

Improving Equity in the NDIS

Independent Advisory Council to the NDIS
Formal Advice – May 2022

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Section 1: Improving Equity in the NDIS

1 Executive Summary

The aim of this Advice is to improve equity of access, participation, and outcomes in the NDIS¹ with specific reference to participants who identify as Aboriginal and Torres Strait Islanders², as culturally and linguistically diverse (CALD) and as lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual (LGBTIQA+³). This will require a related aim of ensuring the NDIS has the competence and capacity to enable all people with disability and where appropriate their families, to feel culturally safe.

The evidence base for this Advice is built on the relevant research literature and detailed consultations with leaders in the Aboriginal and Torres Strait Islanders, CALD and LGBTIQA+ communities. The assumption that diversity is inherently supported in a person-centred Scheme such as the NDIS was found not to be correct with evidence of design and delivery features that make it more difficult for some participants to access and maximise the opportunities available.

The evidence highlighted the fact that people with disability experience the same diversity of characteristics and life experiences as the broader population including being part of a group or groups that may have experienced exclusion, discrimination, and stigma. Whilst there are similarities within groups related to their experience, each person's sense of themselves and their sense of the 'best' way to meet their disability support needs, is shaped by their disability, the potentially multiple characteristics of disadvantage they experience and their own social, cultural, linguistic, psychological, and religious characteristics.

Hence Council recommends that the NDIA and Partners in the Community (PiTC) embrace the diversity inherent in NDIS participants and like Australia's Disability Strategy, underpin all work with an intersectional⁴ framework that acknowledges the dynamics of power and social inequality in society and facilitates an understanding of the multiple forms of discrimination and disadvantage arising from the overlapping characteristics that are not privileged by society. An intersectional framework will assist the NDIA to better understand and respond to complexity and work towards creating and sustaining a NDIS that is inclusive, safe, responsive, and accountable for all.

Leaders of the three communities acknowledged the many NDIA strategies aimed at delivering equity but actuarial data continues to show differential access, participation and outcomes for participants of these groups. There was consensus that to make a difference, a more structural approach is required to address the social determinants of the inequity and

¹ Including the NDIA and its Partners in the Community (PiTC) and support providers.

² Aboriginal and Torres Strait Islanders is the term preferred in this Advice. Other names are only used as cited by literature.

³ LGBTIQA+ is the term preferred in this Advice. Other acronyms are only used as cited by literature.

⁴ 'Intersectionality' refers to the ways in which different aspects of a person's identity can expose them to overlapping forms of discrimination and marginalisation. Further information is outlined in S 8.3 and in the glossary

enable the NDIA, PiTC and support providers to become culturally competent organisations that enable participants to feel culturally safe.

The Advice scopes the challenges and enablers to equity and recommends a refreshed approach that is Co-Designed with representatives of the target groups with the vision of

The NDIS is inclusive, safe, and responsive, and assists all Australians with disability to meet their disability support needs in ways that achieve equitable outcomes.

The refreshed approach has intersectionality at its core and is based on solid NDIA foundations of:

- Upholding insurance principles and Scheme sustainability;
- Meeting obligations under human rights conventions as outlined in the *NDIS Act*;
- Ensuring systems, processes, policies, and practices are culturally competent to respond to the rich diversity of NDIS participants; and
- Valuing diversity and cultural safety as core Scheme values.

Principles of engagement to operationalise the refreshed approach assume:

- Shared access to data and information between the NDIA and participants and their representative organisations;
- Elements of Scheme design that impact on participants are Co-Designed and decision making is shared⁵;
- All work aims to:
 - Build the cultural competence of NDIS and PiTC; and
 - Strengthen the systemic approach to participant self-determination, capacity and decision making.

Advice of this nature cannot lead to a simple ‘quick fix’ list of recommendations. Instead, Council calls on the NDIA to:

1. Adopt an intersectional approach to better understand and respond to complexity and work toward creating and sustaining an NDIS that is inclusive, safe and responsive to all;
2. Work with representatives of the target communities⁶ to Co-Design the long-term structural work required to improve equity using the indicators proposed to enable the NDIA and the disability community to monitor progress; and

⁵ consistent with NDIA (March 2022) ‘Our engagement framework’

⁶ Including the LGBTIQ+ community that does not have a peak or Disabled Persons’ Representative Organisation.

3. Work with representatives of the target communities to Co-Design a plan for action over the next 2 years as a first step toward implementing the spirit of the Advice.

A full set of indicators by which the NDIA and the community can monitor progress toward improved equity are provided in the Advice. High level indicators of good practice that will measure improved equity include:

Indicators for participants

- Numbers of participants consistent with ABS data;
- Equitable plan size, plan utilisation, use of non-Agency managed options;
- Equitable social and economic participation including in open employment;
- Equitable outcomes in life domains for participant and families;
- Equitable quality of life measures for participants and families; and
- Equitable reports that NDIS has helped in life domains;
- Equitable reports that people feel safe in their interaction with the NDIA, PiTC and support providers.

Indicators for the NDIA including PiTC

- Systems, information, services and supports deliver outcomes that are fair for all;
- Resource allocation of resources is based on disability support needs and personal and environmental factors; and
- The NDIS has the competence and capacity to enable all people with disability and where appropriate, their families, to feel culturally safe when dealing with the NDIS.

CASE STUDY: Operationalising the refreshed approach to NDIS outreach

The Advice provides a starting point to clarify the way in which the foundations and engagement principles could be operationalised using the function of outreach. Table 1 showcases high level features of the analysis that could be used throughout the Participant Pathway in a Co-Design process to explore what is required to extend this approach at scale.

TABLE 1: OPERATIONALISING THE REFRESHED APPROACH TO NDIS OUTREACH

Outreach	Shared access to data and information	Co-Design and shared decision making⁷	Cultural competence of the NDIS	Systemic approach to self-determination
Insurance principles/ Scheme sustainability	<i>Shared understanding of challenges of participants and Scheme.</i>	<i>Develop joint understanding of insurance principles related outreach.</i>	<i>Understand requirements of cultural safety in context of insurance principles</i>	<i>Work with diverse communities to enable prospective participants to access NDIS or use mainstream services.</i>
Human Rights obligations	<i>Develop data and information to map rights and barriers and enablers to their fulfilment</i>	<i>Develop joint understanding of rights and barriers to their fulfilment related to areas of NDIS responsibility.</i>	<i>Plan outreach requirements of outreach in response to analysis of human rights obligations and cultural requirements</i>	<i>Assist participants and their families/ advocates to know their rights and speak up if their rights are violated</i>
Build systems and approaches that reflect the diversity of Australian society Intersectional considerations	<i>Map challenges on individual and community level</i> <i>Develop data sources to measure impact of multiple disadvantage</i>	<i>Co-Design map of intersectional challenges and develop plan to overcome</i>	<i>Plan outreach processes in response to analysis of removal / mitigation of intersectional challenges</i>	<i>Assist participants and their families to have access to culturally competent, disability friendly services</i>

⁷ consistent with NDIA (March 2022) 'Our engagement framework'

Outreach	Shared access to data and information	Co-Design and shared decision making⁷	Cultural competence of the NDIS	Systemic approach to self-determination
Value diversity and cultural safety	<p>Identify strengths of communities that can be harnessed to support people with disability</p> <p>Showcase strengths and how others can replicate</p>	<p>Map barriers and enablers at individual and systemic level and develop, implement, and monitor approach</p>	<p>Support participants, their families, and communities to identify positive contributions.</p>	<p>Work with individuals, families, and communities to highlight strengths.</p> <p>Co-Design and monitor implementation of approaches that strengthen individual choice, capacity and decision making</p>

Outcome of a refreshed approach to Outreach

People with disability and where appropriate, their families have confidence to approach the NDIS for information, referral and support to be included in community.

NDIA and PiTC that are well connected to and trusted by organisations in the community as well as trusted directly by individuals with disability and families.

Outreach is undertaken by organisations and staff who:

- Are trusted by communities;
- Have demonstrated capability to:
 - Understand challenges and contributions of individuals and communities;
 - Strengthen individual choice, capacity and decision making; and
 - Assist people to select services for which there is likely to be a cultural fit.

2 Aim

The aim of this Advice is to improve equity of access, participation, and outcomes in the NDIS with specific reference to participants who identify as Aboriginal and Torres Strait Islanders, from culturally and linguistically diverse (CALD) communities and as LGBTIQ+⁸. This will require a related aim of ensuring the NDIS has the competence and capacity to enable all people with disability and where appropriate, their families, to feel culturally safe.

The Advice takes the view that the NDIS would be equitable when systems, information, services and supports deliver outcomes that are fair for all, and that the allocation of resources is based on disability support need and personal and environmental factors.

3 Background

3.1 Defining the target group

The literature and the disability community identify four groups of participants for whom the benefits of the NDIS are less evident. They are participants who identify as Aboriginal and Torres Strait Islanders, participants from culturally and linguistically diverse communities (CALD), LGBTIQ+ participants and people identified as 'on the margins', i.e., people with intellectual disability and cognitive impairment who experience additional challenges related to mental health, substance abuse, homelessness and contact with the criminal justice, child protection and out-of-home care systems.

After preliminary investigation, it was decided to address issues of equity for 'people on the margins' through the Intellectual Disability Reference Group in its planned work on the interface between the NDIS and the justice system.

This Advice thereby focuses on people who identify as Aboriginal and Torres Strait Islanders, CALD and LGBTIQ+.

Council is mindful that access, participation, and outcomes also vary by gender, socioeconomic status, mental health status and many other factors. Council highlights concerns related to inequitable access to the NDIS by girls and women noting that while 50.2% of the Australian population are women, only 37% of NDIS participants are women⁹. The multiple discrimination experienced by women and girls is recognised in Article 6 of Convention on the Rights of Persons with Disabilities (CRPD) that calls on States Parties to take all appropriate measures to ensure their full development and empowerment. It is the view of Council that by adopting the recommendations of this Advice, the Agency will be able to refresh its approach and deliver more equitable access, participation and outcomes for all people with disability.

⁸ LGBTIQ+ is the term preferred in this Advice. Other acronyms are only used when used by studies cited.

⁹ NDIS Quarterly Report to Disability Ministers for Q3 2021-2022. Table E.21 Participant profile per quarter by gender – National.

3.2 Approach of the Advice

The Advice is built on published literature and discussion with leaders in the Aboriginal and Torres Strait Islander, CALD and LGBTIQ+ communities to highlight features of the design and delivery of NDIS including the NDIA and its Partners in the Community (PiTC), that make it more difficult for some participants to maximise the opportunities enabled by the NDIS. Other than in the most general terms, the Advice does not address issues related to support providers but identifies areas for action for the NDIS Quality and Safeguards Commission.

The first section of the Advice:

- Outlines strategies used by the NDIA to address concerns related to equity
- Highlights ABS and NDIA data and research findings that provide evidence of inequities in access, outcomes and quality of life
- Explains some of the reasons for the inequities
- Provides commentary on the NDIS Aboriginal and Torres Strait Islander, CALD and LGBTIQ+ Strategies and makes the case for a refreshed approach
- Proposes principles to underpin the refreshed approach
- Demonstrates the application of the refreshed approach in relation to the NDIA function of Outreach; and
- Identifies what good practice in the refreshed approach might look.

The second section reports on discussions with leaders in the Aboriginal and Torres Strait Islander, CALD and LGBTIQ+ communities. The third section provides data from ABS, NDIA and research studies that document inequities experienced by the target populations.

The Advice has been guided by a small group of the Equity and Inclusion Reference Group: Jennifer Cullen, Margherita Coppolino, Ben Garcia-Lee, and Barbel Winter.

4 NDIS Commitment to Equity

The NDIS aims to ensure all people with disability, irrespective of their gender, class, cultural heritage, ethnicity, religion, have equal opportunity to enjoy its benefits. This is not currently the case. The NDIA discomfort with the inequities can be seen in its commitment to data analysis, targeted strategies and consideration in the design and delivery of supports. The approaches have made some difference, but key metrics demonstrate inequities continue to exist.

