

Submission to the Royal Commission on the Culturally and Linguistically Diverse people with disability issues paper

All Australians with disability have a right to high-quality disability support. Central to the National Disability Insurance Scheme (NDIS) is the concept of person-centred services, whereby disability service provision considers the support needs of individuals, inclusive of their many interacting identities; their language and cultural background may be fundamental to who they are and what it means to live a good life.

Unfortunately, there are numerous instances where people from culturally and linguistically diverse backgrounds are not achieving equity of service provision. This submission considers strengths of disability service provision in supporting people from culturally and linguistically diverse backgrounds, and areas for improvement.

Guiding principles

To guide some of the issues addressed in this submission, a number of fundamental principles are important to note. They are aspirational and non-exhaustive.

Equity

Disability service provision must be underpinned by equity: that one person may require more support to achieve the same outcomes as another. In some cases, a person's cultural background may also mean they require extra supports to achieve similar outcomes to those from other backgrounds. A practical example is the use of an interpreter in developing an NDIS plan. The principle of equity suggests that this adjustment should not be seen as an 'add-on' – but is a right, facilitating equitable access to services.

Person-centredness

The NDIS has person-centredness as a primary pillar. Language and culture may be central to a person's identity. Disability services must be delivered in culturally appropriate ways, supporting a person to express their cultural identity. People must not be supported 'regardless of' their cultural background – rather, their background may be a central part of how they receive supports. (See an example in the *Workforce* section, below.)

Importance of co-design

There is a tendency for policy to reflect the implicit views and backgrounds of those making it. Moves towards co-design are an attempt to address this by making decisions with the people they will affect. This may also have important implications where the service user's culture differs from the dominant culture; in some cases, this can mean certain cultural values are assumed to be the 'default'. One example

National Disability Services

Submission to the Disability Royal Commission on the CALD people with disability issues paper

is the way different cultures consider independence and individualism, which is explored in more detail below.

Non-discrimination

Racism and discrimination are unacceptable. While there may be a tendency to focus on explicit and overt displays of these, it is important to understand the subtle and implicit forms racism and discrimination can take. It is often these less-obvious biases which result in institutional forms of discrimination. In some cases, people can experience racial injustice not because of any person *doing* something, but because of a person (or a number of people) *not* doing anything. A lack of cultural diversity among staff may send implicit signals to prospective service users. Organisations should constantly reflect about how they may be upholding racist or racially discriminatory practices: in the same way that organisations should not assume abuse 'couldn't happen here', they should not assume racism or discrimination 'couldn't happen here'.

NDIA CALD Strategy

Published in 2018, the National Disability Insurance Agency's (NDIA) Culturally and Linguistically Diverse Strategy¹ outlines the Agency's approach to working with culturally and linguistically diverse people under the NDIS. An updated strategy is well overdue.

The document notes worthy principles – particularly in respectful engagement with communities – but it lacks clear objectives or concrete actions, making it less likely to 'drive increased participation in the NDIS' by culturally and linguistically diverse people with disability, as the NDIS website suggests.² The strategy asserts its implementation will be driven by an 'Implementation Guide', however NDS has not been able to locate such a guide. The Joint Standing Committee on the NDIS noted in December 2020 that the strategy and the measures the NDIA had taken to increase cultural competency of staff and community partners 'may be insufficient to address issues experienced by people with disability from culturally and linguistically diverse backgrounds seeking to access the NDIS'.³

NDS is not aware of any evidence of a response to the Joint Standing Committee's recommendation in 2020 that the strategy be updated.⁴ Of particular concern is the disparity between the NDIA's expected proportion of NDIS participants from

¹ NDIA. (2018). *Cultural and Linguistic Diversity Strategy 2018*.

<https://www.ndis.gov.au/media/316/download>

² NDIA. (n.d.) *Cultural and Linguistic Diversity Strategy 2018*.

<https://www.ndis.gov.au/about-us/strategies/cultural-and-linguistic-diversity-strategy>

³ Commonwealth of Australia. (2020). *Joint Standing Committee on the NDIS: General issues*, p. 105.

https://parlinfo.aph.gov.au/parlInfo/download/committees/reportjnt/024349/toc_pdf/GeneralIssues.pdf;fileType=application%2Fpdf

⁴ *Ibid*, p. 106.

National Disability Services

Submission to the Disability Royal Commission on the CALD people with disability issues paper

culturally and linguistically diverse backgrounds outlined in the strategy ('about 20 percent')⁵ and the actual figure (9.4%)⁶.

