

**Response to Discussion Paper:**

**Review of the National Disability Advocacy Framework**

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EDAC appreciates the opportunity to provide feedback and recommendations to the Department of Social Service’s review of the National Disability Advocacy Framework (NDAF) 2015. EDAC endorses the main thrust of the current Framework. What follows is the vision EDAC has for advocacy within the NDIS environment.

**About EDAC:**

The Ethnic Disability Advocacy Centre Inc was established in 1995 to protect and promote the rights and interests of people from culturally and linguistically diverse (CaLD) backgrounds) with disability, their families and carers through the provision of individual and systemic advocacy. The Ethnic Disability Advocacy Centre (EDAC) is funded by the Australian Department of Social Services (DSS) and the Western Australian Disability Services Commission (DSC).

Most of EDAC’s clients seek individual and systemic advocacy and present with multiple complex cases. EDAC’s clients report that they are usually marginalised and denied supports and services sometimes by the mainstream service providers due to:

* their lack of English language proficiency;
* their lack of knowledge of what supports and services are available for them as those supports and services may or may not have been available in their country of origin;
* cultural and religious barriers that their own families and ethnic communities may put on them or they put on themselves as disability is perceived negatively in some cultures; or
* gender issues.

EDAC’s individual advocates work one on one with people from CaLD backgrounds with disability, their families and carers to address their issues and facilitate their access to necessary supports and services, that meet their individual needs.

EDAC’s systemic advocacy work is informed by the individual advocacy cases to influence positive changes to the legislation, policy and practises to improve the lives of people from CaLD backgrounds with disability, their families and carers.

EDAC also delivers a range of other services linked to our advocacy work. Cultural competency training is provided to disability and mental health support services to ensure their services are culturally responsive to the needs of CaLD clients. This training is linked to National Standards for Disability Services (NSDS) and National Mental Health Standards. “Living a Good Life” information forums are delivered to recently arrived migrants and refugees; discussion at these forums focuses on human/disability rights, equal access to relevant supports and services, meanings of disability, advocacy, accessibility of services, etc. Professional language interpreters are used at all sessions. EDAC’s EthnicAbility Radio program goes on air every Monday evening from 7:30 – 8:00 pm where disability and ethnicity issues are discussed in terms of new and existing services, changes to government policies, legislation, etc.

**EDAC’s vision of advocacy in the NDIS environment:**

EDAC strongly believes that advocacy services should not be provided by the NDIS, as was recommended by the Productivity Commission 2011, and should be funded by the Department of Social Services to avoid any potential conflict of interest. Independent individual advocacy has been identified as an integral part of the NDIS environment. It is commendable that recurrent funding has been provided to national peak bodies to address systemic issues. However, it is vital that systemic advocacy for people in minority groups, e.g. CaLD people with disability must be maintained to influence positive change in legislation, policy and service practise in each state and territory and work towards promoting inclusive communities and awareness of disability issues.

Individual issues can take on a larger perspective. One person’s problem with a system can be representative of a systemic barrier. Individual advocacy on its own cannot bring about systems change. It is therefore crucial that agencies that provide individual advocacy to minority groups are financially resourced to work towards systemic changes to attitudes, policies and legislation that impacts negatively on the lives of individuals with disability. Systemic advocacy seeks incremental changes or reform necessary for long term positive impact on ensure inclusiveness across all systems.

As mentioned above, EDAC’s individual and systemic advocacy work involves advocating to federal, state and local governments, not-for-profit organisations and private businesses to improve their services and policies to be more inclusive of people from CaLD backgrounds with disability, their families and carers. Some examples of EDAC’s systemic advocacy include, but is not limited to:

* Advocating to mainstream agencies to work with interpreters if English is their service users’ second or third language;
* Advocating to DES providers to work more efficiently and productively when assisting people from non-English speaking backgrounds (NESB) with disability with their job readiness, job search and to keep their jobs;
* To advocate to Department of Housing for the provision of accessible and affordable accommodations;
* To Adult Migrant English Program (AMEP) providers to provide more appropriate support to the newcomers with disability while they study their 510 hours of AMEP;
* Formal responses/submissions to government inquiries, review of policies and legislation. This document is an example of this work EDAC undertakes

Families of people with disability from CaLD backgrounds are usually isolated from their own ethnic communities. Informing ethnic community members of disability/human rights and equal participation in all aspects of community life for people with disability encourages them to be more inclusive of people with disability, their families and carers in their own communities. It also encourages community members to be more proactive in assisting people with disability to access the appropriate supports and services they would need.

The current principles of the NDAF are not adequate enough to support people with disability from minority groups such as CaLD and Aboriginal and Torres Strait Islander people in the National Disability Insurance Scheme (NDIS) environment. The National Disability Insurance Agency (NDIA) quarterly report to COAG Disability Reform Council on 31 March 2015 stated that only four per cent of NDIS participants in the trial sites were from CaLD backgrounds. In 2014, the NDIA senior management consulted with representatives of people from CaLD backgrounds with disability to strategise ways of engaging CaLD people with disability. However those strategies were not put into practice. Australian Bureau of Statistics Survey of Disability, Aging and Carers 2012 indicated that more than 4.2 million Australians live with disability. National Ethnic Disability Alliance (NEDA) reported in their Consumer Engagement and Disability Employment Services project 2014 that more than one million or close to 25 per cent of those people with disability are from CaLD backgrounds. For more information please see NEDA’s website at: [www.neda.org.au](http://www.neda.org.au)

EDAC would recommend that advocacy providers in each state and territory should be appropriately resourced to provide self-advocacy training as well as individual and systemic advocacy to people with disability from CaLD and information on the importance and value in participating in the NDIS to get continuous supports and services to meet each individual’s specific needs. Such resources should be tailored to meet the individual needs of people with disability including a focus on geographic and demographic factor.

