



## National Ethnic Disability Alliance

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Joint Standing Committee on the National Disability Scheme  
PO Box 6100  
Parliament House  
CANBERRA ACT 2600

Via email: [ndis.sen@aph.gov.au](mailto:ndis.sen@aph.gov.au)

### **RE: Brief submission to the Joint Standing Committee - *Inquiry into the future of the NDIS***

National Ethnic Disability Alliance (NEDA) welcomes the opportunity to briefly provide preliminary key views to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) new inquiry into the future of the NDIS.

#### **About NEDA**

NEDA is a national Disabled People's Organisation (DPO) that advocates for the human rights of people with disability from Culturally and Linguistically Diverse (CaLD), and migrant and refugee backgrounds. NEDA is a founding member of DPO Australia, an alliance of four national DPOs, which are organisations constituted and governed by people with disability.

NEDA makes this brief submission to express our concern into the inequity between NDIS participants (particularly for the CaLD community) and concerns on the over-prioritisation of Scheme sustainability.

#### **Submission**

##### Drivers of inequality in plan funding between NDIS participants

A central pillar that underpins the NDIS is the concept of "choice and control" to create individualised funding packages for NDIS participants to achieve their goals. This creates an underlying assumption that NDIS participants understand their own needs, understand Australia's complex systems of services, and have proficient English.

The structure of the NDIS requires a certain level of self-advocacy that people with disability may not necessarily possess when it comes to understanding how their plans are being implemented and how decisions are being made. This issue is further compounded for the cohort of CaLD people with disability, particularly from new and emerging communities, who experience increased disadvantage due to the nexus of belonging to two stigmatised groups. The assumed reliance on self-advocacy

and emphasis on personalised plans creates inequality in plan funding for people who experience increased disadvantage, such as CaLD people with disability.<sup>1</sup>

Another driver of inequality is language. The NDIS system is a complex one for people who are English speakers and have a history within the disability service system in Australia – for those who are new to all of this, the process is overwhelming. Participants have access to language interpreting services during planning meetings; however, language interpreting supports are not part of NDIS plans and the lack of translated materials seriously impact equitable participation. CaLD participants often rely on family members or interpreters who may or may not know NDIS terminology, which in turn can lead to inadequate funding compared to an NDIS participants who do not experience this increased disadvantage. The focus on individualisation further marginalises CaLD people with disability who rely on family and informal supports to navigate the complexities of the NDIS.

#### *Measures that could address any inequitable variation in plan funding*

A disability service program that is individually tailored requires people with a disability to be fully aware of what services they are eligible for, and how to use these services to improve their quality of life. While choice is vital and reflects the social model of disability emphasised in the UN Convention on the Rights of People with Disability, adequate support must be provided in a user-driven model for users to be able to make a fully informed choice.

Long-term community development and engagement programs, such as the National Community Connectors Program (NCCP), that assist in not only engaging with the NDIS but to also empower development of self-advocacy as it is understood in the social model of disability, are needed to combat inequality in plan funding for the CaLD community. NEDA was awarded funding by the National Disability Insurance Agency to conduct the short-lived CaLD National Community Connector Program and while the initial impacts were favourable, it did not have the necessary time to establish a consistent service delivery and measurable outcomes.<sup>2</sup>

#### Financial and actuarial modelling and forecasting of the scheme

NEDA welcomes the decision to release the full NDIS Annual Financial Sustainability Report (AFSR), which has not been released in full in previous years, as part of a move towards greater transparency. However, NEDA has concerns over the assumptions and methodologies used to make projections about the NDIS and participants.

The Agency's continued warnings that the Scheme is in danger of serious financial unsustainability are based on the projections found in the AFSR, however, there is insufficient data to support these projections. The Scheme has only been fully rolled out nationally since 2019 and at best the projections rely on two years' worth of data. It is prudent in making projections to have at least five years of full data. Additionally, the growth projections in the AFSR for participant growth exceed the projections made by the Australian Bureau of Statistics (ABS) for the same period.

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<sup>1</sup> For further critiques of personalisation in social care, please see, Carey et al (2021), *Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals* <https://doi.org/10.1111/1467-8500.12508>. See also, Malbon, et al, (2019). *Personalisation schemes in social care: Are they growing social and health inequalities?* <https://doi.org/10.1186/s12889-019-7168-4>.

<sup>2</sup> The CaLD National Community Connector Program ran from July 2020 to June 2021, however, it took some time for all Community Connectors to be employed who were later instructed not to accept new clients after April 2021. This meant that the direct service delivery component of local programs effectively operated for between 6 and 9 months.