A revamped culturally and linguistically diverse Strategy should include:

- A clear figure representing the expected proportion of NDIS participants from culturally and linguistically diverse backgrounds (and assumptions used to reach this figure).
- A concrete set of actions the NDIA and community partners will undertake to reach this target, with milestones and indications of how progress will be reported.
- A commitment to regular reporting of outcomes for culturally and linguistically diverse versus non-culturally and linguistically diverse NDIS participants, and associated actions being undertaken to achieve parity.
- A clear commitment to Scheme equity: that no participant will be worse off due to their cultural or linguistic background.
- Consideration for 'meeting communities where they are' – including by engaging community leaders, and providing information at community forums.
- A recognition of various communities' preferences for communications and engagement – including face-to-face, or at a community centre.
- Actions for how to address the reluctance some communities have for using government services.
- Consideration given to introducing the role of culturally and linguistically diverse liaison officers in harder to reach communities.

The 2018 strategy notes various factors – such as language, length of time in Australia and geographic location – can affect a person's confidence and ability to access supports.⁷ An updated strategy should include actions the NDIA will undertake to address these identified factors. In 2019, an extensive report comparing data on culturally and linguistically diverse and other participants was published by the NDIA.⁸ This level of transparency is welcome; it should be regularly repeated, and extended to provide an analysis to inform actions.

NDIS Access

The NDIS is achieving life-changing results for many people with disability. However, it cannot support a person to achieve their goals if they cannot access the scheme; much less if they do not know of its existence. It has been suggested that knowledge

⁵ NDIA. (2018). *Cultural and Linguistic Diversity Strategy 2018*, p. 5.
<https://www.ndis.gov.au/media/316/download>

⁶ NDIA. (2021). *NDIS Quarterly Report to disability ministers: 31 March 2021*, p 111.
<https://www.ndis.gov.au/about-us/publications/quarterly-reports>

⁷ NDIA. (2018). *Cultural and Linguistic Diversity Strategy 2018*, p. 9.
<https://www.ndis.gov.au/media/316/download>

⁸ NDIA. (2019). *Culturally and Linguistically Diverse participants: 30 June 2019*.
<https://data.ndis.gov.au/media/1946/download>

National Disability Services

Submission to the Disability Royal Commission on the CALD people with disability issues paper

of the existence of services is as important, if not more important, than ‘the multi-lingual information on service availability, eligibility and application process, and provision of culturally appropriate services’.⁹

Using NDIA figures, the percentage of culturally and linguistically diverse people with disability utilising the NDIS is less than half what was originally anticipated.

Cultural attitudes may impact on a person with disability’s (and their family’s) decisions to access disability support. Some people may distrust government services; others may see supporting a family member with disability as a duty of the family.¹⁰ While these may create particularly difficult scenarios, they should not be viewed as a reason to not give a culturally and linguistically diverse person with disability every opportunity to access and engage with the NDIS.

In some cases, a person with disability’s views can differ from those of their family or their community. The role of both advocates and disability service providers can be particularly relevant if a culturally and linguistically diverse person is at odds with their informal supports – whether that be highlighting a person’s entitlements to services, or addressing potential stigma.

For the culturally and linguistically diverse people who do apply for the NDIS, they are less likely to be found eligible than other applicants: the NDIA reports a 76% success rate for culturally and linguistically diverse versus 83% for non-culturally and linguistically diverse applicants.¹¹

Access to the scheme is unfortunately not uniform for all people with disability. There are indications that characteristics like assertiveness, command of English, socio-economic status, geographic location and social capital may have an impact on a person’s likelihood of achieving a package – as well as the size of the package.¹² This is supported by academic research that suggests personalisation schemes can entrench social inequalities.¹³ The Tune Review identified disengagement (including

⁹ Zhou, Q. (2016). Accessing disability services by people from culturally and linguistically diverse backgrounds in Australia. *Disability and Rehabilitation*, 38(2), p. 851. <https://doi.org/10.3109/09638288.2015.1062925>

¹⁰ Boughtwood, D., Shanley, C., Adams, J., Santalucia, Y., Kyriazopoulos, H., Pond, D., & Rowland, J. (2011). Culturally and linguistically diverse (CALD) families dealing with dementia: An examination of the experiences and perceptions of multicultural community link workers. *Journal of Cross-Cultural Gerontology*, 26(4), 365–377. <https://doi.org/10.1007/s10823-011-9155-9>

¹¹ NDIA. (2019). *Culturally and Linguistically Diverse participants: 30 June 2019*, p. 7. <https://data.ndis.gov.au/media/1946/download>