NDIA strategies on which work to improve equity can be built on the following foundations:

- Co-Design principles have been enshrined in the NDIS Act.
- The NDIA has committed to a stronger partnership with participants and the disability community and work is well progressed to implement Co-Design as the way in which the NDIA works with people with disability and their representative organisations in the design and delivery of support. The new *'Our engagement framework'* is a living document designed to guide, support, and strengthen NDIA engagement with the disability community including, for example, work to develop of a new person-centred model that delivers consistency and equity in access and planning outcomes.
- The Co-Design Advisory Group has prioritised culturally competent engagement with CALD and Aboriginal and Torres Strait Islander communities for 2022.
- The Participant Service Charter and Participant Service Guarantee are enshrined in legislation and the NDIA has committed to enhancing the quality of the NDIS experience for participants and providers including that every interaction with a participant is transparent, responsive, respectful, empowering and connected.
- The PiTC program is being refocused with a new best practice service model almost finalised and market engagement for the consideration of options for future delivery of Partner services.
- The Office of the Scheme Actuary provides data and analysis that among other features highlights issues of concern. Data analysis most relevant to this Advice is seen in the progress updates of Aboriginal and Torres Strait Islander and CALD participants in 2021 and the deep dives in 2019.
- The 2017 Aboriginal and Torres Strait Islander Strategy made commitments to:
 - Improve cultural competency to ensure processes, operational procedures and timeframes are culturally responsive
 - Local solutions recognising that the NDIS cannot be delivered through a one size fits all approach and that “underlying local solutions is the NDIA’s role as a connector, enabler and facilitator, rather than a doer. Often the most potent act the NDIA can take is to support local communities to build and implement their own solutions”¹⁰
 - Use its market enablement role to support providers to provide the right services in the right locations in the ‘proper way’
 - Support the infrastructure required within and across the NDIA to embed ‘proper way’ practices such as organisational policies, procedures, systems, and practice guides.
- The NDIA has undertaken additional enhancements to improve service responsiveness for Aboriginal and Torres Strait Islander participants including:

¹⁰ NDIA, ATSI Strategy p18

- Mobile Max that is trialling improved approaches to deliver information to participants and future participants through the use of digital hubs;
 - Planning guidance for staff;
 - Aboriginal and Torres Strait Islander Employment Strategy,
 - Aboriginal Disability Liaison Officers;
 - Innovations in early childhood services; and
 - An MOU with the NT Government Interpreter service.
- The 2018 CALD Strategy made commitments to:
 - Continue to build its (NDIA's) understanding of the interests and needs of people with disability from CALD backgrounds when exercising choice and control.
 - Embed this understanding in the design, planning, development, and administration of the NDIS, while ensuring the financial sustainability of the Scheme.
 - Continue to enhance the quality of the NDIS experience for participants and providers in a way which enhances cultural and language needs.
 - Use its market stewardship role to improve the functioning of the NDIS marketplace to better support people from CALD backgrounds.
 - Enhance the cultural competency within the NDIA and PiTC.
 - The 2020 LGBTIQ+ Strategy made commitments to every participant being treated with dignity, accepted without judgement or fear of disrespect, understood as having autonomy over their own body and how it is described and respected for their choices, needs and relationships and not asked intrusive questions.
 - Work has commenced on a Remote and Very Remote refresh to better serve participants.
 - The thin markets strategy has worked to ensure services in remote and very remote areas.
 - There has been a National Community Connector program with target groups including Aboriginal and Torres Strait Islander and CALD communities.
 - There has been a Remote Community Connector Program that also funds access clinics to bring Aboriginal and Torres Strait Islander communities into the NDIS, supports strategies to help children with disability or developmental delay and has intervened in the market in small communities.

- The 2021-25 Corporate Plan commits the NDIA to develop a market with high quality competitive and innovative supports and services including:
 - Support for market development and innovation so that participants have access to a greater range of supports and services; and
 - Collaboration with local communities, participants and their representatives and providers to drive market improvements that are culturally safe and best meet their needs.¹¹
- Complex Needs Pathway¹² (CNP) criteria for access identify the compounding nature of disadvantage experienced by some participants such that 19% of participants on the CNP identify as Aboriginal and Torres Strait Islander and 9% identify as from a CALD background.

These are strong foundations upon which to improve equity. However, inequities remain.

5 Evidence of Inequities

Appendices A, B and C provide detailed data drawn from the Australian Institute of Health and Welfare (AIHW), Australian Bureau of Statistics (ABS), the NDIA and recent research in relation to access and outcomes of participants who identify as who identify as Aboriginal and Torres Strait Islander, CALD and LGBTIQ+.

5.1 Inequities in accessing mainstream services

The AIHW 2020 report, *People with Disability in Australia*, indicates that current data makes it difficult to directly compare health-care access issues for people with disability with those for people without disability. However, available data suggest that people with disability are more likely than the general Australian population to face barriers, such as cost, when accessing some types of health services.¹³

The Report however provides insights into barriers experienced by people with disability in accessing health services including:

- 3 in 10 (29%) wait 1 or more days after making an appointment to see a GP for urgent medical care;
- Delaying or avoiding appointments due to cost (1 in 13 (7.6%) for GP appointments, 1 in 22 (4.6%) for specialist appointments and 1 in 28 (3.6%) for hospitalisation);

¹¹ NDIA (2021) Corporate Plan 2021-25, p32

¹² designed to provide skilled support for people with disability with personal and situational factors that are beyond the standard NDIS Service Delivery model

¹³ Australian Institute of Health and Welfare 2020. *People with disability in Australia 2020: in brief*. Cat. no. DIS 77. Canberra: AIHW.

- 1 in 5 (21%) who see 3 or more health professionals for the same health condition report issues caused by lack of communication among them;
- 1 in 29 (3.5%) experience disability discrimination from health staff (GP, nurse or hospital staff);
- 1 in 8 (12%) have difficulty accessing medical facilities (GP, dentist, or hospital); and
- 1 in 5 (18%) who need help with health-care activities have their need only partly met or not met at all.

5.2 Vaccination rates

NDIA data of vaccination rates (October 2021) for the general population, for NDIS participants and those of Aboriginal and Torres Strait Islander and CALD background highlights the inequities in access to life saving vaccinations for COVID protection and provides a snapshot of disadvantage.

Target group	% Fully vaccinated	1 dose	Unvaccinated / Unmatched
General Australian population	75.5%	12.1%	12.4%
NDIS participants (general)	63.16%	12.64%	24.20%
Aboriginal and Torres Strait Islander NDIS participants	47.54%	12.57%	39.89%
CALD NDIS participants	53.54%	11.81%	34.66%
LGBTIQA+ participants	No data available	No data available	No data available

5.3 Aboriginal and Torres Strait Islander data¹⁴

The National Aboriginal and Torres Strait Islander Social Survey (2015) and NDIA data indicates that Aboriginal and Torres Strait Islander participants experience:

- Higher rates of disability across all age groups
- Significantly higher rates of disability compared to the general population including physical (14.8% compared with 11.4%), psychosocial disability (6.6% compared with

¹⁴ Sources documented in appendix

3.8%) intellectual disability (5.9% compared with 2.5%) and head injury, stroke or acquired brain injury (2.1% compared to 1.1%)

- Almost twice the crude rate of discrimination due to disability
- Lower labour force participation (41.7% of Aboriginal and Torres Strait Islander people with disability participated in the labour force compared to 53% of non-Aboriginal and Torres Strait Islander people with disability and 83% of people with no reported disability)
- Less favourable outcomes from the NDIS in many areas of life including being less likely to believe that the 'NDIS has helped'. Specifically, families and carers of Indigenous participants:
 - Under 14 were more likely to deteriorate in relation to the level of support available for their family, their health and wellbeing, and being satisfied with the amount of say they had in the implementation of their child's plan; and
 - 25 + were significantly less likely to say that the NDIS improved the level of support for their families.

5.4 CALD data¹⁵

The NDIA has been concerned about the inequity arising from the under-representation of NDIS participants of CALD background, being 9.2% (December 2021) compared to the expected rate of 18.9%.¹⁶ Accordingly, the Office of the Scheme Actuary has undertaken significant statistical analysis to better understand the reason for this difference – specifically, whether a number of CALD people are yet to join the NDIS, or whether the NDIS is under-reporting the number of CALD participants in the Scheme based on the data collected on country of birth and main language spoken at home.

The analysis, reported in the Quarterly Report of September 2021, indicates that it is likely that CALD participants are joining the Scheme but have not been identified as CALD in the data collected. With the introduction of the new ICT system, the opportunity to collect improved data on participants should allow better identification of CALD participants to identify the extent of any inequities in this area.¹⁷ In addition the number of CALD participants now excludes participants who identify as Aboriginal and Torres Strait Islander. In previous reports, Aboriginal and Torres Strait Islander participants were included if their main language spoken at home was not English.

¹⁵ Sources documented in appendix

¹⁶ Expected CALD percentages are derived from the 2016 ABS Census and exclude Indigenous people. Previous results have included Indigenous people (where their language spoken at home was not English).

¹⁷ NDIS Quarterly Report September 2021 P21 Accessed <https://www.ndis.gov.au/about-us/publications/quarterly-reports/archived-quarterly-reports-2021-22> 30 March 2022

CALD participants are less likely to see that the NDIS had helped to improve outcomes, where, compared to non-CALD participants, CALD participants:

- Aged 15-24 were less likely to say that the NDIS has helped improve outcomes related to choice and control, daily living activities and social and community participation and were more likely to deteriorate in all transitions
- Aged 25+ were less likely to say that the NDIS has helped for the domains of choice and control, daily living, home, and work with a gap of 3-4% gap between CALD and non-CALD participants for these domains.

Compared to families and carers of non-CALD participants, families, and carers of CALD participants:

- Birth to school entry were more likely to say that the NDIS has helped to improve their health and wellbeing (47.6%) compared to those come from a non-CALD background (41.6%), however they were less likely to say that they were satisfied with the amount of say they had in developing (69.8% versus 73.7%) and implementing (62.1% versus 64.8%) their child's plan
- Of participants 25+, were less likely to think that their family member with disability gets to the support they need and were less likely to say that the NDIS helped them understand their rights and to advocate effectively.

5.5 LGBTIQ+ data¹⁸

There is little or no ABS and NDIA data for this target group. Evidence drawn from recent studies of LGBTIQ+ people indicate that 11.8% reported a profound or severe disability and a lower level of acceptance by health and support services than participants not reporting a disability or long-term health condition (29.9% compared to 50.6%). They also reported being treated unfairly by others in the past 12 months because of their disability or long-term health condition (77.7%).

Evidence drawn from recent studies of LGBTIQ+ people with disability demonstrate that, compared to LGBTIQ+ people without disability they:

- have twice the rates of anxiety and psychological distress
- experience higher rates of crime and victimisation
- are subject to higher rates of discrimination and abuse, and
- experience restrictions on freedom of sexual expression.

In addition, transgender and gender diverse people with disability experience even greater discrimination when accessing services than Lesbian, Gay, and Bisexual people with

¹⁸ Sources documented in appendix

disability and are less likely to access aged care services due to fear and anticipation of discrimination.

Evidence from recent studies of LGBTIQIA+ people with disability aged 14 to 21 indicated:

- Considerably higher rates of attempted suicide than young LGBTIQIA+ people without disability (15 % compared to 6% for those without disability).
- Of those who reported having an intellectual disability:
 - 94.8% reported 'high' or 'very high' levels of psychological distress
 - 91.3% reported suicidal ideation in their lifetime
- There were higher rates of harassment and assault, including verbal, physical and sexual, compared to the broader category of disability; and
- There was a feeling of less acceptance in the LGBTIQIA+ community and more difficulty in using LGBTIQIA+ services and venues that were used by LGBTIQIA+ young people with other disabilities.

6 Reasons for Inequities

The NDIS is not unique in facing challenges to ensure equity for minority populations. All levels of government, the community and private sectors incorporate dominant cultural values in policy and service design and as a result, people who live with characteristics not privileged by society face challenges to gaining the benefits experienced by others. This can be seen in the 'othering' of Aboriginal and Torres Strait Islander people where the NDIA requires Aboriginal and Torres Strait Islander people to adjust to the NDIS processes rather than requiring the NDIA to design process that work for Aboriginal and Torres Strait Islander people.¹⁹ Similarly, the social construction of minority groups as less powerful consolidates their disenfranchised and marginalised status, tarnishing the potential for their significant contribution based on the richness of culture and experience.²⁰

Some of the reasons for the inequities relate to design features of the NDIS as a market-based system in which individuals with disability are supposed to become informed consumers who purchase services and supports to meet their needs and in principle facilitate the 'lifestyle of choice'. However, people enter the marketplace from different starting points where sexism, racism, homophobia, biphobia, transphobia, intersex discrimination, ableism, ageism, and stigma have restricted their voice, choice, and control. They must also engage with services and supports that feel culturally unsafe and hence

¹⁹ Gilroy, J (2019), Avoiding 'Othering': How should disability policy be established with Indigenous people? Croakey

²⁰ Kenning (2017) in Awata, M, (2018), Facilitators of successful service engagement of people with disabilities from culturally and linguistically diverse backgrounds, Thesis submitted for the degree of Graduate Diploma in Research methods, College of Education, Psychology and Social Work, Flinders University, South Australia.

without deliberate strategies to address organisational and community attitudes, many people with disability will not get to the starting line of testing eligibility for the NDIS.

