

# NEDA's Submission to the National Disability Insurance Scheme Secretariat – NDIS Draft Rules 2013



NATIONAL ETHNIC  
DISABILITY ALLIANCE



## Overview of NDIS Rules Submission

The National Ethnic Disability Alliance (NEDA) welcomes the opportunity to provide responses on the Draft Rules for the National Disability Insurance Scheme (NDIS) in relation to the client groups that our member organisations support, individuals from non-English Speaking Backgrounds (NESB) and/or culturally and linguistically diverse backgrounds (CaLD) with a disability. NEDA is pleased that the NDIS is all for Australians living with a disability and to allow them with the supports needed in exercising their full rights.

NEDA is aware of the significance of the NDIS Draft Rules and we have been tasked by our funding body, Commonwealth Department of Families, Community Services and Indigenous Affairs (FaHCSIA), to carry out additional research, to conduct consultation from NEDA membership organisations to inform the submission document and ensure that policies and procedures are in place to support the diverse needs of participants from NESB and/or CaLD backgrounds with a disability. NEDA welcomes this opportunity to contribute to the discussions of NDIS Draft Rules by highlighting the specific needs of individuals from NESB and/or CaLD backgrounds with a disability, as well as to recognise the multiple disadvantages faced by these communities.

It is clear that the Draft Rules provide a greater level of detail on how NDIS will work and to ensure that the client groups that NEDA represents, individuals from NESB/CaLD communities with a disability, are well-represented, able to access the scheme; and the supports available to meet their complex needs.

In this submission, NEDA has responded to questions that are most relevance for individuals from NESB and/or CaLD backgrounds with a disability. It is crucial that the complex needs of individuals from NESB and/or CaLD backgrounds with a disability are reflected and well-represented in the Draft Rules.

More importantly, in looking at NDIS Draft Rules and promoting the rights and needs of individuals from NESB and/or CaLD backgrounds with a disability, it is important for the Government to uphold its obligations to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in providing support to regardless of their eligibility to the NDIS. As stated in Article 25:

“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability and states parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.”<sup>1</sup>

NEDA believes that the enactment of the UN CRPD is crucial in ensuring that equal rights are extended to individuals with a disability, particularly individuals from a NESB and/or CaLD communities with a disability, within the NDIS.

## About NEDA

NEDA is the national peak organisation representing the rights and interests of people from NESB and/or CaLD with disability, their families and carers throughout Australia. NEDA is funded by the Commonwealth Department of Families, Community Services and Indigenous Affairs (FaHCSIA) to provide policy advice to the Australian government and other agencies on national issues affecting people from NESB and/or CaLD with disability, their families and carers.

<sup>1</sup> *UN Convention on the Rights of Persons with Disabilities*, available at <http://www.un.org/disabilities/default.asp?id=285>

In states and territories where no NESB/CaLD disability advocacy agency exists, NEDA undertakes development work to establish a structure that can support people from NESB and/or CaLD backgrounds with disability, their families and carers; and continues to play an important role in ensuring that the scheme is inclusive of individuals from non-English Speaking Backgrounds (NESB) and/or culturally and linguistically diverse backgrounds (CaLD) with a disability. It is important that the NDIS actively promote the equal participation of people from NESB and/or CaLD backgrounds with a disability in all aspects of Australian society. More importantly, NEDA continues to suggest that it would be important for the NDIS to provide effective and culturally responsive services that meet the diverse needs of individuals from NESB and/or CaLD communities with a disability.

## Responses

### 3. The different roles of NDIS

3.1.1 *The rule may prescribe matters for and in relation to this chapter (relating to the types of assistance for people with disability provided by the Agency). Clause 17*

3.1.2 *What guidance should the rules provide the Agency about how to support people in referring them to community or mainstream supports, or to other support systems?*

The Agency should provide general information and referral services to non-participants and advise them to other types of support services. Within the context of NESB/CaLD individuals with disabilities, who may not be part of the NDIS, it is important that the Agency provide information and referral services that are able to accommodate to the cultural, linguistic and religious needs of non-participants.

More importantly, NEDA recommends the importance of providing culturally appropriate and sensitive information to individuals from NESB/CaLD backgrounds with a disability, as well as their family members and/or carers so that they are able to fully comprehend the new disability support system and how the scheme will work.

It is crucial for the Agency to identify the most appropriate service for individuals from NESB/CaLD communities and to ensure that the process for equal access to these services are funded too. For instance, the Agency should have the information and capacity to refer non-participants from NESB/CaLD backgrounds to ethno-specific service provision. In this case, the information provided must be individualised and personalised towards the needs of those from NESB/CaLD backgrounds.