¹² Hui, F., Cortese, C., Nikidehaghani, M., Chapple, S. & McCombie, K. (2018). *Hard to Reach: Examining the National Disability Insurance Scheme Experience, A Case study in Wollongong*. University of Wollongong Australia. <https://documents.uow.edu.au/content/groups/public/@web/@bus/documents/doc/uow252343.pdf>

¹³ Carey, G., Crammond, B. & Malbon, E. (2019). Personalisation schemes in social care and inequality: review of the evidence and early theorising. *International Journal for Equity in Health*, 18. <https://doi.org/10.1186/s12939-019-1075-2>

National Disability Services

Submission to the Disability Royal Commission on the CALD people with disability issues paper

by culturally and linguistically diverse people) as one of the biggest risks in implementing independent assessments.¹⁴

People with disability from culturally and linguistically diverse backgrounds may not have the same access to medical documentation and identity records required to apply for NDIS access. A newly-arrived migrant may not be able to simply contact their GP and request medical records in the way an Australian-born person may. This is borne out in the data: 'evidence not provided' was the reason given for 50% of prospective culturally and linguistically diverse participants denied NDIS access, compared to 38% of other participants denied access.¹⁵ Further, medical records are sometimes key in appeals decisions.¹⁶

Disability service provision

A series of challenges exist for culturally and linguistically diverse people with disability who are able to access services. A short summary of each of these is included below.

Communication

- **NDIS language and processes:** The NDIS is a complex scheme and its 'language' can be particularly difficult to grasp, even for native English speakers. In many instances, there are not simple translations for concepts like 'goal', 'plan' or 'coordinator'. The Joint Standing Committee on the NDIS identified systemic issues 'such as complex language and bureaucratic processes – which are compounded by CALD-specific challenges such as language barriers and gaps in the cultural competency of serviced [sic] providers'.¹⁷
- **Interpreters:** The availability of interpreters varies across geography and language groups. Where interpreters are not available, or deemed (by the NDIA or LAC) to be unnecessary, there is evidence of bilingual LACs or

¹⁴ Commonwealth of Australia. (2020). *Joint Standing Committee on the NDIS: General issues*, p. 27.

https://parlinfo.aph.gov.au/parlInfo/download/committees/reportjnt/024349/toc_pdf/Generalissues.pdf;fileType=application%2Fpdf

¹⁵ NDIA. (2019). *Culturally and Linguistically Diverse participants: 30 June 2019*, p. 23. <https://data.ndis.gov.au/media/1946/download>

¹⁶ University of Notre Dame Australia & the Multicultural Disability Advocacy Association. (n.d.). *Submission to the Joint Standing Committee on the NDIS Inquiry into General Issues around the implementation and Performance of the NDIS*, p. 5. <https://www.aph.gov.au/DocumentStore.ashx?id=8699f19c-192e-48ac-9ca9-c81be5115517&subId=685495>

¹⁷ Commonwealth of Australia. (2020). *Joint Standing Committee on the NDIS: General issues*, p. 101.

https://parlinfo.aph.gov.au/parlInfo/download/committees/reportjnt/024349/toc_pdf/Generalissues.pdf;fileType=application%2Fpdf

National Disability Services

Submission to the Disability Royal Commission on the CALD people with disability issues paper

informal supports being used instead.¹⁸ Providers sometimes opt for quick informal interpreting where the alternative (for example, a two-week lag in booking an interpreter) is impractical. The use of informal supports for interpreting is potentially problematic – especially where the informal support may be abusive or exploitative.

Having a right to interpretation is different from knowing about that right. There are suggestions that it is not common knowledge (including among NDIA staff and LACs) that NDIS plans can be made available in languages other than English.¹⁹

- **Translation is not communication:** Having documents in multiple languages is an essential part of the NDIS; however it is often not sufficient for communities to receive the message. It would be naïve to presume people will go to the NDIS website to seek out information – particularly if they recently arrived in Australia or if English is not their first language.²⁰ What is needed is pro-active ‘reaching in’ to communities: engaging with community leaders, making information available in community newsletters, and the development of recognition and rapport over time.
- **Language may mask disability:** NDS has heard of an instance where a person’s previously undiagnosed psychosocial disability came to light due to the involvement of a translator. While no psychosocial disability was detected when the person spoke in broken English, an interpreter’s identification that they were not making sense in their native language was the trigger for considering a diagnosis.

