

NEDA's response to the National Disability Insurance Scheme Bill 2012 (Draft) and the Inclusion of NESB/ CALD Communities, A Submission to Senate Standing Committees on Community Affairs:



**NATIONAL ETHNIC
DISABILITY ALLIANCE**



Foreword

With the first stage of the National Disability Insurance Scheme (NDIS) to be launched in July 2013, people with disabilities in Australia would expect to see their rights and well-being issues being addressed. People with disabilities generally regard this scheme as a way to exercise power over their own lives and choose the type of support services they require from a range of providers or individuals. NEDA welcomes and applauds the release of the draft legislation of the NDIS that was introduced in November 2012.

The National Ethnic Disability Alliance (NEDA) is the national peak organisation representing the rights and interests of people from non-English speaking background (NESB) and/or culturally and linguistically diverse background (CALD) with disability, their families and carers throughout Australia. NEDA actively promotes the equal participation of people from NESB/ CALD backgrounds with disability in all aspects of Australian society. It manages a range of projects relating to NESB/ CALD communities 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/CALD communities with disability.

NEDA is pleased that the NDIS is all for Australians and what seems to be a universal scheme. NEDA continues to play an important role in ensuring that the scheme is inclusive of people from NESB/CALD backgrounds with a disability.

While the Bill recognises the right of individuals with disability to exercise choice and control over the planning of their supports and funding arrangements, NEDA believes that there is a lack of recognition towards the complex cultural, linguistic and gender needs of individuals from NESB/CALD backgrounds with a disability.

Therefore, NEDA has produced its response to the *National Disability Insurance Scheme Bill 2012* and emphasises the importance of addressing the cultural, linguistic, religious and gender needs of participants from NESB/CALD backgrounds. NEDA also encourages the *Act* to be more inclusive of migrants with disability who may be disadvantaged because they do not meet the eligibility requirements due to the residency conditions.

NEDA's recommendations outlined in this submission report are as follows:

- ensure that a universal system that addresses the needs of participants from NESB/CALD backgrounds is in place;
- reconsider the residence requirements and grant access to disability services to temporary tax paying migrants (on skilled visas) as they should receive similar entitlements as tax paying permanent residents, and;
- improve accuracy and assessments that determine the diagnosis of intellectual, cognitive, neurological, sensory or physical impairments; and to consider cultural and linguistic influences on the diagnosis.

Chapter 1 - Introduction

Section 3: Objects of the Act

Recommendation

Refer to 3(1) (h) As the Commonwealth Government signed and ratified the UNCRPD in 2008, it is necessary for the Government to put policies and laws in place to make this happen. As it is mentioned that there are “certain obligations,” it is suggested that NDIS will not be able to respond to every part of the UN CRPD article. NEDA suggests that the NDIS Bill give effect to **full** obligations to the UN CRPD and aim to satisfy the principles of the UN CRPD. As such, NEDA proposes that the NDIS be situated within a human rights frameworks, conventions and anti-discrimination laws in order to address other human rights obligations that would be relevant to NDIS and promote the rights of participants from NESB/CALD communities.

Recommendation

Refer to 3(1)(g) *“raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability”*

NEDA recommends for the Bill to acknowledge the additional barriers that people from NESB/CALD communities with disability may face. *NEDA further supports a comment from its member organisation, AMPARO Advocacy to include the following point to this section:*

- (i) *Ensure equitable access to the NDIS by people with disability who may experience additional barriers, including Aboriginal and Torres Strait Islanders and people from culturally and linguistically diverse backgrounds.*

Section 4: General principles guiding actions under this Act

Recommendation

Refer to 4(9) and ensure that the legislation acknowledges and mentions **both** cultural and linguistic needs in order to cater to participants from non-English Speaking Backgrounds (NESB)/ culturally and linguistically diverse communities (CALD).

Refer to 4 (4) *“People with disability **should** be supported to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.”*

Clearly, the draft NDIS law works on the basis that there may be instances where taking over control and choice for the person is appropriate, rather than providing the person with assistance. NEDA proposes that participants be given full exercise of choice and control on the pursuit of their goals and the planning and delivery of their supports. This is particularly important for participants from NESB/CALD backgrounds in order to promote self-determination.