Other reasons for inequities relate to distrust of government, differing views of self and disability, tension between cultural values and the resulting orientation of the service system and the compounding nature of intersectional disadvantage that impact on the life chances and service engagement of many in marginalised communities.

Action to address these challenges is timely and could have profound impact.

6.1 NDIS design

Disability leaders in the target communities reported that community members say:

- “NDIA processes are white fella centric and leave some people behind.”
- “People are struggling with challenges that are perceived to lie in individuals rather than in systems.”
- The question should not be “How are the needs of Aboriginal and Torres Strait Islander people different? The question should be “How should disability policy be established with Aboriginal and Torres Strait Islander people with disability”.
- “NDIS is designed without considering diversity and intersectionality.”
- “After my application was rejected, I was sent a survey seeking feedback on my recent interaction with the Agency. The online survey disadvantages people who don’t have access to technology. In addition, both the email and survey were in English only and made no mention of any language support should it be required.

The NDIS was a paradigm shift from the traditional welfare response, encouraging citizenship rather than client-hood, building capacity rather than rewarding crisis and dependence and funding individuals rather than services. Whilst this represented an enormous improvement for most participants, the lower-than-expected level of uptake by people with disability in some marginalised groups, the lack of culturally specific services and the lack of translated materials suggests that insufficient attention was paid to ensuring that culturally appropriate and safe approaches to engagement. As a result, individuals in the most marginalised groups were not effectively supported to engage with the NDIS and gain its benefits.

The NDIS relies on individuals being willing and able to navigate, self-advocate, set goals, make choices and decisions. This includes proving eligibility and engaging with services and supports designed to build capacity with the goal of reducing dependence on formal support. These are skills and concepts that require proficiency in English, sociocultural literacy, and

informal support.²¹ Dependent on one's access to such skills and resources, people may fare better or worse than others in terms of both how onerous the experience is and whether they get the 'personalised' supports the scheme was designed to deliver.²² Challenges with skills and resources for navigating the NDIS appear to be exacerbated for already vulnerable or disadvantaged groups.

The traditional response to concerns about system design is to locate challenges in the individual (rather than the system) leading governments to blame the victim and respond via neglect, segregation, or institutionalisation. The NDIS has not sought to neglect, segregate or provide an institutionalised response to people less able to navigate the Scheme, but the differential metrics for some marginalised groups suggests that the response has not provided what is required.

An NDIS built on an acknowledgement that its design contributes to inequities would draw on the lived experience of people in marginalised communities and evidence from literature to adjust its design.

6.2 Cultural competence of disability and community services

Disability leaders in the target communities reported that community members say:

- “People do not feel safe in the current system.”
- “Many providers are not responsive.”
- The NDIS has a pretence of being individualised, but my cultural background is not considered. I want my kitchen modified so I can cook (traditional Chinese food). The NDIA rejects my request, offering just a benchtop to make sandwiches. I don't eat sandwiches.”
- “A culturally competent NDIS would not have barriers to participation associated with English proficiency or digital literacy, different understandings of disability, different cultural expectations, or different world view.”
- Cultural competence is often translated into cultural awareness training and employing more staff of CALD background. When done badly, cultural awareness training can create stereotypes and present cultures as homogenous. Coming from a CALD background is not a qualification for cultural competence.”
- “Large providers are the antithesis of culturally safe services. Cultural safety needs to be built on relationships and trust. People need to feel understood, cared for and have a sense of belonging.”

²¹ Soldatic, K, van Toorn, G, Dowse, L & Muir, K, (2014) Intellectual Disability and Complex Intersections: Marginalisation under the National Disability Insurance Scheme, Research and Practice in Intellectual and Developmental Disabilities, 1:1, 6-16, DOI: 10.1080/23297018.2014.906050

²² Carey, G, Malbon, E, Blackwell, J (2021) Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals Centre for Social Impact, University of New South Wales, Sydney, New South Wales, Australia

- “People seek support workers from the LGBTIQ+ community because LGBTIQ+ people with disability don’t feel safe with faith-based providers, many of which have normalisation at their core. They want to change people to fit into society’s expectations.”

Many disability and community services are built on unexamined assumptions that benefit some and impede engagement and marginalise others. Many services have entrenched ways of working that appear to assume either a mono-cultural Australia (that never existed) or were informed from times where the cultural mix in any given society was different. They lack the connection and nuanced understanding of ways to enable people from diverse backgrounds to feel that use of the service will not undermine cultural obligations to family, community, and religion.

A lack of Aboriginal and Torres Strait Islander disability service providers and culturally competent services is one of the main drivers for poor access to services and poorer outcomes for Aboriginal and Torres Strait Islander people.²³

Few services are culturally competent for Aboriginal and Torres Strait Islander people with research highlighting that a low level of cultural competence in the initial stages of the disability assessment and planning processes exacerbated participant confusion and distrust towards assessment staff and the NDIS. Given difficulties in communication, participant understanding of the NDIS was generally limited.²⁴ For some, the lack of engagement with services was due to “apprehended discrimination” wherein frequent exposure to various forms of discrimination transforms into a “rational expectation of discrimination”, leading a person to avoid certain situations.²⁵

Geographical location can also be a factor in relation to equity. Aboriginal and Torres Strait Islander people in remote and very remote areas are a significant distance from specialist services and professionals. As a result, there is a lack of appropriate early diagnosis and culturally responsive support for Aboriginal and Torres Strait Islander children and adults with disability.

Studies²⁶ reveal language as a critical factor in service engagement with challenges arising from the lack of written material in community languages. In addition, there is a lack of interpreters who are skilled not only in their language of origin, but who also have an

²³ NACCHO (2021) Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with disability Accessed <https://disability.royalcommission.gov.au/system/files/submission/ISS.001.00443.PDF> 10 March 2022

²⁴ Ferdinand, A, Massey, L, Cullen, J, Temple, J, Meiselbach, J, Paradies, Y, Baynam, G, Savarirayan, R and Kelaher, M, (2021) Culturally competent communication in Indigenous disability assessment: a qualitative study Ferdinand et al. International Journal for Equity in Health (2021) 20:68 <https://doi.org/10.1186/s12939-021-01402-9> \

²⁵ Avery, S. (2018) Culture is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability, Sydney, Australia, First People’s Disability Network (Australia).

²⁶ Awata, M, (2018), Facilitators of successful service engagement of people with disabilities from culturally and linguistically diverse backgrounds, Thesis submitted for the degree of Graduate Diploma in Research methods, College of Education, Psychology and Social Work, Flinders University, South Australia.

understanding of disability that is grounded in human rights. Bicultural workers to assist with engagement in and navigation of the system are largely not available.

Cultural competence is core to accreditation of a service as LGBTIQ+ inclusive with research²⁷ that over 75% of LGBTIQ+ service users indicating they would be more likely to use a service if it has been accredited as LGBTIQ-inclusive.

Many disability support organisations still do not have policies regarding sexuality and relationships, let alone policies for same-sex sexual expression. When policies are non-existent or are not clearly communicated to service providers and service users, or offer unequal rights, there is a risk that staff may deny or negatively influence the service users based on their own attitudes and beliefs.²⁸

LGBTIQ+ people with disability also experience barriers to inclusion from the LGBTIQ+ community and civil society because of:

- The problematisation and infantilisation of the sexuality of people with intellectual disability in a way that views them as fundamentally incapable of living proud LGBTIQ+ lives;
- Little or no knowledge of disability support practices that could facilitate inclusion of LGBTIQ+ people with intellectual disability; and
- Lack of budget allocation to include intersectional specific supports such as support for LGBTIQ+ people with disability from CALD communities.²⁹

An NDIS built on an acknowledgement of cultural safety would work continuously to build its own cultural competence and that of its PiTC and would require cultural competence of support providers.

6.3 Compounding nature of intersectional disadvantage

Disability leaders in the target communities reported that community members say:

- “Incarceration rates among Aboriginal people is huge, but the intersection of race and disability blows those figures right out of the water.”
- “Women with disability from CALD communities face multiple barriers: most must negotiate the barriers put up by mainstream communities as well as challenge many of the traditional beliefs, norms and expectations of their cultural and linguistic community.”

²⁷ Hill, A. O., Bourne, A., McNair, R., Carman, M. & Lyons, A. (2020). *Private Lives 3: The health and wellbeing of LGBTIQ people in Australia*. ARCSHS Monograph Series No. 122. Melbourne, Australia: Australian Research Centre in Sex, Health and Society, La Trobe University.

²⁸ Wilson, N, Bright, A, MacDonald, J, Frawley, P, Hayman, B, Gallego, G, (2018) A narrative review of literature about people with intellectual disability who identify as lesbian, gay, bisexual, transgender, intersex or questioning, *Journal of Intellectual Disabilities* v22(2) 171-196

²⁹ Parsons M, Despott N and Power R (2021). *Our Rainbow Lives*. Melbourne: Inclusion Melbourne and Rainbow Health Victoria.

- “Many LGBTIQ+ people with disability feel excluded from their CALD community as well as from disability and LGBTIQ+ communities.”
- “LGBTIQ+ people with disability are not a homogenous community, we have different experiences based on our bodies, our gender identities, our intersex status, our sexualities, our relationships, our impairments, and these differences intersect with our ethnicity, culture, socio-economic status etc and create an individual. All these factors don’t really get a chance to be considered in a holistic way in the NDIS.”

Evidence shows that people with disability continue to be at greater risk of traumatic experiences, including neglect, abuse, and violence, than people without disability.³⁰ These experiences can trigger trauma³¹ and can have a significant and recurring impact on a person’s life.

Many Aboriginal and Torres Strait Islander people with disability have complex support needs related to mental health, substance misuse, homelessness, trauma, violence and victimisation, intergenerational and circumstantial disadvantage or involvement in child protection and criminal justice systems.³²

Many people with disability of CALD backgrounds experience needs related to mental health, trauma, socio-economic disadvantage, low English proficiency and low level of understanding of how to navigate complex Australian service systems.

Many LGBTIQ+ people with disability do not have the protective factors against depression (being in a relationship; receiving social support from peers, friends, and family; and having a sense of belonging to a community). Given the relationship between symptoms of depression, active participation and social inclusion, it is not surprising many LGBTIQ+ people with disability experience greater level of exclusion, bullying, harassment, exploitation, and abuse.³³

An NDIS built on an acknowledgement of the compounding nature of intersectional disadvantage would demonstrate the way in which these factors are considered at access and across the Participant Pathway and would have stronger case management to negotiate support across interfaces.

6.4 Distrust of government

Disability leaders in the target communities reported that community members say:

- “You can’t trust government - in my country government was not there to help you.”

³⁰ <https://www.nds.org.au/news/nds-launches-trauma-informed-support-films>

³¹ Trauma is a psychological and physiological response to the event(s) that occurs when both internal and external resources are inadequate to cope with external threat. The trauma is characterised by an individual’s experience of an event, rather than the event itself.

³² Dowse, L, Dew, A and Sewell, A (2019) Background paper for ASID position statement on intellectual disability and complex support needs, Research and Practice in Intellectual and Developmental Disabilities, V6, No1, p5-13

³³ Wilson, N et al (2018) op cit.

- “If I seek help for my child, government might remove him.”
- “The current (LGBTIQA+) Strategy had a silent launch. This is a pattern of addressing our communities, off to the side, anticipating that backlash could be coming. It’s not a controversial topic and LGBTIQA+ people with disability are not a dirty secret.”
- “They are not listening to the community. Over and over, things get reinvented. There is a high turnover of staff in government which is frustrating, bad for staff and bad for participants.”

A common element of disadvantage arises from the prevalence of individual and collective experiences of historical trauma for these groups, resulting in a generalised level of distrust towards government.

For Aboriginal and Torres Strait Islander people, the impact of colonisation, historical policies of ‘protection’ aimed at separation and segregation, the Stolen Generation’ and persistent high rates of incarceration, have led to mistrust of governmental institutions. Many parents have particular concern that seeking assistance for a child with additional needs may lead to the removal of the child. These factors contribute to a lack of timely engagement.³⁴

Many in the CALD community are reluctant to engage with the NDIS based on their experience of persecution and mental and physical trauma perpetrated by people in power before coming to Australia.