NEDA also supports the Disability Advocacy Network of Australia (DANA) on how the Rules should amplify the proposed legislative provision to specify ongoing that a proportion of NDIS annual expenditure be allocated to the provision of independent disability advocacy and information.

#### **Recommendation:**

There should be better clarity in the Rules in regards to general supports for individuals from NESB and/or CaLD communities who are not eligible for the NDIS and should include the following:

- Information on individual choice and the most effective care and support services in addressing their cultural, linguistic and religious needs and;

- Provide referral to relevant services for which the NDIS was not directly responsible ie. community support groups for NESB/CaLD individuals with disabilities who are not part of the scheme.

NEDA suggests that in supporting people in referring them to community or mainstream supports, or to other support systems, it is crucial that the Rules ensure that the Agency supports the use of external and independent agencies to assist individuals and families from NESB/CaLD communities with the planning processes in providing culturally acceptable support and accessing on a case-to-case basis on what cultural constraints needs to be addressed prior to referring them to the appropriate agency. This will also help the individual's plan to be inclusive and self-directed.

## 4. Eligibility for becoming a participant

### Question

4.1.1 *Should the rule also set out the types of information the Agency will need to establish that a person meets the age requirements? What types of evidence are appropriate to determine if a person meets the age requirements?*

In considering the age requirement and NESB/CaLD groups, the Rules does not consider that migrants do not gain access to the Disability Support Pension after they've met the ten-year waiting period. It is crucial that NDIS considers that while the age eligibility is intended to not duplicate other service systems, there should be an exception made for migrants who do not receive DSP and may need to receive support from NDIS after the age of 65.

### Question

4.2.1 *What factors should be taken in to account in deciding whether a person meets the residence requirements? What types of evidence are appropriate to determine if a person meets the residence requirements?*

Residency requirement for SCV holders or permanent residents needs to be amended and the Rules needs to assess what support will be provided when someone is in the waiting process of obtaining permanent residency (PR). The average waiting period for obtaining permanent residency is 9-18 months and this would greatly affect migrants with disabilities from benefiting from the scheme. NEDA continues to hold its position in regards to residency requirements that the NDIS be made accessible to all tax-paying residents in Australia.

### Recommendation:

#### 4.4 Disability requirements

4.4.1 *How much detail on the criteria for determining the disability requirements should be set out in the rules?*

4.4.2 *Should there be any guidelines on people being able to provide existing assessments to meet the disability requirements?*

Disability requirements should allow for circumstances when establishing the permanent nature of disability and determining disability requirements, the Agency needs to allow a periodical re-assessment of people's needs, particularly for participants from NESB/CaLD backgrounds with disabilities as their circumstances will change at key transition points like resettling in a new

country and/or environment, getting a job, culture shock or even losing a natural support. NEDA suggests for details on the criteria to be as transparent as possible in order to be informed on the process of how permanent disability is determined and assessed.

The Rules should take into consideration a second opinion that will allow for a review and in ensuring an equal and fair assessment for NESB/CALD participants, especially if a national tool is in place to determine disability requirements. NEDA suggests for the Agency to develop and use assessment tools that is culturally sensitive and appropriate.

**Recommendation:**

There also needs to be provisions in place for people such as refugees, asylum seekers or those from Aboriginal and Torres Strait Islander who may have difficulty proving their age. Assessors should have the capacity to accommodate to certain individual situations, particularly amongst NESB/CALD groups. The Rules need to take into account the social and cultural context of the person (ie. Relationships, supports, family) as this is an important criteria in early intervention.

It is important for the rules to determine disability on the basis of a functional assessment of what a person can do. In the context of participants from NESB/CALD backgrounds with disabilities, it is important that they are not tied down to the basis of diagnosis. Due to cultural, educational, gender and other factors that needs to be considered in regards to individual circumstances, the Rules need to allow the assessment process to take into consideration these factors in order to guarantee the most culturally appropriate support that they need.

**4.5 Early intervention requirements**

4.5.1 *What criteria would be useful for considering the benefits of early intervention for mitigating or preventing deterioration in a person's functional capacity to undertake activities such as mobility, self-care or self-management?*

4.5.2 *How can the support provided by families and other carers be made more sustainable by early intervention?*

In considering the benefits of early intervention, it is important that NDIS include the following criteria for participants from NESB/CALD backgrounds in supporting them:

- To maintain daily life roles, functions such as employment, housing, family, social and cultural participation;
- Early interventions that are culturally appropriate and sensitive; and
- To consider social, cultural and religious contexts in responding to the symptoms in early intervention.