NEDA further recommends that the general principles stated in this section are consistent with the UN CRPD, human rights framework and anti-discrimination law. This is important to ensure that people with disability have the same entitlements as other members in Australian society. As such, this section needs to be reassessed to include a section on advocacy that guarantees participants in the scheme to access independent advocacy when necessary. The inclusion of advocacy will be further discussed in *Part 4 – Definitions*.

Section 5: General principles guiding actions of people who may do acts or things on behalf of others

Recommendation

Refer to 5(d). The Act should take into account ‘cultural, linguistic and **gender** circumstances of people with disability.’ NEDA suggests that it is important to address cultural biases based on gender and disability. There can be a lack of attention to the specific problems of women with disabilities from NESB/CALD communities who may be restrained by cultural and gender roles and face double discrimination due to their disability. Underlying the double discrimination is negative attitudes about women combined with negative attitudes toward disability that often cut across cultures in NESB/CALD communities.

Likewise, refer to 5 (a), in consideration of gender and cultural roles, and the limits that are placed by the law in which “a person with disability can be involved in decision making processes ‘*where possible*’ it is crucial to understand that gender may affect women from NESB/CALD backgrounds with disabilities due to traditional expectations of gender roles in which they are often at risk of exploitation and negligent treatment from their male counterparts; and men may manipulate their power in making the decisions for women from NESB/CALD backgrounds with disabilities.

In addition, these cultural restrictions can lead to women from NESB/CALD backgrounds with a disability to face exclusion in decision-making. They are often stereotyped as passive, dependent or insecure and often resulting in women with disabilities being denied the right to participate in decision-making processes that affect their lives.

NEDA does not wish to participate in a dialogue considering gender, but we do acknowledge that gender issues compound concerns around NESB/CALD communities. However, NEDA strongly recommends for the legislation to take into consideration how decisions made by women from NESB/CALD backgrounds with a disability can be supported to the fullest extent possible; and the impact of gender roles (within cultural identities) on disability.

Section 7: Provision of notice, approved form or information under this Act etc

Recommendation

Refer to (7)1 NEDA recommends for the legislation to guarantee that participants from NESB/CALD backgrounds have access to a bilingual/bicultural person and a professional interpreter who is the ‘giver of the notice’ in order to guarantee that information is conveyed and explained in the right way to participants from NESB/CALD backgrounds.

Part 4 – Definitions

Section 9: Developmental delay

Recommendation

The definition of developmental delay puts an upper age limit, in which a child must prove that their disability is permanent and support is needed for a lifetime. NEDA opposes the definition as, from a cultural context, developmental delay may not be acknowledged by family members and/or carers until a child enters the educational system. Furthermore, families from NESB/CALD communities may not regard 'developmental delay' as a lack of English language skills, change of environment and/or other cultural factors. Therefore, NEDA strongly believes that the legislation should not give an upper age limit for developmental delay. The issue of an age upper limit is more problematic when it comes to humanitarian and refugee children whose developmental delay may not be recognized or assessed until well after the age limit proposed by the legislation.

Additionally, it is important to understand that in determining whether a child has developmental delay, standardised tools of referral and assessment may not take into consideration the implications of culture and language on a child's developmental delay. Therefore, NEDA suggests for alternative tools of assessment to accommodate children from diverse forms of backgrounds and avoid any form of 'misdiagnosis.'

Other Matters

NEDA strongly recommends for the legislation to make advocacy available. A clear definition of advocacy is needed in order to promote the rights of people from NESB/CALD communities with a disability. Independent advocacy is essential for participants from NESB/CALD communities as they face additional barriers and NEDA believes that advocacy has the advantage of achieving systemic changes that they require. Advocacy is especially critical for people from NESB/CALD backgrounds with disability as it allows them to access the system appropriately and are involved in the choices and decision making processes. Also, advocacy will help to effectively communicate their wishes and prevent unnecessary exploitation and discrimination as the lack of English language skill and understanding of the system and support services.