Quality and Safeguarding

- **Complaints:** The NDIA notes ‘the complaint rate for CALD participants has been consistently lower than for other participants over the last ten quarters’.²¹ At March 2019, 6.6% of non-culturally and linguistically diverse participants made complaints compared to 4.7% of culturally and linguistically diverse

¹⁸ Commonwealth of Australia. (2020). *Joint Standing Committee on the NDIS: General issues*, p. 102.

https://parlinfo.aph.gov.au/parlInfo/download/committees/reportjnt/024349/toc_pdf/GeneralIssues.pdf;fileType=application%2Fpdf

¹⁹ Commonwealth of Australia. (2020). *Joint Standing Committee on the NDIS: General issues*, p. 103.

https://parlinfo.aph.gov.au/parlInfo/download/committees/reportjnt/024349/toc_pdf/GeneralIssues.pdf;fileType=application%2Fpdf

²⁰ Zhou, Q. (2016). Accessing disability services by people from culturally and linguistically diverse backgrounds in Australia. *Disability and Rehabilitation*, 38(2), p. 850-51. <https://doi.org/10.3109/09638288.2015.1062925>

²¹ NDIA. (2019). *Culturally and Linguistically Diverse participants: 30 June 2019*, p. 31. <https://data.ndis.gov.au/media/1946/download>

National Disability Services

Submission to the Disability Royal Commission on the CALD people with disability issues paper

participants.²² NDS members suggest the propensity for people from some cultural backgrounds to complain is lower as they consider complaining to be 'making a fuss'. If this translates to the reporting of abuse and exploitation, the implications are particularly concerning. A national version of the Victorian Ombudsman's highly successful '[It's OK to Complain!](#)' campaign, redesigned for culturally and linguistically diverse communities, may go some way to addressing this hesitancy.

- **Risks:** Lack of knowledge of Australian law and government services – combined with a reluctance to 'make a fuss' – may place some culturally and linguistically diverse people with disability at greater risk of being taken advantage of. Any ambiguities about 'sharp practice' in NDIS service provision may be more easily exploited using language barriers or lack of knowledge. In some cases, service users prioritise strong cultural connection with workers over traditional hallmarks of service quality. In an ideal scenario, a culturally and linguistically diverse service user would have access to high-quality supports and strong cultural connection.

Workforce

- **Demographics:** People from culturally and linguistically diverse backgrounds may have certain preferences about the person supporting them – including gender and/or cultural background. For example, for religious reasons a person receiving personal care may only wish to be supported by someone of the same gender. These requests should be facilitated as far as is possible. Still, service providers are faced with difficult questions about whether it is appropriate to recruit for people from a specific cultural background. These objectives will only be able to be sustainably met with by national workforce strategy which considers cultural diversity as essential to the provision of person-centred services. NDS has heard some culturally and linguistically diverse service users prefer gig-based providers due to their ability to select the worker (based on their cultural background) directly.
- **Relationships:** NDS members highlight the importance of relationships, and of building rapport, in supporting culturally and linguistically diverse participants and their families. The building of a strong personal relationship between providers and families is a positive thing, but it can lead to challenges. A reliance on personal relationships can mean a tenuousness of service provision: for example, a particular worker moving to another job may mean a participant or family disengages entirely from services. Consideration of an NDIS culturally and linguistically diverse liaison officer-type role may address this.

²² NDIA. (2019). *Culturally and Linguistically Diverse participants: 30 June 2019*, p. 9. <https://data.ndis.gov.au/media/1946/download>

National Disability Services

Submission to the Disability Royal Commission on the CALD people with disability issues paper

NDIS design

- **Independence and individualism:** A key aspiration built into the NDIS is independence: the notion that, with good supports, a person with disability may become less reliant on others, and that this is a positive thing. It may be useful to reflect on the extent to which this reflects Anglo virtues, where other cultures may prioritise family or community over individualism and independence. Concepts such as filial piety (that children should care for their parents)²³ and the Spanish concept of *familismo* (the needs of the family are prioritised over individuals in the family)²⁴ are points of contrast. While independence is a key aspiration for many people with disability, attention should be paid to what the service user's priorities and values are, rather than assume certain values are universal.
- **NDIS market:** The NDIS market is not necessarily conducive to smaller providers, outside of specialisation. For culturally and linguistically diverse organisations, depending on the cultural backgrounds they support, specialisation can be prohibitive and may not give them the scale they need to be sustainable. As a result, ethno-specific providers may need to expand in other areas – providing both disability and aged care supports, for example.

There is a need for greater support for ethno-specific service providers; as well as 'mainstream' (non-ethno-specific) providers becoming more culturally appropriate. A culturally and linguistically diverse provider noted the lack of incentive for mainstream providers to support culturally and linguistically diverse service users – given the extra 'friction' created at each interaction due to the need for interpretation services, for example.