In ensuring that the support provided by families and other carers be made more sustainable by early intervention, it is important for NDIS to consider cultural beliefs and understandings of disability and how carers of NESB/CaLD groups may refuse to accept early intervention.

The Rules needs to consider that some carers from NESB/CALD groups might not accept early intervention, or even to acknowledge the disability itself. There needs to be safeguards in place that addresses issues relating to cultural and linguistic needs of the children and the families from NESB/CALD groups, and the desired outcome of an early intervention.

For example, in providing early intervention for development delay of a child, NEDA suggests that in considering the cultural beliefs of participants from NESB/CALD backgrounds, prior to providing support that is sustainable (through early intervention). In providing an appropriate and sustainable support, it is important that NDIS explore cultural backgrounds of the participant and to be aware of existing cultural biases towards disability or impairment, family environment and relationships that exist within NESB/CaLD groups.

***Recommendation:***

The Rules needs to consider individual circumstances, educate carers as family members and/or carers from NESB/CaLD backgrounds as cultural beliefs from the parents on a child's disability is likely to shape the parents' context and beliefs about the treatment and intervention.

In coping with the challenges that they may face in dealing with children with disability and the process of early intervention, the Agency has to increase the capabilities of the family in understanding disability and various behaviours around it. More importantly, it needs to consider the strategies to implement and manage certain behaviours as such family members and/or carers from NESB/CaLD communities may not aware of early intervention strategies that are available in service provision.

It is crucial for the Rules to determine whether a family-centred approach or a person-centred approach would be a better early intervention approach for participants from NESB/CaLD backgrounds, and to take into consideration lived experiences, family structures and cultural beliefs.

## **5. Participants' plans**

### *5.1.1 What methods or criteria should be used to determine those supports that would not be provided or funded by the NDIS?*

In determining the supports that will not be provided or funded by the NDIS, it is important for the Scheme to guarantee that participants from NESB/CaLD backgrounds are able to live appropriately as they will require services that will allow them to stay connected within their cultural and/or religious community.

The Rules should also embrace the importance of other kinds of supports and, by implication, the involvement of a wide range of support providers. In support of DANA's statement, NEDA agrees that the Rules should not be use, and potentially limit, these other supports. Rather, the Rules should be indicative of the broad categories of outcomes in respect of which supports might be purchased using NDIS funding and should reiterate the principle that supports would not be funded where the provision of those supports would potentially breach an individual's human rights.

## **5.2 Management of plans**

### *5.2.1 What criteria should be used by the Agency in deciding whether there is an unreasonable risk for the participant in self-managing funding?*

The Agency needs to consider cultural and gender roles and the idea of the **"dignity of risk"** among NESB/CALD groups. It is important that the scheme allows individuals from NESB/CALD groups to have a great degree of autonomy and self-determination. A risk-based monitoring process in its criteria needs to be in place in deciding how individualized funding is spent, ensuring

it is legal and consistent with the plan, particularly within the context of NESB/CALD communities, as participants may or may not be manipulated by their carers/family members. For instance, in considering gender, ethnicity and disability, the Agency needs to address the risks that women may face due to gender/cultural roles.

Participants from NESB/CaLD backgrounds need to be able to be directly involved and engaged with the development of their plans and managing their plans in order to control any risks involved. This needs to be exercised in the processes to support the participants' plans and in doing so; NEDA continues to suggest that a personalized and/or person-centered approach is implemented in decision-making particularly among participants from NESB/CALD backgrounds.

As such, it is important for the Agency to assess participants' relationship with significant others as in some NESB/CaLD groups, a woman may not be given appropriate support to self-manage funds and this might lead to a risk of misuse of funds by others within the family members and/or carers. As such, NEDA continues to emphasize that supports and management of plans should be sensitive to gender-specific requirement, such as the roles of women within the household. There should also be flexibility within the participant's plan in accommodating to the participant's social, cultural and religious context and support and the complexity of their needs.

***Recommendation:***

In addition, it is suggested from the outcomes of the NEDA/National Disability Carer's Alliance Parliamentary Roundtable (held on the 12 March 2013) that individuals from NESB and/or CaLD communities with a disability needs to be empowered and understand their rights under the new disability support system that aims to advance self-directed plans. The following recommendations are highlighted:

- Delegates at the roundtable highlighted that training needs to be a two-way process and to educate service providers and support workers, as well as family members and/or carers of NESB and/or CaLD communities (ie. advocacy training). A holistic approach is recommended to educate both service providers, as well as individuals from NESB and/or CaLD communities, and their carers and;
- To address and understand the stigma that exists amongst NESB and/or CaLD families need to be taken into account into the planning and training processes of the NDIS, and decision-making in a participant's plan.