Therefore, there is a need to insert a definition and/or section on advocacy which is beneficial in promoting positive change to the structure and policy of the NDIS; and to address and recognise the complex needs and varying needs of people from NESB/CALD communities with a disability. Without a doubt, advocacy plays an essential role for people from NESB/CALD backgrounds with disability so that they can gain access to the system appropriately.

Chapter 2 – Assistance for People with Disability and Others

Section 15: Agency may provide information

Recommendation

Refer to 15 (2) In providing timely and accurate information to people with disability (and others involved), it is important for the Act to ensure that, in using its best endeavours, the Agency will seek to accommodate the cultural and linguistic circumstances of participants from NESB/CALD backgrounds. In doing so, NEDA suggests for the Agency to have bilingual staff and/or offer professional interpreting services to participants from NESB/CALD backgrounds.

Section 22 Age Requirements

NEDA opposes the 65 year age cap entirely as the age requirement implies that people with disability may not receive adequate disability support from the aged care system. This may work against people from NESB/CALD backgrounds as it is found that there is a critical and current issue for older NESB/CALD people to gain access to health services as they face barriers in accessing appropriate health and aged care services.¹ The data further suggests that immigrants from countries such as Vietnam, Malaysia, the Indian subcontinent and the Philippines will become a more significant part of the younger old and these changes will have implications for provision of health and aged services. NEDA proposes that NDIS consider that older immigrants from NESB/CALD communities may eventually need access to support services as they become more susceptible to cognitive or neurological impairments.

Section 23 Residence Requirements

NEDA supports that a request to become a participant of the National Disability Insurance Scheme should be available to anyone who legally resides in Australia. However, it does appear that Section 23 appears to be restricted. It is important to realise that failure to provide necessary supports to migrants is inhumane and will inhibit the capacity of the person and their family carers to contribute to Australian society. Furthermore, it is important to realise that there is a 10 year residency period before migrants with a disability are eligible for the Disability Support Pension.

Recommendations:

1. Other than participants who reside in Australia/permanent residents/special category visa (SCV holder), NEDA recommends for NDIS to extend the scheme to general skilled visa holders/migrants (GSM) with a disability and/or family members in the family stream of Australia's Migration Program. The argument presented by NEDA is that professionals and/or residents in the GSM program are able to: (Source: <http://www.immi.gov.au/skilled/general-skilled-migration/885/>)
 - (a) be eligible for Australian citizenship
 - (b) access certain social security payments
 - (c) live and work in Australia on a permanent basis
 - (d) receive subsidised healthcare through Medicare and the Pharmaceutical Benefits Scheme (PBS)

Under these circumstances, NEDA believes the NDIS should be accessible to skilled

¹ http://humanrights.gov.au/about/media/media_releases/op_ed/20120608_CLAD.html

migrants (under the GSM program) and they should be able to make a request to the Agency to become a participant in the National Disability Insurance Scheme.

2. NEDA recommends for the NDIS to be extended to asylum seekers with disabilities during the period which their applications for protection visas are processed. NEDA believes that asylum seekers with disabilities will need assistance to settle successfully while they await for the outcome of their protection claims. While exemptions to Asylum Seeker Assistance Scheme eligibility criteria may be available to vulnerable asylum seekers with a disability who are unavailable to work, this may not be sufficiently adequate.² There needs to be a consideration of accommodating the needs of persons with disabilities in the asylum process; and NEDA suggests that the scheme extends access to asylum seekers with disability through a referral and needs assessment in which an applicant can have a discussion on their needs to guarantee a progress to successful settlement once their protection claims have been processed. NEDA further recommends that NDIS assess the unmet needs of asylum seekers with disabilities and identify any type of support that can be provided through the scheme.

Clearly for people in all of these categories who are excluded from the scheme, the lack of access to receive critical disability supports amounts to an abuse of human rights, and this is another breach against migrants from NESB/CALD communities with disabilities and their fundamental human rights in which access to disability supports as outlined in the UN CRPD is being denied.