The Deaf community

Many people in the Deaf community identify as culturally and linguistically diverse. Their first language may be Auslan (Australian Sign Language); English may be a second or third language. It must not be assumed that all Deaf people are able to understand written English. In addition, some Deaf people do not associate deafness with disability.

For people who speak Auslan, disadvantage can occur in forums where Auslan is not being spoken and there are no interpreters available. A lack of Auslan interpreters has persisted across many parts of Australia – often more pronounced in regional and rural areas.

The use of interpreters is particularly pertinent when considering abuse. Access to an Auslan interpreter may impact a Deaf person's willingness to disclose abuse.

²³ Shea, J., Moore, K. & Zhang, H. (2020). Introduction. In Shea, J., Moore, K. & Zhang, H. (Eds.), *Beyond Filial Piety: Rethinking Aging and Caregiving in Contemporary East Asian Societies* (pp. 1-40). Berghahn Books Incorporated.

²⁴ Toro-Morn, M. I. (2012). Familismo. In: S. Loue & M. Sajatovic (Eds), *Encyclopedia of Immigrant Health* (pp. 672-4). Springer, New York, NY.

National Disability Services

Submission to the Disability Royal Commission on the CALD people with disability issues paper

Aforementioned issues also arise if the person's (particularly informal) interpreter is also their abuser. There are particular risks for Deaf children who are not identified as Deaf, as lack of ability to communicate can lead to isolation.²⁵ Some Deaf children are discouraged from speaking in Auslan, with the view that encouragement to speak English is a positive thing. Some risk factors identified for Deaf children experiencing abuse are: no exposure to other Deaf people; deprivation of early language development; and discouragement from learning about the Deaf community.²⁶

Asylum seekers and migration

People with disability seeking asylum face additional challenges on top of those identified above. They may have histories of abuse and trauma; they may have undertaken a gruelling journey to reach Australia; returning to their country of origin may be dangerous; and it is likely they have limited access to the medical documentation often required for NDIS access.

NDIS requirements include that the person be an Australian citizen, or hold a permanent visa²⁷ and there are additional residence requirements based on the state the person lives in. While people who have been granted refugee status are given permanent residency (and so may be eligible for the NDIS), those seeking asylum are not. As a result, a person's access to disability services can turn on their success in seeking refugee status.

The eligibility process to become a refugee includes meeting health requirements, including for family members.²⁸ These include that a person must not have a health requirement considered 'a significant healthcare and community service cost to the Australian community'.²⁹

Closely related are a series of cases – some attracting media attention – where migrant (non-asylum-seeking) families have faced deportation due to a family member's disability being considered to create an 'undue cost' to the Australian community under the *Migration Act 1958*. This is still the case, despite a Joint Standing Committee Inquiry noting in 2010 that the policy 'reflects old-fashioned

²⁵ Ridgeway, S. M. (1993). Abuse and Deaf Children: Some Factors to Consider. *Child Abuse Review*, 2, pp. 166-173. <https://doi.org/10.1002/car.2380020306>

²⁶ Ibid.

²⁷ Or a 'special category visa', available only to New Zealand citizens. See: NDIA. (2019). *Access to the NDIS - The residence requirements*.

<https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-residence-requirements>

²⁸ Department of Home Affairs. (2021). *Subclass 200, 201, 203 and 204: Refugee category visas*. <https://immi.homeaffairs.gov.au/visas/getting-a-visa/visa-listing/refugee-200#Eligibility>

²⁹ Department of Home Affairs. (2020). *Health: Protecting health care and community services*. <https://immi.homeaffairs.gov.au/help-support/meeting-our-requirements/health/protecting-health-care-and-community-services>

National Disability Services

Submission to the Disability Royal Commission on the CALD people with disability issues paper

approaches to disability in particular and so unfairly discriminates against those who have disability'.³⁰

Conclusion

Every person with disability living in Australia is entitled to high-quality disability services. For many, their language or cultural background forms a large part of who they are – and this should be considered in the way services are provided to them. There is a role of ethno-specific disability providers, as well as improvement in the cultural awareness of 'mainstream' providers. A renewed NDIS Culturally and Linguistically Diverse strategy is an opportunity to set out concrete actions for ensuring culturally and linguistically diverse people with disability can access supports on the same basis as other people with disability.

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National Disability Services is the peak industry body for non-government disability services. It represents service providers across Australia in their work to deliver high-quality supports and life opportunities for people with disability. Its Australia-wide membership includes almost 1200 non-government organisations which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.

³⁰ Commonwealth of Australia. (2010). *Enabling Australia: Inquiry into the Migration Treatment of Disability*, Joint Standing Committee on Migration. p. x.
https://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=mig/disability/report.htm