

31 March 2021



Hon Kevin Andrews MP
Chair, Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Mr. Andrews,

The Ethnic Communities' Council of Victoria (ECCV) commends the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) for holding an Inquiry into Independent Assessments and commends the Committee for making particular reference to the suitability of independent assessments for people from culturally and linguistically diverse (CALD) backgrounds.

This submission has been prepared based on ECCV's experience delivering the National Community Connector Program (NCCP). The NCCP is funded by the NDIA in order to increase access to the NDIS for people from CALD backgrounds.

This submission addresses the following Terms of Reference for this Inquiry:

- d. the independence, qualifications, training, expertise and quality assurance of assessors;*
- e. the appropriateness of the assessment tools selected for use in independent assessments to determine plan funding;*
- f. the implications of independent assessments for access to and eligibility for the NDIS;*
- j. the appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds.*

About ECCV

The Ethnic Communities' Council of Victoria (ECCV) is the peak advocacy body in Victoria for multicultural communities and people from culturally and linguistically diverse backgrounds. ECCV has over 220 member organisations, including ethnic associations and multicultural service providers, and eight regional ethnic communities' councils across the state.

Since 1974, we have been advocating for human rights, freedom, respect, equality and dignity for ethnic and multicultural communities, and for the building of a socially cohesive and inclusive Victorian community. ECCV has a long history in advocating for the rights of multicultural communities, informing practice and influencing policy on a range of issues including disability, aged care, health, employment, culturally responsive services and equitable access.

ECCV has long advocated for people with disabilities from multicultural communities. For more than four years we have been funded by the Victorian Government to deliver disability and NDIS focused projects to empower people with disability from culturally and linguistically diverse (CALD) backgrounds, their families and communities to effectively navigate the Australian disability system. Recently, ECCV has been contracted through the Commonwealth's National Community Connectors Program.

About the National Community Connector Program (NCCP)

The National Community Connector Program is a national initiative that aims to provide additional support for selected population groups including:

- Culturally and linguistically diverse communities
- Aboriginal and Torres Strait Islander (ATSI) communities
- People with disabilities living in rural and regional areas
- People with psychosocial disabilities
- Ageing carers

The NCCP was developed in response to the NDIA's recognition of the challenges to accessing support faced by these identified population groups. The above listed population groups, especially people from Aboriginal and Torres Strait Islander communities and CALD communities, have a disproportionately low NDIS participation rate.¹ One of the main goals of the NCCP is to help increase the number of people from these populations who access the NDIS.

The Federation of Ethnic Communities' Councils of Australia (FECCA) and the National Ethnic Disability Alliance (NEDA) are leading the rollout of the CALD Community Connector Program across Australia. ECCV is contracted by FECCA to employ Community Connectors in the Hume, Moreland, Darebin, Whittlesea, Brimbank, and Shepparton Local Government Areas.

Community Connectors work closely with these target communities to build trust and capacity. They raise awareness about the NDIS, provide information, and culturally tailored, one-on-one support to community members.

At ECCV, the Community Connector team are all from CALD backgrounds and have a strong understanding of the NDIS as participants, carers, or through previous work experience. The team has been engaging in outreach since December 2020. In this time, Community Connectors have organised over 45 community engagement activities and have assisted over 50 families.

¹ NDIA (2019) 'Culturally and Linguistically Diverse Report', available at <https://data.ndis.gov.au/reports-and-analyses/participant-groups/culturally-and-linguistically-diverse-report#:~:text=As%20of%2030%20June%202019,cent%20of%20all%20Scheme%20participants>

Community Connectors have found that the families they work with face a range of challenges when accessing government services. This submission is primarily informed by the experience of the Community Connectors team.

ECCV also thanks the National Ethnic Disability Alliance (NEDA), Victorian Aboriginal Community Controlled Health Organisation (VACCHO), and Migrant Information Centre (MIC) for their input and feedback on this submission.

Key issues

1. Low rates of participation in the NDIS by people with disability from CALD backgrounds

The proportion of NDIS participants from CALD backgrounds in the NDIS continues to be disproportionately low. People from CALD backgrounds are 7% more likely to be found ineligible for NDIS access than non-CALD applicants.²

The proposal to introduce independent assessments must be considered in the light of these inequitable outcomes for people from CALD communities. No proposal that has the potential to create further barriers for people from CALD backgrounds should go forward.

2. Barriers to NDIS participation for people from CALD backgrounds

From the perspective of the Community Connectors team, there are several barriers to accessing the NDIS for people from CALD backgrounds.

Currently, NDIS applicants need to gather several supporting documents from their GP, allied health practitioners, therapists, and any other support services they use. These supporting documents are gathered over a series of appointments so that specialists can gather information that is comprehensive and accurate.