Many LGBTIQA+ people with disability lack confidence in the positive intention of government based on the lack of specific protections in existing rights frameworks, the higher level of exclusion from both disability and LGBTIQA+ communities and the lack of respect in, for example, the use of affirming language or personal pronouns of choice.

An NDIS built on an acknowledgement that some distrust government would include active outreach from community partners in marginalised communities to act as cultural interpreters and guides who can help build trust in the NDIS.

6.5 Self-perception is different to government perception

Disability leaders in the target communities reported that community members say

- “The NDIS does not even count all people of CALD background. Children and many second-generation adults with disability experience similar barriers to overseas born people with disability.”
- “There is no data to see how LGBTIQA+ people with disability are going. The NDIA doesn’t even count us.”

³⁴ Collings, A. Dew, T. Gordon, M. Spencer & L. Dowse (2018) Intersectional Disadvantage: Exploring Differences Between Aboriginal and Non-Aboriginal Parents with Intellectual Disability in the New South Wales Child Protection System, Journal of Public Child Welfare, 12:2, 170-189, DOI: 10.1080/15548732.2017.1379456

Government's representation of Aboriginal and Torres Strait Islander people in NDIS documents tends to focus on thin markets in rural and remote Aboriginal and Torres Strait Islander communities. This focus obscures the identification of broader accessibility problems in NDIS policy and services for Aboriginal and Torres Strait Islander people with disability regardless of geographical location.³⁵

Government perception that Aboriginal and Torres Strait Islander people may not recognise their own needs and lack capacity to make "good" choices fails to account for the social and historical disempowerment and disillusionment of Aboriginal and Torres Strait Islander people, by the government and disability services and underpins Aboriginal and Torres Strait Islander non-involvement in services.³⁶

The variation is highlighted for many of CALD background by the NDIS definition of CALD status that is attached to people whose country of birth is not English speaking (Australia, New Zealand, the United Kingdom, the United States of America, Canada, or South Africa) or their primary language spoken at home is not English. This assumes that the impacts of ethnicity, colour, nationality, refugee or asylum-seeking background, migration or visa status, language and religion remain in the first generation and only extends to further generations where they retain a language other than English at home. Significant literature attests to the intergenerational impacts of CALD identities that may be experienced by later generations. For these reasons, CALD disability advocates identify people of CALD background as those who have one or both parents born in a non-English speaking country, arguing that for many children and adults with disability, their primary language and cultural identification is that of the parents and hence they experience similar challenges as their parents.

In addition, the language describing a person to be of a 'culturally and linguistically diverse background' demonstrates the deeply ingrained dominant Anglo-Saxon culture of Australian institutions that group together and other all people whose language and culture is not that of some historical past.

For LGBTIQ+ people with disability, the wide variations of gender, sex, sexual orientation, and gender identity means that many LGBTIQ+ people with disability have a different view of self than that assigned to them by the Government and community.

An NDIS built on an acknowledgement that people perceive themselves in ways different from government perception would enable people to experience cultural safety when engaging with NDIS processes, services and supports and would collect data that enables all to feel counted.

6.6 Views of disability

Disability leaders in the target communities reported that community members say:

³⁵ Gordon, T, Dew, A, Dowse, L (2019) Listen, learn, build, deliver? Aboriginal and Torres Strait Islander policy in the National Disability Insurance Scheme, Australian Journal of Social Issues (2-19) v54, p224-244

³⁶ Gordon, T, Dew, A, Dowse, L (2019) op cit

- “If people know she has a disability, her siblings will have trouble finding marriage partners”
- “LGBTIQA+ people with disability don’t have a way to tell our own success stories, to be in control of the narrative.”

The criteria for identifying disability have varied over time and continue to vary between pieces of enabling legislation and government programs. It is therefore not surprising that the views of disability are also changing and are understood differently in different communities.

Over the last 100 years western ideas and concepts of disability have changed significantly. The current views are relatively new to many Aboriginal and Torres Strait Islander communities, where families primarily focus on a person’s personality, strengths and skills, not their deficits.³⁷ There are also marked differences between the needs identified by Aboriginal and Torres Strait Islander people with disability and the supports mainstream services are designed to provide.³⁸ It is thereby not surprising that some Aboriginal and Torres Strait Islander people do not identify as having a disability as defined by current policy and service provision. This limits engagement with services specific to ‘disabilities’ and contributes to under-reporting and under-utilisation of disability services.³⁹

In almost all communities, stigma (or fear thereof) can be a factor in determining whether a person identifies as having a disability. This can be seen in people trying to ‘pass’ as not having a disability and people indicating their disability is not as ‘bad’ as someone else’s. Stigma is usually based on false assumptions, for example that people with disability are unable to learn or that their impairment is ‘catching’⁴⁰ and often lies at the root of the discrimination and exclusion.⁴¹

Studies have identified stigma as a culturally determined barrier that impacts successful engagement in disability services in some communities.⁴² For example, some cultures perceive seeking external help for certain conditions such as depressive symptoms to be inappropriate. This is due to cultural beliefs which subscribe to the notion that it is within the control of the individual to manage their emotions, thoughts, and behaviours. Feelings of blame, due to individuals subscribing to the same discourses that oppress them, may prevent seeking help from disability, health, or other services.⁴³

In addition, people’s reliance on their community for support or for future marriage partners may hinder them from identifying forms of disability that are not overtly noticeable. This can result in some children with intellectual disability being denied opportunities for early

³⁷ Gilroy, J (2019), Avoiding ‘Othering’: How should disability policy be established with Indigenous people? Croakey

³⁸ Gordon, T, Dew, A, Dowse, L (2019) op cit.

³⁹ Gordon, T, Dew, A, Dowse, L (2019) op cit.

⁴⁰ https://www.bond.org.uk/sites/default/files/resource-documents/stigma_disability_and_development.pdf

⁴¹ https://www.bond.org.uk/sites/default/files/resource-documents/stigma_disability_and_development.pdf

⁴² Awata, M (2018) op cit.

⁴³ Awata, M (2018) op cit.

childhood intervention⁴⁴ for fear of the impact on future opportunities for the child and their siblings.

An NDIS built on an acknowledgement of differing views of disability would include systems navigators who are trusted by people of the marginalised community to translate community perceptions of disability to the NDIA and support providers able to deliver culturally competent services.

⁴⁴ Soldatic (2014) op cit.

6.7 Tension between different cultural values relating to service systems

Disability leaders in the target communities reported that community members say:

- “My mother is angry with me that I seek support from the NDIS when she can provide that help”
- “It’s wrong to take a wheelchair when Aunty can’t get one.”

The individualised person-centred approach of the NDIS is not always compatible with the cultural values of some participants. Significantly, the NDIS asks people to value self over others (family and community) and this can conflict, for example, with Aboriginal and Torres Strait Islander people whose identities are inextricably bound with extended family ties, community and culture, all of which are central to social and emotional well-being.^{45 46} For some people of CALD background being part of the family, accepting other people’s decisions and honouring the family are more important than independence and dependence.⁴⁷

Cultural and religious factors⁴⁸ influence how western concepts of disability and health are understood and can have a role in facilitating or creating barriers to service engagement with challenges arising when services seek to deliver support in ways that conflict with the inner emotional or spiritual life of the service user.

An NDIS built on an acknowledgement that within the population there is a diversity of values and views of disability, would take greater account of family and community expectations and responsibilities (including having processes to negotiate aspirations of participants that conflict with cultural expectations) and would include cultural guides that assist the NDIA and support providers to deliver culturally competent services.

7 NDIS Equity Strategies

The NDIS is committed to equity. It’s targeted, strategies and design enhancements were well intentioned but actuarial data continues to show differential access, participation, and outcomes.

The views of leaders in each disability community provide insights into why and how the strategies have not succeeded. The view, synthesised from all sources, is that the strategies have not made an impact on the assumptions and infrastructure of the NDIS and hence fell short of what is required to enable people who experience multiple compounding

⁴⁵ Avery, S. (2018) Culture is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability, Sydney, Australia, First People’s Disability Network (Australia).

⁴⁶ Dew A; Vaughan P; McEntyre E; Dowse L, 2019, "Our ways to planning': Preparing organisations to plan with Aboriginal and Torres Strait Islander people with disability', *Australian Aboriginal Studies*, vol. 2, p3-18 <https://search.informit.com.au/documentSummary;dn=807372348968731;res=IELIND>

⁴⁷ Awata, M (2018) op cit.

⁴⁸ such as gendered roles of caring, the importance and role of family, a view that relies on community and family rather than Government and self and different explanations of causes of disability

disadvantages to gain the support they needed. Leaders argued that the Strategies resulted in superficial, ad hoc, and inconsistent activities that have not built the cultural competence of the NDIA, PiTC and support providers nor given voice and authority to the target groups for whom the Strategies are designed.

Discussion related to the Aboriginal and Torres Strait Islander Strategy suggested that preamble to the original strategy was sound, but the action plans require reworking with Aboriginal and Torres Strait Islander communities. Discussion related to the CALD Strategy reflected frustration, summarised with “*the Strategy didn’t even have an implementation plan.*” The LGBTIQ+ disability community criticised the LGBTIQ+ Strategy as “*a Strategy for the NDIA, not the NDIS*”, and expressed deep disappointment that “*the Strategy was never even launched publicly*” reflecting a perceived reticence on the part of the Agency to own the Strategy with pride.

Community leaders cautioned against a simplistic view of cultural competence, the view for example, that a CALD background can or cannot be a qualification for cultural competence or that a cultural awareness training session represents cultural competence. The LGBTIQ+ community noted that the claim to cultural competence and lasting cultural safety requires deep thoughtful work that can be achieved by certification by Rainbow Tick accreditation process.⁴⁹

7.1 The case for change

The literature and community leaders agree that challenges in current design and delivery must be understood from the diverse perspectives of participants and that significant structural work is required by the NDIA, PiTC and support providers to become culturally competent organisations that enable all participants to feel culturally safe.

Insights into the depth of work required to achieve equity can be taken from a literature review⁵⁰ on cultural competency and cultural safety that concluded that eliminating indigenous and ethnic health inequities requires addressing the determinants of health inequities. These include institutionalised racism and ensuring a health care system that delivers appropriate and equitable care.⁵¹

To achieve equity, the review favoured the goal of cultural safety rather than cultural competence because cultural safety requires practitioners to critique the ‘taken for granted’ power structures and to be prepared to challenge their own culture and cultural systems rather than prioritise becoming ‘competent’ in the cultures of others. The review cautioned that cultural safety should be defined by patients and their communities and measured through progress towards achieving health equity.

⁴⁹ <https://rainbowhealthaustralia.org.au/rainbow-tick>

⁵⁰ Curtis, E., Jones, R., Tipene-Leach, D. et al. Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. *Int J Equity Health* 18, 174 (2019). <https://doi.org/10.1186/s12939-019-1082-3>

⁵¹ Curtis, E., (2019) *ibid*

The review also highlighted the growing recognition of the importance of cultural competency and cultural safety at both individual health practitioner and organisational levels with some jurisdictions including cultural competency in health professional licensing legislation, health professional accreditation standards, and pre-service and in-service training programmes.⁵²

A refreshed approach is required to achieve equity for Aboriginal and Torres Strait Islander, CALD and LGBTIQ+ participants in the NDIS. If the NDIA aspires to all participants feeling culturally safe, a structural approach is required to address the multiplicity of barriers to access and participation that thwart the achievement of equitable outcomes.

8 The Way Forward

Vision: The National Disability Insurance Scheme⁵³ is inclusive, safe, and responsive, and assists all Australians with disability to meet their disability support needs in ways that achieve equitable outcomes.

Consensus of disability community leaders and the literature suggest that intersectionality must be at the core of the refreshed approach and progress toward the vision would be built on current principles with fresh understandings. These are:

- **Insurance principles:** Upholding insurance principles and Scheme sustainability.
- **Human rights obligations:** Assisting the NDIA to meet its obligations under human rights conventions.
- **Intersectional considerations:** ensuring systems, processes, policies, and practices are culturally competent to respond to the rich diversity of NDIS participants.
- **Diversity and cultural safety:** Valuing diversity and cultural safety as core Scheme values.