## **6. Information sharing**

*6.1.1 Under what circumstances would you consider it reasonable for the CEO of the Agency to disclose information to a Commonwealth or state or territory authority?*

*6.1.2 Are there any other protections to information that are not covered?*

There needs to be better information in the Rules about the broader privacy framework for the NDIS and how entities participating in the NDIS will be covered by privacy law. There needs to be a right balance, particularly for participants from NESB/CALD backgrounds in which it is important to consider the cultural sensitivity of their personal information, some of whom may have experienced torture and trauma.

It is important that the Agency implement privacy-sensitive alternatives in protecting participant's privacy and their personal information as its is not clear in the Rules concerning the types of information which may be released or if there might be a level of scrutiny towards the participant (ie. private information, criminal record etc).

The Rules should state that participants will be guaranteed the best privacy protection of their personal information. Also, it is not clearly stated if there is a requirement for the CEO to inform or notify a participant if specific information has been disclosed. This should be made a compulsory requirement in the Rules.

## 8. Children

8.1.1 *What criteria would a decision-maker need to take into account to appoint someone other than a parent to act on behalf of a child?*

8.1.2 *What criteria should be considered in deciding whether a child under the age of 18 should be making decisions about their supports?*

The Rules need specify that both parents and the child be guaranteed access to independent advocacy support. This is particularly important for NESB/CaLD families and children with disabilities as the parent would take full responsibility as a decision-maker within certain cultural context and in some cases, this may not be beneficial to the child. NEDA strongly recommends that both parents and the child are granted independent advocacy. NEDA endorses *The Disability Advocacy Network of Australia (DANA)* statement on “this is a crucially important decision and the Rules must specify that both parents and the child be guaranteed access to independent advocacy support.”

The Rules should clearly state the types of circumstances that will allow a representative or decision-maker for a child’s representative. In this case, a child should be given access to independent advocacy (any participant under the age of 18). There needs to be a solid foundation established during the early elementary years, before adulthood, for their children with disabilities as otherwise they will not be prepared to assume greater control over their lives when the time comes to do so – especially for children from NESB/CaLD background where parents may be over-protective of their child and may not encourage them to be the sole decision-maker.

Another important factor for the Agency to consider in working with children is to have facilitators that will allow them to learn self-advocacy. This is crucial for children from NESB/CALD communities with a disability, as they need to be able to express and acknowledge any personal aspirations of the planning and review processes of their plans.

The UNCRPD recognizes that ‘children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child.’<sup>2</sup> It is important that the NDIS allows children with disabilities to exercise choice and control over their plans and help them to develop a sense of ownership and responsibility, especially amongst NESB/CALD communities as children with disabilities from ethnic groups might not be accepted by family members and not encouraged to advocate for themselves.

NEDA strongly believes that in allowing children, particularly those from NESB/CaLD communities, to learn self-advocacy will allow them to gain control over one’s life, applying self-determination skills and goal setting. The Scheme should encourage this process of learning and applying such skills in leading successful transitions to adulthood.

More importantly, there needs to be a mention in the Rules in regards to family members and/or carers of children from NESB/CaLD communities with a disability, and the types of informal support

<sup>2</sup> Convention on the Rights of People with Disabilities, available on <http://www.un.org/disabilities/convention/conventionfull.shtml>

services, in which in most cases, families and/or carers play an important role in the needs of children from NESB/CaLD communities with a disability.

***Recommendation:***

NEDA suggests for better recognition of families and/or carers as there needs to be safeguards and provision in place to recognise the rights of carers, as well as the supports families provide for children with a disability, particularly amongst NESB and/or CaLD communities.

## **9. Supporting decision-making**

*9.1.1 What criteria should guide the decision to appoint a nominee?*

*9.1.2 What criteria should be used to select an appropriate nominee?*

*9.1.5 Who should never be considered as a nominee?*

In the selection process of an appropriate nominee, it is important that the authority lies to an independent body and not the Agency. There needs to be safeguards in place for all people with disability, particularly for individuals from NESB/CaLD backgrounds with a disability, in order to promote self-autonomy and self-determination that can be restricted within cultural boundaries that exists in some ethnic communities.

NEDA suggests that there needs to be an application process in the selection of an appropriate nominee in which an assessment of the nominee's character and capacity (ie. thorough screening and quality references) has to be in place. This process is crucial in determining whether a nominee is able to act in the client's interest and to allow the client to have self-determination, as well as ensuring that the relationship that the participant has with the appointed nominee is positive.