ECCV Community Connectors have reported that CALD communities continue to find the NDIS access process difficult to navigate and confusing.

“A mother from a Chinese background approached me to help gain NDIS access for her 15-year-old son. Her son had been diagnosed with autism as a child and she just thought it was something he would grow out of. Her doctor told her to apply for NDIS access back then, but she found it overwhelming and didn’t understand the process. She is now attempting to apply for access again as her son’s needs become more severe.”

² NDIS (2019) Culturally and Linguistically Diverse participants | 30 June 2019 | 1 Culturally and Linguistically Diverse participants’, available at: <https://data.ndis.gov.au/media/1946/download#:~:text=As%20of%2030%20June%202019,8.4%25%20of%20all%20sc heme%20participants.>

ECCV Community Connector

Some of the major barriers include the current access process, a lack of engagement with mainstream service providers, the stigma around disability, and access to interpreting and translation services. In order to gain NDIS access, potential participants are required to gather supporting evidence from their GP, therapists, specialists, and schools. In cultures where disability still carries a heavy stigma and is often hidden, the act of seeking evidence to support the existence of disability can be confronting and emotionally challenging.

The shame and stigma around disability is a major barrier that prevents families from CALD backgrounds from seeking NDIS access. ECCV is concerned that independent assessments will present yet another hurdle for CALD communities to overcome when trying to access the NDIS. ECCV is concerned that the NDIA has not sufficiently consulted CALD community organisations, relevant peak bodies, or people with disabilities from CALD backgrounds and their carers. Several disability advocacy organisations have come out in condemnation of the independent assessment proposal, arguing it is inhumane and forces people with disabilities to perform activities they cannot complete.³

One of the first families supported by the ECCV Community Connectors was hesitant to seek NDIS access, despite their child living with an intellectual disability since birth. The parents were older and spoke English as a second language. They found the NDIS access process confusing and required several one-on-one sessions with a Community Connector to build their trust and understanding of the NDIS before successfully gaining access. Their first access request was denied because not enough information about the child and her disability was shared. The mother was very reluctant to share details about her daughter's disability and was very protective over her. The Community Connector had to slowly build a relationship with the family for them to trust her.

3. Concerns about implications for access for people from CALD backgrounds if independent assessments are introduced

Despite barriers within the current access process, the proposed independent assessment is unlikely to improve access, and is likely to create further barriers for people from CALD backgrounds.

One of the most common concerns raised by Community Connectors about independent assessments is that they cannot accurately capture a diverse range of disabilities and are unsuitable for a diverse range of people.⁴ Community Connectors have raised concerns about the appropriateness of participants having to demonstrate incapability and self-rank their abilities in front of a panel. According to one Community Connector, questions around financial literacy and

³ Office of the Public Advocate (2020) 'Position statement: NDIS Independent Assessments', available at: <https://www.publicadvocate.vic.gov.au/media-centre/415-opa-position-statement-ndis-independent-assessments>

⁴ Every Australian Counts (2021) 'Disability sector statement on the Australian Government's planned reforms to the National Disability Insurance Scheme (NDIS)', available at: <https://everyaustraliancounts.com.au/ndis-sector-statement/>

personal care are often experienced as disrespectful, intrusive and confronting. She reported that members from her community would feel even more uncomfortable if an assessor of a different gender was asking these questions.

ECCV is also concerned that independent assessors will not be able to gain a genuine understanding of a person's functional capacity in a standardised, three-hour assessment. The NDIS has identified only 6 tools to test all current and future NDIS participants, regardless of their age, disability, sexuality, or cultural or linguistic background. This will be insufficient to accurately capture the support needs of people with disability from CALD backgrounds. The NDIS held a limited number of pilots to test the viability of the assessment tools between 2019 and 2020. In the first trial, only 35 people out of 513 were from CALD backgrounds. In the second trial, 10 people out of 99 were from CALD backgrounds.⁵ Notably, the NDIS Selection of Assessment Tools paper reports that only 3 of the 6 tools have cultural validity (defined as the degree to which the performance of the items on a translated or culturally adapted measurement instrument are an adequate reflection of the performance of the items of the original version of the measurement instrument).⁶

ECCV is concerned that the independent assessments will be an intimidating new hurdle that participants will be forced to undertake. ECCV has repeatedly heard that the news of independent assessments would result in feelings of stigma and fear. Developing trust to disclose experience of disability requires time and skilled, culturally responsive practice. ECCV has seen no evidence that assessors will possess sufficient knowledge and competency to elicit accurate assessments from people from CALD backgrounds.