Principles of engagement to operationalise the refreshed approach assume:

- **Shared access to data and information:** Shared access to data and information between the NDIA and participants and their representative organisations.
- **Co-Design and shared decision making⁵⁴:** Elements of Scheme design that impact on participants are Co-Designed and decision making is shared.
- All work aims to create:
 - **Cultural Competence:** Build the cultural competence of NDIS and PiTC;

⁵² Curtis, E., (2019) *ibid*

⁵³ including the NDIA, PiTC and registered providers

⁵⁴ consistent with NDIA (March 2022) *'Our engagement framework'*

- **A Systemic approach to self-determination:** Strengthen the systemic approach to participant self-determination, capacity and decision making.

8.1 Insurance principles

The focus on insurance principles⁵⁵ is fundamental to the NDIS and in this Advice, ensures key attention is drawn to the dual goals of positive outcomes for people with disability and the sustainability of the NDIS.

Council is of the view that improving equity will contribute to Scheme sustainability by reducing waste and ensuring support is well targeted. The focus on building the capacity of people to reduce their long-term need for care and support, investment in research, encouragement of innovation and the ability to act at the systemic level contribute to the achievement of the dual goals. The removal of the ILC from NDIA control however reduces one of the key levers for balancing the two goals.

8.2 Human rights obligations

The focus on human rights assists the NDIA to meet its obligations under Human Rights Conventions.

The *NDIS Act, 2013* affirms the obligation of the NDIS to give effect to Australia's obligations under international rights conventions, namely the *Convention on the Rights of Persons with Disabilities (2006)*, the *International Covenant on Civil and Political Rights (1966)*, the *International Covenant on Economic, Social and Cultural Rights (1966)*, the *Convention on the Rights of the Child (1989)*, the *Convention on the Elimination of All Forms of Discrimination Against Women (1979)* and the *Convention on the Elimination of All Forms of Racial Discrimination (1965)*.

Of specific relevance to LGBTIQ+ people with disability are the *Yogyakarta Principles (YP+10)* that affirm existing international legal standards as they apply to all persons on grounds of their sexual orientation, gender identity, gender expression and sex characteristics. States must comply with these principles both as a legal obligation and as an aspect of their commitment to universal human rights.

The Care Quality Commission in the UK has embedded a human-rights based approach in its regulatory framework since 2014 and describes the approach as a powerful driver for change.⁵⁶ Service inspection reports are mapped against nine human rights themes based on the CRPD and have identified many areas in which people using residential services had

⁵⁵ <https://www.ndis.gov.au/about-us/operational-guidelines/overview-ndis-operational-guideline/overview-ndis-operational-guideline-about-ndis>

⁵⁶ Care Quality Commission (2019) Our human rights approach for how we regulate health and social care services. Accessed <https://www.cqc.org.uk/files/human-rights-approach-our-regulation-health-social-care-services> 31 March 2022

little control over their lives.⁵⁷ A similar approach by the NDIA and the NDIS Quality and Safeguards Commission would assist the NDIA to meet its obligations under Human Rights Conventions.

8.3 Intersectional considerations

The focus on intersectionality assists the NDIA to recognise and remove systems in the NDIS that create barriers for some and privilege others.

Like *Australia's Disability Strategy 2021-2031*, the Advice uses an intersectional approach as a framework to understand the complex systems and structures that privilege some people and create barriers for others.

Some of the overlapping characteristics that create barriers and marginalise people include Aboriginality, gender, sex, sexual orientation, gender identity, ethnicity, colour, nationality, refugee or asylum seeker background, migration or visa status, language, religion, ability, age, mental health, socioeconomic status, housing status, geographic location, medical record, or criminal record.

Some of the attitudes, systems and structures in society and organisations that interact to create inequality and result in exclusion include sexism, racism, homophobia, biphobia, transphobia, intersex discrimination, ableism, ageism, and stigma.⁵⁸

An intersectional framework acknowledges the dynamics of power and social inequality in society and facilitates an understanding of the multiple forms of discrimination and disadvantage arising from the overlapping characteristics that are not privileged by society. An intersectional framework will thereby assist the NDIA to better understand and respond to complexity and work towards creating and sustaining an NDIS that is inclusive, safe, responsive, and accountable for all.

8.4 Diversity and cultural safety

The focus on valuing diversity and cultural safety assists the NDIA to enable all Australians with disability to feel able to feel safe to use the NDIS.

Cultural competence has evolved as one of the leading approaches to address health and social equity disparities between Aboriginal and Torres Strait Islander people and non-Indigenous peoples. Aboriginal and Torres Strait Islander scholars emphasise that cultural competence is not a skill-set competency/attribute or a training course. For Aboriginal and Torres Strait Islander people, cultural competence requires the moral-value of *“cultural*

⁵⁷ Murphy, K, Bantry-White, E, (2021) Behind closed doors: human rights in residential care for people with intellectual disability in Ireland, *Disability & Society* 2021 v36, No. 5 p750-771 Accessed <https://app.dimensions.ai/details/publication/pub.1127943011> 31 March 2022

⁵⁸ Victorian Government, *Understanding Intersectionality*, Accessed 18 November 2021 at <https://www.vic.gov.au/understanding-intersectionality>

*humility – a life-long process of self-reflection and self-critique that an individual engages to examine his/her own cultural identity and beliefs when learning about another culture”.*⁵⁹

Council uses the Australian Human Rights Commission concept of cultural safety as ‘an environment that is safe for people: where there is no assault, challenge or denial of identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience of learning, living, and working together with dignity and true listening.’⁶⁰ The concept was originally developed to apply to health service delivery for Māori communities and then adopted for use by First Nations peoples, including by Aboriginal and Torres Strait Islander communities. It was later expanded to apply to health and community service delivery for other groups, including CALD and LGBTIQ+ communities.

One of the major barriers to people of minority groups accessing and using the NDIS is that they report not feeling culturally safe. Three interrelated elements are crucial in facilitating cultural safety: firstly, assisting people to develop cultural humility, secondly, requiring organisations to establish universal policies, systems and processes that establish and demonstrate cultural safety and finally, strengthening the capacity, decision making and choice that empower individual, families and communities.

8.5 Principles for engagement in the refreshed approach

Council recommends all work applies the following principles for engagement and offers examples of what good practice would look like:

Shared access to data and information

The NDIA provides significant data about its operations and the outcomes of its participants. Disability leaders from the three target communities expressed concern however that the NDIA did not always measure what needed to be measured and did not share information key to understanding its positions. The destructive impact of lack of shared data and information can be seen in the hostile impasse between the disability community and the NDIA over the issue of independent assessments. Lessons have been learnt and there are new requirements around Co-Design with the NDIA actively sharing information and hosting seminars to ensure the financial challenges to Scheme sustainability are understood.

In this context, the requirements around sharing data and information for the design, delivery, and evaluation of services with service users is obvious. What is also required however is for representatives of the target populations to be involved in deciding what data should be collected, how it should be collected, how it should be disseminated and the nature of insights to inform its analysis.

⁵⁹ Tervalon, M., & Murray-Garcia, J. (1998). Cultural Humility Versus Cultural Competence: A Critical Distinction in Defining Physician Training Outcomes in Multicultural Education. *Journal of Health Care for the Poor and Underserved* 9(2), 117-125. Doi:10.1353/hpu.2010.0233

⁶⁰ Australian Human Rights Commission, *Social Justice Report* (October 2011)

Good practice would be seen in data requirements for the design, delivery and evaluation of services are Co-Designed (with representatives of all appropriate groups) including the identification of data needs, methods of collection, analysis and utilisation.

Co-Design and shared decision-making⁶¹

Each individual and each community would like to be involved in the design and delivery of supports for their lives. The NDIA has many mechanisms designed to hear the voice of participants. Leaders in the three disability communities spoke of the challenges of people from their communities in participating and having their voice heard via current approaches.

In recent months, the Co-Design Advisory Group, made up of representatives of the NDIA, Disability Representative Organisations and Council, has developed *Our engagement framework* a living document designed to guide, support, and strengthen NDIA engagement with the disability community. *Our engagement framework* should underpin the Co-Design and shared decision-making foreshadowed in this Advice. Council noted the lack of representation of LGBTIQ+ people with disability in current processes and recommends their voice is formally included. Council also noted the important role of storytelling and suggests the Co-Design Advisory Group examine its possible utility.

Co-Design within an intersectional framework includes inclusion of voices of all NDIS participants and consideration of their interests in relation to all work.

Good practice will be defined by the Co-Design Advisory Group.

Build cultural competence to enable cultural safety

The Participant Service Guarantee commitment that every interaction with a participant is transparent, responsive, respectful, empowering and connected provides a strong foundation for the aspiration that each participant feels safe in their interaction with the NDIS.

Unfortunately, some elements of Scheme design, developed to empower people with disability to lead good lives, in fact create barriers for some. The Advice has outlined a broad range of challenges experienced by participants and calls on the NDIA to acknowledge the dynamics of power and social inequality, understand the multiple forms of discrimination, trauma and disadvantage arising from the overlapping characteristics not privileged by society and respond better to complexity. These steps will support a pathway to creating and sustaining an NDIS that is inclusive, safe, responsive, and accountable to all.

The target disability communities acknowledge the reasonable underpinnings of the existing Strategies but indicate that the actions chosen to implement the Strategies provided ad hoc, inconsistent, and superficial steps to realise the aspirations of the Strategies. Community leaders called on the NDIA to Co-Design a deeper more structural approach to become a culturally competent organisation that enables participants to feel culturally safe. Each of the

⁶¹ consistent with NDIA (March 2022) '*Our engagement framework*'

target communities require their own nuanced approach that is Co-Designed and monitored with their chosen representatives.

Good practice would be seen in the NDIA, PiTC and support providers operating as culturally competent organisations so that Aboriginal and Torres Strait Islander, CALD and LGBTIQ+ people with disability, their families and communities can experience cultural safety. Work to establish cultural safety is Co-Designed with representatives of each target community.

Elements that would indicate cultural competence include those organisations:

- having relationships of trust and respect with people with disability, participants, communities and staff of the target group based on behaviours, attitudes and policies that support and sustain self-determination, human rights, culturally safe systems, ongoing learning and reflection, accountability and transparency;
- having policies, processes and practices that enable participants to experience cultural safety;
- providing training and development, time and opportunities for reflection to enable staff to be culturally humble; and
- enable people to feel confident that they will be treated with dignity, accepted without judgement or fear of disrespect, and not have to compromise who they are, where they belong and what is important to them to use those services.

Strengthen the systemic approach to self-determination, capacity and decision making

Many (but certainly not all) in the target populations seek services from within their own communities for the perceived assurance of shared cultural knowledge and assistance to interpret NDIA concepts of individual choice and decision making into their cultural frame.

The literature demonstrates that options grounded in communities are well placed to develop, incubate and deliver culturally responsive services in the NDIS environment. This view was shared by disability leaders from Aboriginal and Torres Strait Islander and CALD communities who were pleased and proud of their Community Connector Programs arguing that potential and actual NDIS participants were more likely to develop trust in services that understood their language, culture, and history. This was seen as a first step to developing participant choice and decision-making.

Community leaders lamented the short-term nature of the program, reporting that the potency of their Community Connector programs was reduced by the very short time frame of contracts because significant engagement was often required to enable people to feel comfortable to come forward to use Community Connectors. Whilst this may not have matched NDIS timeframes, it must be judged in the context of people who have not previously come forward, often in the many years that the NDIS has been available in their area. Many community leaders saw value in extending the role of the Community Connector programs beyond outreach and connection to the full suite of roles found in PiTC, arguing

that once trust had been established, community members wanted assistance from connectors in a broader range of activities.

The Remote Community Connector (RCC) program is more longstanding. Commenced in 2017 as a trial in the Northern Territory's East Arnhem region and South Australia's APY Lands, the RCC program engaged Indigenous-controlled Service Partners to deliver RCC services in remote locations and provides a cultural connection between remote communities and the NDIA. The program has expanded and as of March 2022, supports more than 8,000 participants through 41 Service Partners with over 200 RCCs working in more than 300 communities across NT, QLD, SA and WA.

The RCC Program support participants to engage in access and planning-related activities, connect with Service Providers, engage in their funded supports, and make best use of their plan. The NDIA reports that the RCCs provide valuable community feedback and other information to assist the NDIA and service providers to better understand the local community environment. In addition, as part of the Connectors Branch of the NDIA, the RCC Program provides insights to contribute to innovative commissioning models and the design and implementation of solutions tailored to participants in remote communities.

The voices of Aboriginal and Torres Strait Islander, CALD and LGBTIQ+ leaders are most nuanced in the area of enabling pathways to self-determination. Consistent with other areas of Aboriginal and Torres Strait Islander policy, leaders seek to strengthen the Aboriginal and Torres Strait Islander community-controlled services sector to deliver supports to people with disability. Leaders in the CALD disability community on the other hand seek partnerships: between LACs and CALD community organisations and between disability and CALD services, in all cases to increase the cultural competence of the former and the knowledge of contemporary disability practice of the latter. Leaders in the LGBTIQ+ disability community propose strengthening self-determination at the individual level seeking to strengthen empowerment and rights through peer led initiatives.