**NEDA recommends that the following criteria be considered in appointing a nominee:**

- Understand an individual's personal and cultural context (characterised by the roles and responses of marital partner, family members, work colleagues, etc.) and consider the relevance of all these roles prior to appointing a nominee;
- Provide training to appointed nominees to ensure they understand the criteria needed to the full participation and control of people from NESB/CALD groups with disability;
- The appointed nominee needs to be informed and aware of services available in their catering role as it is the responsibility of NDIS to ensure that nominees are aware of ethno-specific service provision within their communities and;
- Appointed nominees need to understand the importance of confidentiality within their ethnic communities and they do not have any stigma around disability and/or mental illness.

NEDA further argues that it is important for the Agency to understand the cultural and social roles that exists within the lives of participants from NESB/CaLD communities. Some participants from NESB and/or CaLD backgrounds might be at risk of facing potential abuse or misuse of funds from their carer and/or family member. In such potential cases, the Agency has an obligation to not

appoint them as a nominee, or to cancel their appointment and to make certain that appropriate authorities investigate allegations of abuse by participants.

NEDA also recommends that there is both initial and ongoing training for nominees and this should be made as a requirement, as this will be beneficial for the nominee in dealing with the participant's condition and/or disease.

Supporting participants living in remote areas will pose challenges; appointing nominees will also sometimes be difficult. Under current arrangements, some service providers act in correspondence nominee roles for some people who live in remote areas (e.g. for communicating with Centrelink). Consideration must be given to the NDIS Agency allowing this as other options may not be available. Requirements for managing any conflict of interest (or perceived conflict) could be established.

## 10. Other Matters

### 10.1 Workforce Strategy for NDIS

The Draft Rules have not addressed the issue of workforce strategy and NEDA is concerned, particularly for individuals from NESB and/or CaLD communities with disabilities living in remote areas that the scheme will not have the capacity to provide them with culturally and linguistically appropriate and sensitive services due to the current limitations in the workforce.

NEDA believes that provisions and safeguards need to be implemented to ensure that the needs of participants from NESB and/or CaLD backgrounds are adequately addressed. An effective workforce strategy needs to be in place for participants within the scheme to be properly supported and receive appropriate services for their individual needs, particularly for participants from NESB and/or CaLD communities with a disability.

Following this, there needs to be focus on building the capacity of the support system, not only for individuals and their family members and/or carers, but also for disability support organisations. NEDA believes that there needs to be a development of a detailed workforce strategy and training program based on input, ideas, involvement of staff, individuals and their families strengthening the capabilities or proficiencies that will be required of organisations and the workforce in order to operate in the new environment and this includes: a human rights culture; customer and community focus; and integrated infrastructure.<sup>3</sup>

Recently, it is stated by (insert source of reference?David Bowen the current disability sector employs 130,000 people, 75,000 of which are full-time position and they are expecting an increase of additional 65, 000 full-time. This equates to 120,000 new positions being created and an estimated 90% increase for the demand of staff in the disability support sector. INCLUDE LIMITATIONS OF PART-TIME STAFF)

NEDA has concerns towards how such processes will be addressed and strongly suggests for NDIS to consider these implications in the Rules and to implement policies and frameworks to protect the participants. A sector development component needs to be considered in order to develop a national safeguards framework to make sure that there is a sufficient skilled and responsive workforce to meet the care and support needs of people from NESB and/or CaLD communities with a disability, as well as to achieve service quality and positive client outcomes.

NEDA strongly suggests for the following strategies to be considered:

- To research, identify and document in the Rules on what may constitute of good practice within the workforce development
- To conduct disability support and service system workforce forums and implment strategies needed within the workforce to allow training in addressing the social and cultural needs of a participant and;
- NDIS to develop a national workforce strategy framework for the scheme.

As a result, a key challenge for the NDIS is to ensure that a workforce strategy is in place for this to be advanced within the scheme as service providers need to have the capacity to respond to the

<sup>3</sup> Pricewaterhouse Coopers“Disability expectations: investing in better life, a strong Australia,” p. 57, available at <http://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf>

needs and preferences of each individual client, particularly for individuals from NESB and/or CaLD communities with a disability.

## **10.2 Block Funding and the NDIS**

Another issue that needs to be addressed is the use of block funding in the scheme. NEDA strongly believes that there needs to be the use of block funding in regard to remote and isolated communities as most felt that the need for this type of funding is paramount to the provision of service to those with disability and even more so to those of NESB and/or CaLD communities who are living in remote locations where services are limited, and may be isolated from gaining culturally and linguistically appropriate information.

As some groups may need the block funding /support in order to service their consumer.

**Submission Title:** The National Ethnic Disability Alliance Submission to the National Disability Insurance Scheme Secretariat, National Disability Insurance Scheme Rules

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