"Families would feel confronted and ashamed if they had to share personal information and demonstrated their incapacity in front of a panel of strangers. It took weeks to get some participants to trust me and start sharing details of how their disability affects them"

ECCV Community Connector

There are also concerns about the organisations that have been contracted to hire assessors. NDIA recently announced the eight private organisations that will be responsible for hiring assessors in Victoria. According to NDIA, they were selected based on "capability, experience, and expertise".⁷ There is no mention of the organisations displaying strong levels of cultural competency and awareness. The selection criteria for assessors only addresses allied health professionals who have a minimum of 12 months clinical experience, have previously used standardised assessment tools, and have experience in working with a variety of clients. ECCV is concerned that there are

⁵ NDIS (2021) 'Independent Assessments: Pilot learning and ongoing evaluations', available at: <https://www.ndis.gov.au/media/2686/download>

⁶ NDIA (2020) 'Selection of Assessment tools', page 19, from <https://www.ndis.gov.au/media/2683/download>

⁷ NDIA (2021) 'Independent Assessment Panel Announced', found at <https://www.ndis.gov.au/news/6118-independent-assessment-panel-announced>

insufficient measures in place to ensure that assessors are culturally competent to address the needs of people from CALD backgrounds.

4. Opportunities to improve cultural responsiveness and access to NDIS for people from CALD backgrounds

Updating the NDIA Cultural and Linguistic Diversity Strategy to reflect best practice approaches to cultural responsiveness

The NDIA Cultural and Linguistic Diversity Strategy for 2018 aimed to build the NDIA's understanding of CALD communities, embed this understanding into the design and administration of the NDIS, and to enhance the NDIS experience for CALD participants.⁸ The Strategy must reflect current best practice approaches to cultural responsiveness. This includes co-design and co-production of cultural responsiveness initiatives with people with lived experience and specialists.

The Strategy must also put stronger accountability measures in place for sub-contractors regarding their cultural responsiveness. This must include any sub-contractors providing assessments, Local Area Coordination, and Early Childhood Early Intervention Coordination. ECCV strongly recommends that all Partners in the Community (PITCs) have strong accountability for demonstrated cultural awareness and requirements to undertake regular cultural competency training built into contracts, monitoring and evaluation.

Co-design access pathways with people with disability and their families

ECCV strongly recommends that the NDIA reviews its access process by co-designing the process with people with disability. This process should involve specific attention to the access pathways for people from CALD backgrounds, Aboriginal and Torres Strait Islander Peoples, people living in rural and regional areas, and ageing carers of people with disabilities. Stronger engagement should include greater representation of CALD communities in future trials and pilots. ECCV recommends ongoing community consultations to ensure the future of the NDIS is community-informed and lead.

Continue funding for the NCCP for a minimum of 3 years

The NCCP provides free, culturally responsive support to underrepresented community groups.

The NCCP is funded until 30 June 2021. ECCV strongly recommends that the Commonwealth Government extends the Program.

Building trust and understanding within CALD communities takes time. It would be detrimental to community trust and perception to offer the NCCP as a short-term solution to one of the NDIA's most ongoing issues.

⁸ NDIS (2018) Culturally and Linguistically Diverse Strategy 2018, available at: <https://www.ndis.gov.au/about-us/strategies/cultural-and-linguistic-diversity-strategy>

Some CALD communities may have complex relationships with government agencies and therefore may find it harder to actively seek assistance and engage with services. Community Connectors from similar cultural backgrounds can help address these barriers and fears. Some people from CALD backgrounds have stigmas and feelings of shame in relation to disability. The NDIS does not address these cultural factors as barriers to gaining access. Community Connectors have been actively engaging with their communities to help break down these stigmas. Many Community Connectors openly shared their experience of living with disability and how they gained NDIS access for themselves. This has encouraged more community members to step forward and begin their NDIS journeys.

Community Connectors provide confidential, person-centered support. This helps community members feel secure and build their knowledge of the NDIS at their own pace.

ECCV recommends that the Commonwealth Government extends the NCCP for a minimum of 3 years.

Conclusion

Thank you for the opportunity to contribute to the Committee's Inquiry. ECCV is pleased to contribute to this Inquiry from the direct experience of working with people who are excluded and who face barriers to accessing the NDIS. ECCV hopes the Committee will centre the lived experience of people facing barriers to access in its findings and recommendations.

For further information please contact ECCV Executive Officer Chris Christoforou on 03 9354 9555 or eccv@eccv.org.au.

Sincerely,

A handwritten signature in black ink, appearing to read 'Eddie Micallef', enclosed in a thin black rectangular border.

Eddie Micallef
Chairperson