Section 24 Disability requirements

This section mentions the processes and assessments around whether a person meets the disability requirements in which a person must have an impairment which is attributable to *“one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition.”* There is little specification how this will be applied and if disability requirements will be decided by a medical model of eligibility. In addition, Section 24 appears to be more restrictive than the equivalent Social Security Act provision. To be consistent with the UNCRPD the impairment in (1)(b) should be or be likely to be “long-term” and the person’s support needs in 1(e) likely to continue “long-term”. Many people currently in receipt of disability supports may be unable to establish permanence.

NEDA is concerned how assessments and processes may work against participants from NESB/CALD backgrounds. For example in carrying out intellectual, cognitive or neurological assessments to determine psychiatric conditions, there might be a misdiagnosis of cognitive impairment due to a standardised assessment test or tool which may not accommodate cultural differences.

Recommendations:

NEDA proposes for NDIS to consider screening tests and assessments that incorporate individual measures that are sensitive to cultural and educational background. Therefore the following measures are proposed:

² <http://www.immi.gov.au/media/fact-sheets/62assistance.htm#b>

- (a) to ensure that any neurological, cognitive, intellectual and/or sensory assessments include measures that are properly validated for use among NESB/CALD communities
- (b) to include cultural factors, socioeconomic status and other variables that may affect test performance
- (c) to include measures that are sensitive to cognitive impairment across broad educational backgrounds in ethnic communities

Furthermore, in proving that a disability is permanent, refer to 24, “*For the purposes of subsection (1), an impairment or impairments that vary in intensity may be permanent, and the person’s support needs in relation to such an impairment or impairments may be likely to continue for the person’s lifetime, despite the variation,*” it should be noted that critical supports should not be dependent on whether a disability is permanent, but only on whether it has a significant impact on a person’s ability to function in everyday life.

Section 34 Reasonable and necessary supports

Refer to (b) *the support will assist the participant to undertake activities, so as to facilitate the participant’s social and economic participation.* As part of facilitating the participant’s social and economic participation, it is necessary for NDIS to include professional interpreting services as part of participants’ support plans.

Recommendation:

There is no mention of (additional) supports necessary for participants from CALD/NESB backgrounds that will require extra assistance/supports due to their cultural and linguistic circumstances. For example, it should be included in the legislation for participants from CALD/NESB participants to gain access to interpreting services that would be considered as extra assistance (rather than to be included in their plan, which may affect the amounts they are entitled to).

Section 40 Effect of temporary absence on plans

Refer to 40 (3) *If a participant for whom a plan is in effect is temporarily absent from Australia after the end of the grace period for the absence, the participant’s plan is suspended from the end of the grace period until the participant returns to Australia.*

Recommendation

This may affect participants from NESB/CALD communities as allowances should be made for those who are unable to return to Australia within the grace period due to factors such as family emergencies that are beyond their control or bereavement. Once again, there needs to be a special consideration for the needs of NESB/CALD communities who may need to return to their home country for emergency purposes for a period longer than the grace period prescribed.

Section 44 Circumstances in which participant must not manage plan to specified extent

Refer to (2) *The statement of participant supports in a participant’s plan must not*

provide that the participant is to manage the funding for supports under his or her plan to a particular extent if the CEO is satisfied that management of the plan to that extent would (a) present an unreasonable risk to the participant;

Recommendation

NEDA promotes the idea of 'dignity of risk' among people with disabilities. The term 'dignity of risk' is used to promote the right of individuals and for them to take some risk to engage in life experiences. The dignity of risk, or the right to failure, is a value first championed by advocates for people with physical disabilities, and people with disability may feel subject to a double standard in attitudes towards their ability for self-determination. In the process of receiving treatment they seem to have somehow given up their "right" to make risky or potentially self-defeating choices without intervention from authorities, clinicians, service providers or even family members wishing to protect them.³ As such, it is important for the law to consider this concept of dignity of risk in order to place emphasis on self-determination and personal choice.