The NDIA is currently engaging with the community as it finalises its approach for commissioning PiTC services in 2022. It is therefore timely to identify the best way for PiTC to contribute to strengthening the systemic approach to self-determination, capacity and decision making. Leaders of the disability communities consulted recommended strengthening the relationship between PiTC and organisations that understand and can speak for targeted communities. Areas in which the relationship could be strengthened include:

- ensuring that PiTC workforce reflects the population of their geographical area;
- supporting specific customer cohorts through specialisation to enable more responsive support and strengthen the culture necessary to promote cultural safety;
- engaging in learning and collaboration with organisations from targeted communities based on human rights, intersectionality, and cultural safety frameworks to ensure LAC practice respects and operationalises the expression of these concepts for different individuals and communities; and

- increasing accountability to local communities by inviting representatives of targeted communities to be involved in the selection of PiTC and for local representatives to monitor the delivery and contribute to reviews of PiTC performance.

Good practice would be seen in:

People with disability:

- Being supported at access and on the Participant Pathway by staff who understand the person’s culture, history, and language; and
- Having increased access to community led / community trusted services and supports. The views of the community are taken into account in commissioning services for target populations in the ILC.
- NDIA Outcomes data reporting that people feel safe in their interaction with the NDIA, PiTC and support providers.

PiTC:

- Workforce that reflects the population of their geographical area and includes support for specialisation of roles; and
- Having strong collaborative relationships with organisations authorised to speak on behalf of local targeted communities including relationships related to learning and development and accountability.

NDIA

- Strengthening the Aboriginal and Torres Strait Islander community-controlled sector to deliver disability support;
- Incentivising providers to work in partnership with organisations in target populations to build the capacity of both organisations
- Preferring the recruitment, training and support of Aboriginal and Torres Strait Islander people living in the community in direct disability service roles within their communities to supports the retention of Aboriginal and Torres Strait Islander staff.

9 Indicators of Good Practice

9.1 In participants

- Numbers of participants consistent with ABS data.
- Use of interpreters consistent with need projected via ABS data.
- Equitable plan size, plan utilisation, use of non-Agency managed options.

- Equitable social and economic participation including in open employment.
- Equity in measures of:
 - choosing who they live with;
 - who make most of the decision in their lives;
 - who have difficulty in accessing health services; and
 - who have family and friends outside their home / who are not paid to call on for practical, emotional support and when in crisis.
- Equitable outcomes in life domains for participant.
- Equitable outcomes for families.
- Equitable quality of life measures for participants and families.
- Equitable reports that NDIS has helped in life domains.
- Equitable reports that people feel safe in their interaction with the NDIA, PiTC and support providers.

On the Participant Pathway, prospective participants, and participants:

- Are informed of their rights and have support and confidence to choose services based on their cultural competence.
- Report feeling safe to use the NDIS including at access, in planning, plan implementation and connecting to mainstream and community services and supports.
- Are supported at access and on the Participant Pathway by staff who understand the person's culture, history, and language
- Choose from mainstream, disability or Aboriginal/ CALD/ LGBTIQ+ specific services that are culturally safe and disability safe
- See themselves represented in the NDIS as both participants and workers at all levels of the NDIA, PiTC and support providers
- Have increased access to community led / community trusted services and supports that are favoured for the delivery of ILC services for the target population.

9.2 In the NDIA and PiTC

- NDIS is equitable as systems, information, services and supports deliver outcomes that are fair for all, and resource allocation of resources is based on disability support needs and personal and environmental factors.

- The NDIS has the competence and capacity to enable all people with disability and where appropriate, their families, to feel culturally safe when dealing with the NDIS.
- The impact of all NDIA and PiTC work is reviewed for its impact on equity and inclusion.
- The Board and staff of the NDIA mirror the diversity of communities.
- Data requirements for planning and the design, delivery and evaluation of services are Co-Designed including the identification of data needs, methods of collection, analysis, utilisation, and review.
- Co-Design and shared decision making⁶² are used when planning, designing, developing, and implementing supports for target populations and work to establish and monitor cultural safety is Co-Designed with representatives of each target community.
- There is rigorous engagement to become culturally competent organisations that can enable participants to experience cultural safety. Indicators include that the NDIA and PiTC:
 - have strong collaborative relationships with organisations authorised to speak on behalf of local targeted communities including relationships related to learning and development and accountability.
 - have a workforce that reflects the population of their geographical area and includes support for specialisation of roles.
 - have staff who are culturally humble.
 - have relationships of trust and respect with people with disability, participants, communities, and staff of the target group based on behaviours, attitudes and policies that support and sustain self-determination, human rights, culturally safe systems, ongoing learning and reflection, accountability and transparency.
 - have policies, processes and practices that enable participants to experience cultural safety.
- NDIA processes for information gathering for access and planning assist prospective participants who do not have evidence of disability to prove eligibility.
- LACs can draw participant's attention to culturally competent services.
- NDIA and PiTC actively assist participants at interface, negotiating and as appropriate, escalate when mainstream access prevented.

⁶² consistent with NDIA (March 2022) 'Our engagement framework'

- The market steward role of the NDIA extends from geographical and product considerations to include consideration of target groups with levers including but not limited to:
 - NDIS readiness grants
 - Incentives to providers to work in partnership with organisations in target populations to build the capacity of both organisations.
 - Other strategies to drive “collaboration with local communities, participants and their representatives and providers to drive market improvements that are culturally safe and best meet their needs”.⁶³
- NDIA and PiTC practices are evaluated against human rights indicators with committed action to address human rights abuses.

9.3 In the NDIS Quality and Safeguards Commission

Whilst recognising that the NDIA has no control over the work of the NDIS Quality and Safeguards Commission, the consensus view of disability leaders was that good practice in the NDIS Quality and Safeguards Commission would include requirements for cultural competence included in standards that are monitored for compliance.

9.4 In Department of Social Services (DSS)

Whilst recognising that the NDIA has no control over the work of DSS, leaders of the Aboriginal and Torres Strait Islander disability community argued for good practice of DSS seen in community controlled / community trusted services favoured for the delivery of ILC services for the Aboriginal and Torres Strait Islander people with disability.

⁶³ NDIA (2021) Corporate Plan 2021-25, p32

10 Operationalising the Refreshed Approach on the Participant Pathway

The Advice provides a starting point to clarify the way in which the foundations and engagement principles could be operationalised using the function of outreach. Table 1 showcases high level features of the analysis that could be used throughout the Participant Pathway in a Co-Design process to explore what is required to extend this approach at scale.

TABLE 2: OPERATIONALISING THE REFRESHED APPROACH TO NDIS OUTREACH

<i>Outreach</i>	<i>Shared access to data and information</i>	<i>Co-Design and shared decision making⁶⁴</i>	<i>Cultural competence of the NDIS</i>	<i>Systemic approach to self-determination</i>
Insurance principles/ Scheme sustainability	Shared understanding of challenges of participants and Scheme.	Develop joint understanding of insurance principles related outreach.	Understand requirements of cultural safety in context of insurance principles	Work with diverse communities to enable prospective participants to access NDIS or use mainstream services.
Human Rights obligations	Develop data and information to map rights and barriers and enablers to their fulfilment	Develop joint understanding of rights and barriers to their fulfilment related to areas of NDIS responsibility.	Plan outreach requirements of outreach in response to analysis of human rights obligations and cultural requirements	Assist participants and their families/ advocates to know their rights and speak up if their rights are violated
Build systems and approaches that reflect the diversity of Australian society Intersectional considerations	Map challenges on individual and community level Develop data sources to measure impact of multiple disadvantage	Co-Design map of intersectional challenges and develop plan to overcome	Plan outreach processes in response to analysis of removal / mitigation of intersectional challenges	Assist participants and their families to have access to culturally competent, disability friendly services

⁶⁴ consistent with NDIA (March 2022) 'Our engagement framework'

<i>Outreach</i>	<i>Shared access to data and information</i>	<i>Co-Design and shared decision making⁶⁴</i>	<i>Cultural competence of the NDIS</i>	<i>Systemic approach to self-determination</i>
Value diversity and cultural safety	Identify strengths of communities that can be harnessed to support people with disability Showcase strengths and how others can replicate	Map barriers and enablers at individual and systemic level and develop, implement, and monitor approach	Support participants, their families, and communities to identify positive contributions.	Work with individuals, families, and communities to highlight strengths. Co-Design and monitor implementation of approaches that strengthen individual choice, capacity and decision making

In summary, the refreshed approach to outreach involves:

Planning for the outreach function

- Develop shared understanding of **challenges and approaches to mitigate barriers** from participant and Scheme perspective:
 - Map challenges at individual, community, and systems level; and
 - Develop data and information to map challenges related to human rights obligations, intersectionality, diversity, and cultural safety.
- Identify **strengths** of communities that can be harnessed to support people with disability:
 - Showcase strengths and how others can replicate.
- Co-Design approach to outreach considering analysis of requirements related to human rights obligations, intersectionality, diversity, and cultural safety.
- Co-Design strengthened systemic approaches to self-determination, individual choice, capacity and decision making.

Operationalising the outreach function

- Work with diverse communities to enable prospective participants to access NDIS or mainstream and community services as appropriate.
- Assist participants, their families and communities to:

- highlight strengths;
- know their rights and speak up if their rights are violated; and
- have access to culturally competent and disability friendly services.

Outcome of refreshed approach to Outreach

The outcome of the refreshed approach assumes culturally competent NDIA and PiTC that are well connected to and trusted by organisations in the community as well as trusted directly by individuals with disability and families.

People with disability and where appropriate, their families have confidence to approach the NDIS for information, referral and support to be included in community.

Outreach undertaken by organisations and staff who

- Are trusted by communities.
- Have demonstrated capability to:
 - understand challenges and contributions of individuals and communities;
 - strengthen individual choice, capacity and decision making; and
 - assist people to select services for which there is likely to be a cultural fit.

11 Conclusion and Recommendations

The NDIA aims to ensure that all people with disability, irrespective of the gender, class, cultural heritage, ethnicity, religion, have equal opportunity to enjoy its benefits. It has sought to put in place systems, services and supports that deliver outcomes that are fair for all, and to allocate resources based on disability support need and personal and environmental factors. These strategies have not yet succeeded in delivering equity, a cause for great concern, both to the NDIA and the disability community.

Improving equity in the NDIS requires long and continuous work that must interrogate the assumptions and infrastructure of Scheme design that unintentionally privilege some and create barriers for others.

Council's Advice has examined the issue of equity for people with disability from Aboriginal and Torres Strait Islander, CALD and LGBTIQ+ communities and drew on discussion with leaders of these communities to understand the barriers and provide a pathway to the future.

The key view, synthesised from all sources, is that the targeted strategies and Scheme enhancements have not yet had the impact required on the assumptions and infrastructure of the NDIS to enable people who experience multiple compounding disadvantages to experience equitable access, participation and outcomes. Leaders argued that the Strategies resulted in superficial, ad hoc, and inconsistent activities that have not built the

cultural competence of the NDIA, PiTC and providers nor given voice and authority to the target groups for whom the strategies are designed.

The Advice calls for a new more structural approach to enable the NDIA, PiTC and support providers to become organisations that enable participants to feel culturally safe. It calls on the NDIS to embrace the diversity of its participants and underpin all work with an intersectional framework to better understand and respond to complexity and work towards creating and sustaining a NDIS that is inclusive, safe, responsive, and accountable for all. The Advice outlines principles to guide the path forward and argues that equity will only be achieved through Co-Design processes that transform organisations to meet cultural expectations of participants. Data and information to measure progress and outcomes must be Co-Designed so that all stakeholders have confidence that the right elements are being measured.

Advice of this nature cannot lead to a simple ‘quick fix’ list of recommendations. Instead, Council calls on the NDIA to:

1. Adopt an intersectional approach to better understand and respond to complexity and work toward creating and sustaining an NDIS that is inclusive, safe, and responsive to all.
2. Work with representatives of the target communities⁶⁵ to Co-Design the long-term structural work required to improve equity using the indicators of success proposed to enable the NDIA and the disability community to monitor progress.
3. Work with representatives of the target communities to Co-Design a plan for action over the next 2 years as a first step toward implementing the spirit of the Advice.

