility is require for a smooth transition to aged care services.

### **Conclusion and Recommendations**

The CSTDAs have failed people from NESB with disability. Most of them can't get a service and for those who are 'lucky' enough to be picked up by the service system they receive a substandard service compare to their Anglo counterparts.

In order for a culturally competent service system to be developed NEDA recommends the following:

- A National Disability Plan should be developed and driven by COAG in consultation with people with disability including people from NESB.
- Funding of services under the CSTDA should link to the vision and objectives set by the preamble with clear benchmarks for measuring performances.
- The next CSTDA should make explicit recognition of the barriers, disadvantages and multiple discrimination experience by people from NESB with disability and that specific, targeted measures should be developed and monitored.
- To ensure an equitable distribution of resources benchmarks such as the services take up rate for people from NESB with disability should be built into the CSTDA.
- Funding of individual and systemic advocacy services should be significantly enhanced to promote full participation and to realise the rights of people with disability.
- Data collection in relation to people from NESB with disability should be improved.
- Research into the needs of people from NESB with disability should be undertaken to develop culturally competent service systems including exploring overseas examples of best practice.
- Action should be undertaken to improve delineation of responsibilities and linkages between service systems administered by different departments, particularly in relation to services for people from NESB with mental illness/psychiatric disability and dual diagnosis.