NEDA strongly believes that losing autonomy because someone is presumed to be a risk is contrary to human rights framework. Some decisions are inherently risk and people with disabilities are entitled to taking this 'risk' as it promotes their autonomy and liberty. This is further discussed in reference to *Part 5- Nominees*.

Chapter 4 – Administration

Section 80 Duty of Nominee to participant

It is stated that "it is the duty of a nominee of a participant to ascertain the wishes of the participant and to act in a manner that promotes the personal and social wellbeing of the participant."

NEDA believes that people with disabilities are usually in the right position to determine their own plan and support services and strongly encourages NDIS to acknowledge that a participant should decide for him or herself what their own "dignity of risk" level is.

As a nominee/guardian to a participant, it is crucial that a nominee practices the principle of dignity and self-determination and respect the knowledge, abilities and experiences that people with a disability possess. Their role should be emphasised on supporting them to make choices and enabling each person to live the life they want to and to be given a choice. Once again, NEDA believes that providing a plan nominee option in NDIS may avert the risk and breaches the human rights approach. It should be emphasized that participants are able to have control over the decision-making and that the role of a nominee is to be part and develop the process of decision-making.

Recommendation

NEDA proposes for the implementation of policies and procedures that reflects and

³ <http://www.openforum.com.au/content/dignity-risk-right-self-governance-people-mental-illness>

promotes the dignity of risk for participants as it should be recognised that participants in the NDIS are the experts in their own experience. In this case, NEDA acknowledges for the nominee of participants from NESB/CALD communities to guarantee the entitlement to the dignity of risk and for appropriate risk management policies and procedures to be put in place in NDIS and applied in implementation too. Therefore, NEDA recommends for the NDIS legislation to ensure that participants are given the same opportunities and choices the same way as any other person in society; and promoting the principles of self-determination and self-management.

Chapter 6 – National Disability Insurance Scheme Launch Transition Agency

Section 118 *Functions of the Agency*

Recommendation

This section should be revised to ensure that as part of the Agency's role, it is important for the Agency to provide advice on improvements to legislation to achieve the objects of the *Act* as stated in Section 3. More importantly, in performing its functions, NEDA recommends that the Agency aims to act in a manner that is culturally competent and/or sensitive towards participants from NESB/CALD backgrounds with a disability; and to ensure a culturally responsive manner in addressing the diverse needs of participants from NESB/CALD backgrounds with a disability. NEDA further recommends the following:

- (i) *To promote the National Disability Insurance Scheme to Culturally and Linguistically Diverse Communities through culturally appropriate targeted strategies to ensure awareness of the scheme and its benefits (recommended by member organization of NEDA, AMPARO Advocacy).*

Section 127 and 147 *Appointment of Board Members and Advisory Council*

Recommendation

NEDA suggests for board memberships to include at least one member from NESB/CALD background with disability with the knowledge and experience in the multicultural disability advocacy in order to represent participants from NESB/CALD backgrounds.

Conclusion

NEDA continues to promote the rights of people from NESB/CALD communities with a disability, and advocates for NDIS to consider the particular and complex needs of people from NESB/CALD communities with a disability. It is crucial for NDIS to ensure that people from NESB/CALD communities with disabilities are involved in the scheme's design. NEDA proposes for this to be done by addressing the barriers faced by people from NESB/CALD communities with a disability, their family members and carers as they are often

compounded by issues relating to ethnicity.

NEDA suggests that in the implementation of its strategies, the NDIS legislation will guarantee a strong acknowledgement and representation of the needs and rights of people from NESB/CALD communities with a disability. Without doubt, NEDA recognises that NDIS represents an overall improved disability system in Australia that aims to achieve best outcomes for people with disability.

In this response, NEDA continues to focus on areas of concern of people from NESB/CALD communities with disabilities and to ensure that NDIS is a universal system for them. Therefore, NEDA suggests for NDIS to undertake research and regular monitoring throughout the scheme and its implementation process to avoid unnecessary suffering by people from NESB/CALD communities with disabilities.

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