⁶⁵ Including the LGBTIQ+ community that does not have a peak or Disabled Persons’ Representative Organisation

12 Glossary

Term	Meaning
Australia's Disability Strategy	Australia's Disability Strategy is a whole of government whole of community approach to building an inclusive Australia society that ensures people with disability can fulfill their potential, as equal members of the community. It is Australia's national disability policy framework and sets out a plan for continuing to improve the lives of people with disability over the next 10 years.
CALD	Culturally and linguistically diverse
Cultural competence	<p>Cultural competence is the ability to participate ethically and effectively in personal and professional intercultural settings. It evolves through a developmental process over an extended period and embeds cultural humility into evolving practice. Both individuals and organizations are at various levels of awareness, knowledge, and skills along the cultural competence continuum.⁶⁶</p> <p>At the personal level, cultural competence requires knowing and reflecting on one's own cultural values and world view and their implications for making respectful, reflective, and reasoned choices, including the capacity to imagine and collaborate in cross cultural contexts.</p> <p>At the systemic level, cultural competence requires behaviours, policies, systems, procedures, standards, attitudes, and policies that enable that system to be ethical, effective and work effectively in cross culturally.</p>
Cultural humility	A life-long process of self-reflection and self-critique that an individual engages to examine his/her own cultural identity and beliefs when learning about another culture". ⁶⁷ Cultural humility is ultimately about valuing diversity for the richness and creativity it brings to society.
Cultural safety	<p>Creating an environment that is safe. This means there is no assault, challenge or denial of identity and experience and is seen in:</p> <ul style="list-style-type: none"> • Shared respect, shared meaning, and shared knowledge.

⁶⁶ National Centre for Cultural Competence National Centre for Cultural Competence, 1998, modified from Cross et al 1989 Cross, T., Bazron, B., Dennis, K., & Isaacs, M., (1989). *Towards A Culturally Competent System of Care, Volume I*. Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center. Accessed <https://nccc.georgetown.edu/curricula/culturalcompetence.html> 11 March 2022

⁶⁷ Tervalon, M., & Murray-Garcia, J. (1998). Cultural Humility Versus Cultural Competence: A Critical Distinction in Defining Physician Training Outcomes in Multicultural Education. *Journal of Health Care for the Poor and Underserved* 9(2), 117-125. Doi:10.1353/hpu.2010.0233

Term	Meaning
	<ul style="list-style-type: none"> • The experience of learning together with dignity and truly listening. • Strategic and institutional reform to remove barriers to optimal health, wellbeing and safety. This includes addressing unconscious bias, racism, and discrimination, and supporting self-determination. • Individuals, organisations, and systems ensuring: <ul style="list-style-type: none"> ○ Their cultural values do not negatively impact on people. ○ self-determination including sharing power (decision-making and governance) and resources, especially in relation to the design, delivery, and evaluation of services for people in a target group.⁶⁸
Equity in the NDIS	<p>An equitable society is one in which all can participate and prosper. The goals of equity must be to create conditions that allow all to reach their full potential. In short, equity creates a path from hope to change.⁶⁹</p> <p>The NDIS would be equitable when its systems, information, services and supports deliver outcomes that are fair for all.</p>
Intersectionality	<p>A theoretical approach that understands the interconnected nature of social categorisations – such as gender, sexual orientation, ethnicity, language, religion, class, socioeconomic status, gender identity, ability, or age – which create overlapping and interdependent systems of discrimination or disadvantage for either an individual or group.⁷⁰</p>
LGBTIQA+	<p>‘LGBTIQA+’ is an evolving acronym that stands for lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual. There are many other terms (such as non-binary and pansexual) that people use to describe their experiences of their gender, sexuality, and physiological sex characteristics.</p>
Participant Service Charter	<p>A commitment made by the NDIA to explain what participants can expect when dealing with the NDIA. It commits to offering service that is transparent, responsive, respectful, empowering and connected.</p>

⁶⁸ Developed from the Victorian Department of Health and Human Services, Aboriginal and Torres Strait Islander Cultural Safety Framework

⁶⁹ Victorian Government, Family Safety Victoria, Everybody Matters, Inclusion and equity statement

⁷⁰ Ibid

Term	Meaning
Participant Service Guarantee	NDIA commitment to timeframes for processes under the Participant Service Guarantee
PiTC	Partners in the Community that deliver Local Area Coordination (LAC) and Early Childhood Early Intervention (ECEI) under contract to the NDIA.

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Section 2: Reports of Discussions with Target Communities

Discussion with Leaders in the Aboriginal and Torres Strait Islander disability community

14 Executive Summary

This Report provides feedback to leaders in the Aboriginal and Torres Strait Islander disability community who participated in discussion with the Equity and Inclusion Reference Group of the Independent Advisory Council of the NDIS (Council). The discussion focused on what the NDIA can do to improve equity for Aboriginal and Torres Strait Islander participants. The report will form part of Council Advice to the NDIA Board and will be provided to the Ministerial Council with a statement from the NDIA Management about what has been done, or is to be done, in response to the Advice.

The Advice uses an intersectional approach to understand the complex systems and structures that privilege some people and create barriers for others and the Closing the Gap principles to guide recommendations for future work by the NDIA to improve equity. It records discussion with leaders using the Closing the Gap principles as the organising framework to record what we heard (from leaders), what we know (from research and literature) and what success might look like.

Principle 1: Co-Design and shared decision-making: Strengthening structures to ensure the full involvement of Aboriginal and Torres Strait Islander peoples in Co-Design and shared decision making at the systemic, community and individual level.

What we heard: Aboriginal and Torres Strait Islander communities are not listened to by NDIA decision makers.

What we know: Co-Design with Aboriginal and Torres Strait Islander people is a pre-requisite for policy legitimacy in the indigenous policy domain.

What success looks like

Co-Design and shared decision-making are used when designing, developing and implementing supports for Aboriginal and Torres Strait Islander people with disability.

Principle 2 Enabling cultural safety: Ensuring the NDIA, LAC and ECEI providers (Partners in the Community) and support providers are culturally competent organisations that embed cultural humility, so that Aboriginal and Torres Strait Islander peoples can experience cultural safety.

What we heard: NDIA processes are white fella centric, situated in a colonial hegemonic system that is often the antithesis of Aboriginal and Torres Strait Islander cultural ways of operating and doing business. Their processes leave some people behind.

What we know

- People need specific skill sets to navigate the NDIS. Dependent on one's access to such skills and resources, people may fare better or worse.
- A significant group of Aboriginal and Torres Strait Islander participants face intersectional challenges that make it difficult to get what they need.
- The individualised person-centred approach of the NDIS is incompatible with the worldview held by many Aboriginal people, where identity is bound with extended family ties, community, and culture.
- People have limited understanding of the NDIS and do not trust it.

What we heard: Aboriginal and Torres Strait Islander people need to be involved in the design, development, and delivery of support to enable cultural safety.

What we know:

- Discussion about disability is relatively new in Aboriginal and Torres Strait Islander communities. Most Indigenous people do not self-identify as disabled and indigenous families primarily focus on a person's personality, strengths and skills and not their deficits.
- We need to change the way mainstream services work, including tackling systemic racism to eliminate inequities and deliver appropriate support.
- We need to aim for cultural safety as defined by Aboriginal and Torres Strait Islander people and their communities.
- The Victorian Department of Health has developed the Aboriginal and Torres Strait Islander cultural safety framework to help the department and mainstream Victorian health, human and community services to create culturally safe environments, services and workplaces.
- Alternate ways of planning have been developed for Aboriginal and Torres Strait Islander people.
- Many Aboriginal people with disability living in rural and remote areas are faced with the dilemma of having to leave their Country and family to access disability services thus trading off "better access to services in a metropolitan location with the detrimental health and well-being consequences of leaving Country and community.

- National Aboriginal Community Controlled Organisation⁷¹ called for integrated holistic service response to better serve many Aboriginal and Torres Strait Islander people to engage in multiple service systems that have not had a history of working well together.
- Significantly more Aboriginal and Torres Strait Islander people report having a disability compared to the general population (SDAC, 2015). ILC services especially delivered by Aboriginal Community Controlled Organisations could be an important bridge to improving equity for indigenous people with disability.

What success looks like

The NDIA, Partners in Community and support providers are culturally competent organisations that embed cultural humility so that Aboriginal and Torres Strait Islander people with disability, their families and communities can experience cultural safety.

The requirements and approach to cultural competence and cultural safety are Co-Designed with the Aboriginal and Torres Strait Islander disability community and are monitored with its chosen representatives. Specific requirements of Aboriginal and Torres Strait Islander leaders are documented in the report.

Principle 3: Choice and control: Strengthening Aboriginal and Torres Strait Islander community sector to deliver supports so that Aboriginal and Torres Strait Islander people with disability have opportunities and choice to use Aboriginal and Torres Strait Islander services that are disability safe.

What we heard:

- Trust is an important element of cultural safety and takes time to build.
- We need solutions that allow people to stay on-country with support delivered our way.
- We need our own services that offer good disability support as well as mainstream disability services that are culturally safe. We have to build up an Aboriginal and Torres Strait Islander disability sector to deliver services ourselves.

What we know

- Government working with and strengthening the Aboriginal and Torres Strait Islander community-controlled services sector is mainstream government policy.
- The Twin Tracks approach is essential to provide opportunities, choice and control

⁷¹ National Aboriginal Community Controlled Organisation (NACCHO). (2020). Submission in response to the Productivity Commission draft report – Mental health inquiry.

https://www.pc.gov.au/data/assets/pdf_file/0020/252128/sub1226-mental-health.pdf

- Aboriginal peak bodies, scholars, and advocates presented strong evidence that Aboriginal and Torres Strait Islander community-controlled services play a large part in fostering social inclusion for Aboriginal and Torres Strait Islander people with disability.
- There are already successful, formal sectors of community-controlled services for land, native title, health, legal aid, and media. However, community-controlled sectors are still developing in other areas such as housing, aged care and disability support, despite these service areas including some well-established Aboriginal and Torres Strait Islander community-controlled organisations.
- Community-led research undertaken with Aboriginal people with disability and their family members and workers provides insights into possible partnerships that could build the disability knowledge in Aboriginal organisations and cultural competence in non-Aboriginal led organisations.

What success looks like

- The NDIS has identified Aboriginal and Torres Strait Islander navigation and planning support.
- Disability friendly, Aboriginal Community-controlled services provide an increasing proportion of services and supports to Aboriginal and Torres Strait Islander people with disability.

Principle 4: Shared access to data and information for the design, delivery, and evaluation of supports for Aboriginal and Torres Strait Islander people.

What we heard:

- Aboriginal and community-led scholarly research are essential to the disability advocacy human-rights movement. Research must embody good ethical conduct relating to both Aboriginal and Torres Strait Islander research and disability research as stipulated by the NHMRC and the United Nations.
- The data sets have not been developed by Aboriginal people – we know the priority areas, but we can't get the right data or get access to aggregate and interrogate existing datasets.
- Aboriginal and Torres Strait Islander people want the NDIA to engage in data sovereignty. The data sets have not been developed by Aboriginal people – we know what the issues are, but we can't get the right data.

What we know: Data is critical for effective decision making. It helps to build shared understanding of the issues, to target action, to assess progress, to inform the public and to hold decision makers to account.

What success looks like: Aboriginal and Torres Strait Islander people with disability and their representatives are partners in all elements of data including the identification of data needs, methods of collection, analysis, and utilisation.

The NDIA works with the academic community to create research scholarships (Masters and PHD) to grow the pool of Aboriginal and Torres Strait Islander researchers in disability scholarship.

15 Background

This report provides feedback to Aboriginal and Torres Strait Islander leaders who participated in discussion with the Equity and Inclusion Reference Group of the Independent Advisory Council of the NDIS (Council). The discussion focused on what the NDIA can do to improve equity for participants for whom the benefits of the NDIS are less evident with reference to improving equity for participants of Aboriginal and Torres Strait Islander, CALD backgrounds and LGBTIQ+ participants.

Feedback reported in this paper will form part of Council Advice to the NDIA Board and under S145 of the *NDIS Act, 2013*, will be provided to the Ministerial Council with a statement from the NDIA Management about what has been done, or is to be done, in response to the Advice.

15.1 Equity through an intersectional lens

Equity means that available systems, information, services and supports deliver outcomes that are fair for all and that the allocation of resources is based on disability support need and personal and environmental factors. The NDIS aims to ensure all people with disability, irrespective of their gender, class, religion, cultural heritage etc have equal opportunity to its benefits. This is not currently the case. The NDIA commitment to data analysis and targeted Strategies is testimony to its discomfort with the inequities. The approaches have made some difference, but key metrics demonstrate inequities continue to exist for some groups.