A case study to demonstrate how individual advocacy cases can become systemic advocacy issues to improve the services for people from NESB with disability:

A young man arrived in Australia with a suspected closed brain injury with his family as a humanitarian entrant. As he had never had a formal assessment he was not eligible for any disability supports and services. As a toddler, he and his family were attacked by extremist religious terrorists in their country of origin. As a consequence he was badly wounded and acquired a disability which was not formally diagnosed prior to arriving to Australia.

He had limited English language skills. He had been attending Adult Migrant English classes; however as he was not provided with a teaching assistant (due to no formal diagnosis been made) he stopped attending classes. As recent arrivals to Australia the family had no knowledge of available supports and services.

At the time of referral the client had also been in contact with the justice system. At the first court appearance his legal representative submitted supportive documentation provided by EDAC to the magistrate highlighting the need for a neuro-psychological assessment. This was agreed to by the magistrate and the court hearing was adjourned. Even though the assessment process had been difficult due to client's lack of any formal education and not understanding key concepts, a formal dual intellectual/psycho-social disability diagnosis was made. As an outcome of the diagnosis the formal police charges against the young man were dropped and the court case dismissed.

EDAC's advocate worked closely with the young man, his family and the allied health care provider. In all instances an accredited interpreter was engaged. As the client was living in the NDIS Perth Hills trial, once the formal disability diagnosis was obtained, EDAC's advocate assisted him to apply for the NDIS supports and services. This assistance was required as the client could not read or write English nor could he use a computer. The process set up for registration for NDIS is inflexible. An assumption is made that the person applying has the basic skills (including English language), knowledge and supports to be able to complete the process.

Access issues linked to the NDIS Trial site and disability support services is not unique to this client; other CaLD clients have encountered similar issues. Therefore advocacy totally independent of service provision is necessary to ensure systems change at both local and national level. An individual advocate works alongside the person with disability independent of the service provider.

This case demonstrates how individual advocacy cases can inform systemic advocacy work and that systemic advocacy is absolutely necessary to influence changes to the services, policies and practices to improve the lives of people from NESB with disability and that systemic advocacy must be well resourced in all states and territories.

Australia’s Disability Discrimination Act (1992) currently does not apply to the Migration Act (1958); the Social Security Act (1991) and many other commonwealth parliamentary acts. This may discriminate against people from CaLD backgrounds with disability. If the DDA is not strengthened to apply to the Migration Act and the Social Security Act, applying the principles of the United Nation’s Convention on the Rights of People with Disability (UNCRPD) would be more difficult to apply to the NDAF.

EDAC recommends that the NDAF principles to include the Substantive Equality Framework to reduce/eliminate systemic discrimination in legislation, policies, programs and services. Substantive equality recognises that:

* Rights, opportunities, entitlements and access are not always distributed equally throughout the community;
* Equal application of rules to unequal groups may produce unequal outcomes;
* If the services are tailored for the dominant, majority group then the people in disadvantaged minority groups who are not part of the majority group may miss out on the essential services;
* Systemic discrimination occurs when practises, policies, programs, services and legislation discriminate unfairly on the impact or outcome irrespective of the intention.
* Substantive equality requires intentionally achieving equitable outcomes and equal opportunity by promoting sensitivity to the different and unique needs of people from CaLD, Aboriginal and other disadvantaged backgrounds with disability and by eliminating systemic discrimination in legislation, policy, programs, services and practice;
* Practise and services must be tailored to the individual needs; should be culturally responsive, free from discrimination and developed in partnership with CaLD, Aboriginal and other disadvantaged people with disability, their families and carers; and
* Services are provided by staff who understand, value and respect cultural diversity.

For the outcomes and the outputs of the NDAF to be relevant and inclusive of people from CaLD background and those of Aboriginal and Torres Strait Islanders, EDAC recommends that:

* Advocacy services should be tailored to individual needs;
* Recognise that advocacy for people with complex needs would be multi-dimensional and complex;
* Work together with people with disability, their families and carers in minority groups to develop more appropriate strategies to engage them in the NDIS and in the wider community in employment, health, education, housing, etc.
* People from CaLD background with disability require information advocacy on what supports and services are available for them and how to access those services.
* Funding is provided for advocacy services that are totally independent of service provision to ensure no conflict of interest.
* Individual advocacy work requires a level of systemic advocacy so any advocacy services purchased by government should reflect this

The current NDAF does not support people with disability who are not Australian citizens or permanent residents of Australia. This is contrary to the UNCRPD as it a discriminatory policy. NDAF must recognise the advocacy needs of those people with disability to be afforded basic supports and protection for them to reduce / eliminate any form of discrimination against them.

It is important to acknowledge that issues impacting on the lives of people with disability are broader that access to disability support services. Service issues that EDAC staff advocate on include housing, finances, education and training, employment, transport, legal, etc. Therefore it is crucial that future funding for advocacy services not be tied solely to the NDIS.

EDAC looks forward to the outcome of the review and trusts that the new framework will ensure inclusivity of the needs and aspirations of people with disability from minority groups.