NEDA believes that the Agency's reliance on an actuarial methodology to make decisions on the future of the NDIS does not consider the dynamics of disability on an individual rather than the population as a whole. This poses a problem with the assumptions used by actuaries to make projections of the NDIS. It is unclear what elements of growth have been used in their assumptions and whether there has been adequate consideration into demographical trends, such as the aging of populations, lower migration, lower than expected birth rates and implications of the COVID-19 pandemic on those trends. Whilst the AFSR has been independently reviewed by the Australian Government Actuary, it is essential that any projection produced by the NDIA also be reviewed by demographers and epidemiologists with expertise in disability.

#### *CaLD related assumptions and measures*

NEDA considers the data in relation to CaLD participants is misleading and inaccurate. NEDA has attempted to replicate the Agency's results for verification for other reports and has been unsuccessful, particularly with CaLD estimates. The ABS has an inclusive definition of Cultural and Linguistic Diversity, however there is no national standard understanding of what CaLD is and how to identify and capture CaLD in data-collection systems and processes.

The Agency only collects information on intake language and place of birth, but no information is collected on the person's cultural background. The Agency has assumed that all spoken languages other than English are sufficient to be included in their CaLD determination. This includes First Nations Australians who speak a language other than English, which has an impact in remote and far remote regions in the Northern Territory, South Australia, Western Australia, and Queensland. In these regions the dominant languages spoken are those spoken First Nations Australians. Those First Nations Australians are double counted as both First Nations and CaLD. There are numerous long-established culturally diverse communities who communicate in English in Australia that the NDIS' definition of CaLD excludes. This represents a need for accurate quantitative data to plan for policies that can better respond to the needs of CaLD people with disability.

#### Measures intended to ensure financial sustainability

NEDA is concerned about the over-prioritisation of "scheme sustainability". The Agency has previously argued<sup>3</sup> that to ensure scheme sustainability, the CEO has "residual discretion" to override express criteria in the NDIS Act and Rules to refuse funding supports that are reasonable and necessary. This approach would mean that the Agency has greater power to deny supports as a method to ensure scheme sustainability, which goes against the person-centred approach required under the Act. While it may be necessary to consider risks to financial sustainability, this should be not an independent criterion in assessing reasonable and necessary supports. By conferring this type of discretion to the CEO goes against the very pivotal pillar of choice and control that underpins the NDIS.

One of the potential pitfalls in focusing the future of the NDIS based on risk aversion is that individuals are reduced to bottom lines and departs from the insurance-based long-term approach with the objective of social and economic participation for people with disability, which the NDIS was

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<sup>3</sup> See eg, *NDIA vs McGarrigle* [2017] FCAFC 132 where the Agency argued the CEO should have a discretion to refuse to fund a reasonable and necessary support if it imposes a risk to scheme sustainability. This logic has been more recently followed in *McLaughlin and NDIA* [2021] AATA 496 which agreed that the NDIS Act confers a "residual discretion" to the CEO.

designed for. The NDIS is not a welfare system and instead should focus on lifetime value for participants. The Scheme cannot function transparently if the fear of financial unsustainability drives decisions to override established criteria and policies.

The current reasonable and necessary criteria accounts for financial sustainability considerations when assessing requested supports such as – the support represents value for money (s34(1)(c)) and that the support is most appropriately funded through the NDIS (s34(1)(f)). These expressed criterions along with actuarial evidence is appropriately given effect through the current legislation. To enhance transparency of data and information, the Agency should publish guidelines on how financial sustainability is determined and how it is relevant to individual planning decisions.

## **Conclusion**

The evidence shows that CaLD people with disability, as a cohort, experience significant discrimination, marginalisation and compounding barriers to rights, recognition, and participation.<sup>4</sup> A move towards transparency in decision making will allow the disability community to rebuild a better NDIS for all Australians; however there is more room for improvement to ensure CaLD people with disability and their representative DPOs are genuinely working in partnership to drive NDIS agendas and outcomes.

NEDA would be happy to provide further information regarding our views. We thank you for the opportunity to provide feedback on the inquiry into the future of the NDIS. For further enquiries please contact NEDA's Senior Research & Policy Officer Blanca Ramirez on 0407 423 773 or at [blanca@neda.org.au](mailto:blanca@neda.org.au).

Yours sincerely,



**Dwayne Cranfield**  
Chief Executive Officer

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<sup>4</sup> Please see <https://www.neda.org.au/index.php/publications/barriers-exclusions-support-needs-newly-arrived-refugees-disability> for further information.