Similar to *Australia's Disability Strategy 2021-2031*, this Advice uses an intersectional approach as a framework for understanding the complex systems and structures that privilege some people and create barriers for others.

Some of the overlapping characteristics that create barriers and marginalise people include Indigeneity, gender, sex, sexual orientation, gender identity, ethnicity, colour, nationality, refugee or asylum seeker background, migration or visa status, language, religion, ability, age, mental health, socioeconomic status, housing status, geographic location, medical record or criminal record.

Some of the attitudes, systems and structures in society and organisations that interact to create inequality and result in exclusion include sexism, racism, homophobia, biphobia, transphobia, intersex discrimination, ableism, ageism and stigma.⁷²

An intersectional framework acknowledges the dynamics of power and social inequality in society and facilitates an understanding of the multiple forms of discrimination and disadvantage arising from the overlapping characteristics that are not privileged by society. An intersectional framework will thereby assist the NDIA to better understand and respond to complexity and work towards creating and sustaining an NDIS that is inclusive, safe, responsive, and accountable for all.

15.2 Aboriginal and Torres Strait Islander Engagement Strategy Refresh

In 2017, the NDIA launched its Aboriginal and Torres Strait Islander Engagement Strategy. In July 2021, the NDIA published the Progress Update announcing that it will commence engagement with Aboriginal and Torres Strait Islander stakeholders to develop the refreshed Strategy that will be completed in 2022.

It is anticipated that the work of Council will contribute to the Strategy refresh.

16 Principles for a revised strategy

Leaders in the Aboriginal and Torres Strait Islander community urged the NDIA to slow down in order to improve equity. They urged the NDIA to take the time required for reflection on the organisational and personal values that impact on practice because without reflection, nothing will change.

The Equity and Inclusion Reference Group recommends that the principles underpinning the refreshed Aboriginal and Torres Strait Strategy are based on the Closing the Gap Agreement between all Australian Governments and the Coalition of Aboriginal and Torres Strait Islander Peak Organisations because that pivotal agreement changed the way governments work with Aboriginal and Torres Strait Islander people.

In an NDIS context, the principles could be:

1. Co-Design and shared decision-making: Strengthening structures to ensure the full involvement of Aboriginal and Torres Strait Islander people in Co-Design and shared decision making at the systemic, community and individual level.
2. Enabling cultural safety: Ensuring the NDIA, LAC and ECEI providers (Partners in the Community) and support providers are culturally competent organisations that embed

⁷² Victorian Government, *Understanding Intersectionality*, Accessed 18 November 2021 at <https://www.vic.gov.au/understanding-intersectionality>

cultural humility so that Aboriginal and Torres Strait Islander peoples can experience cultural safety.

3. Choice and control: Strengthening Aboriginal and Torres Strait Islander community sector to deliver supports so that Aboriginal and Torres Strait Islander people with disability have opportunities and choice to use Aboriginal and Torres Strait Islander services that are disability safe.
4. Shared access to data and information (including the Co-Designed identification of data needs, methods of collection, analysis and utilisation) for the design, delivery, and evaluation of services for Aboriginal and Torres Strait Islander people.

The feedback is organised around these key principles to highlight what Aboriginal and Torres Strait Islander leaders told us (what we heard), what we know (from research and reports) and what success might look like.

17 Co-Design and shared decision making

Strengthening structures to ensure the full involvement of Aboriginal and Torres Strait Islander peoples in shared Co-Design and decision making at the systemic, community and individual level.

What we heard

The NDIS has made a difference: “We have to reflect on the glass half full. NDIS has improved a lot of people’s lives. But it has also made people’s lives miserable. I feel like the original Aboriginal and Torres Strait Islander Strategy is sound. It’s the actions/working plan that requires reworking.”

Aboriginal and Torres Strait Islander communities are not being listened to by NDIA decision makers

- “I don’t want my life Co-Designed. It’s my life. You can’t take the Aboriginality out of my disability.”
- “There’s no voice at the table for Aboriginal and Torres Strait Islander people.”
- “They are not listening to the community. Over and over, things get reinvented. There is a high turnover of staff in government which is frustrating, bad for staff and bad for participants.”
- “Language is a massive barrier even for mob whose first language is English.”
- “Even good services take over the voice of families.”

- The question should not be “How are the needs of Aboriginal and Torres Strait Islander people different?”. The question should be “How should disability policy be established with Aboriginal and Torres Strait Islander people?”⁷³

What we know

The voices of Aboriginal and Torres Strait Islander people with disability are critical. Their stories can and have been captured in compelling narrative⁷⁴ that combines traditional research methods and the concept of ‘yarning’, showcasing proud and resilient people exposed to social inequality and injustices that most other Australians take for granted yet drawing strength from their traditional culture of an inclusive society.

In recent years, the requirement for Aboriginal and Torres Strait Islander participation through Co-Design has emerged as a key prerequisite of policy legitimacy in the Aboriginal and Torres Strait Islander policy domain.

Co-Design in Aboriginal and Torres Strait Islander policy is not new. Examples include the previous Council of Australian Governments (COAG) trials aimed at leveraging whole of government coordination along with community partnerships in eight trial communities across the nation and in regional agreements such as the Groote Eylandt Regional Partnership Agreement that operated in two phases from 2008 to 2013. However, these examples and others like them have invariably been geographically limited, ad hoc, and time-limited experiments, and did not signal an across-the-board policy shift by governments.⁷⁵

It is clear however that the December 2018 COAG Closing the Gap decision to engage with the Coalition of Peaks in a partnership agreement based on shared decision-making principles was a major turning point in policy development processes in the Indigenous policy domain.⁷⁶

What success looks like

Co-Design and shared decision-making are used when designing, developing and implementing supports for Aboriginal and Torres Strait Islander people with disability at the systemic, community and individual level.

This could mean:

- a Co-Design process in which Aboriginal and Torres Strait Islander people have the right to choose which organisations and which people are involved.

⁷³ Gilroy, J (2019), Avoiding ‘Othering’: How should disability policy be established with Indigenous people? Croakey

⁷⁴ Avery, S, (2018) Culture is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability, First Peoples Disability Network (Australia), Sydney

⁷⁵ Dillon, M. C. (2021), Codesign in the Indigenous Policy Domain: Risks and opportunities, *Discussion Paper No. 296/2021*, Centre for Aboriginal Economic Policy Research, Australian National University. <https://doi.org/10.25911/WMJK-CE98>

⁷⁶ Dillon, M. C. (2021), op cit

- a formal partnership in which everyone has access to the same information and data to support fair and informed decision making and clarity about who is making decisions, how those decisions will be made and what the decisions will be about.
- Aboriginal and Torres Strait Islander organisations have independent policy support and Advice made available to them to support their decision making.⁷⁷

Participant plans of Aboriginal and Torres Strait Islander people with disability are Co-Designed with their families in ways that ensure cultural safety.

18 Transforming the NDIS to enable cultural safety

Ensuring the NDIA, LAC and ECEI providers (Partners in the Community) and support providers are culturally competent organisations that embed cultural humility so that Aboriginal and Torres Strait Islander peoples can experience cultural safety.

What we heard

NDIA processes are white fella centric and leave some people behind

- “The portal is not accessible to our people.”
- “Virtual online services are difficult in remote areas because the internet is bad. Digital literacy is also a problem.”
- “LACs can’t engage with people, issues with SIL providers and arguments with justice and corrections – their processes don’t work together.”
- “People are unable to use their plan to access a second language interpreter. The NDIA says interpreting is outside the plan and each state and territory must come up with its own local solution. But the NT solution doesn’t work for our clients - an unintended consequence of design that is not being done in collaboration with First Peoples.”
- “It’s not surprising that many black fellas don’t do well with the NDIS because NDIS processes are situated on a colonial hegemonic system that is often the antithesis of Aboriginal and Torres Strait Islander cultural ways of operating and doing business.”
- “Future strategies need to include access to language needs – how can you self-determine if you can’t communicate?”
- “Funding is the same despite costs being different in metropolitan and remote areas. This deprives us of opportunities that would create choice.”

⁷⁷ Coalition of Aboriginal and Torres Strait Islander Peak Organisations (2019) A new way of working. Accessed https://f.hubspotusercontent10.net/hubfs/5328468/NACCHO_April_2020/PDFs/FINAL-discussion-booklet-a-new-way-of-working-09.09.pdf 4 December 2021

- “All positions that help Aboriginal people get into the NDIS are beneficial, but we need more than Community Connectors. We need Evidence, Access and Coordination of Planning (EACP) staff nationally.”
- We need an identified Aboriginal person in the NDIA who can be our champion.
- Good solutions are changed without discussion:
 - “In 2017, we met with families on Groote Eylandt and looked at a collective on country program. We pooled NDIS funding to provide collective choice and control, providing traditional disability supports in client driven and culturally appropriate ways. The NDIS has de-activated the support item in the portal and we can’t find a solution. Ironically the NDIA funded us to produce this DVD to demonstrate this approach to others.”
<https://www.youtube.com/watch?v=ki047Gw0z-k&feature=youtu.be>
- Information provided is inaccurate:
 - “The 2021 Update to Aboriginal and Torres Strait Islander Strategy highlights a trial of whole of community approach to delivering the NDIS in Ngukurr, NT as an example of a local solutions. We provide services in Ngukurr, and we knew nothing about it. Basically, it has fallen over, there is no community approach. We were lied to about collaborating with services. It now seems to be on hold.”

What we know

Studies of NDIS experiences suggest that successfully navigating the administrative systems of the Scheme requires a specific set of skills and resources. Dependent on one’s access to such skills and resources, people may fare better or worse than others in terms of both how onerous the experience is but also whether they get the ‘personalised’ supports the scheme was designed to deliver.^{78 79} Challenges with skills and resources for navigating the NDIS appear to be exacerbated for already vulnerable or disadvantaged groups.

Many Aboriginal and Torres Strait Islander people with disability are extremely disadvantaged as a result of their socioeconomic status, housing status, geographic location, medical record or criminal record, mental health, substance misuse, homelessness, trauma, violence and victimisation, intergenerational and circumstantial disadvantage or involvement in child protection and criminal justice systems.⁸⁰

⁷⁸ Carey, G, Malbon, E, Blackwell, J (2021) Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals Centre for Social Impact, University of New South Wales, Sydney, New South Wales, Australia

⁷⁹ Soldatic, K, van Toorn, G, Dowse, L & Muir, K, (2014) Intellectual Disability and Complex Intersections: Marginalisation under the National Disability Insurance Scheme, Research and Practice in Intellectual and Developmental Disabilities, 1:1, 6-16, DOI: 10.1080/23297018.2014.906050

⁸⁰ Dowse, L, Dew, A and Sewell, A (2019) Background paper for ASID position statement on intellectual disability and complex support needs, Research and Practice in Intellectual and Developmental Disabilities, V6, No1, p5-13

Many experience additional barriers because the individualised person-centred approach of the NDIS is incompatible with the collectivist worldview held by many Aboriginal and Torres Strait Islander people, where identity is inextricably bound with extended family ties, community, and culture, and are identified as central to social and emotional well-being for Aboriginal and Torres Strait Islander people.^{81 82}

Discussion about disability is relatively new in Aboriginal and Torres Strait Islander communities. Most Aboriginal and Torres Strait Islander people do not self-identify as disabled and Aboriginal and Torres Strait Islander families primarily focus on a person's personality, strengths and skills and not their deficits.⁸³ Disability agencies on the other hand conceptualise disability as impairments affecting functioning, when assessing service access eligibility and see Aboriginal and Torres Strait Islander people as culturally different within policies, thereby marginalising people due to their cultural identity.⁸⁴

Importantly, there is a low level of cultural safety in the delivery of many NDIS services with research findings highlighting the limited participant understanding and distrust of the NDIS that impacts on the initial stages of the disability assessment and planning process.⁸⁵

These factors limit the engagement of Aboriginal and Torres Strait Islander people with disability with services. To develop culturally appropriate services, agencies must collaborate with Aboriginal and Torres Strait Islander communities with studies having identified indicators of strategies that could ensure greater and more appropriate participation by Aboriginal and Torres Strait Islander people.⁸⁶

⁸¹ Avery, S. (2018) op cit

⁸² Dew A; Vaughan P; McEntyre E; Dowse L, 2019, 'Our ways to planning': Preparing organisations to plan with Aboriginal and Torres Strait Islander people with disability', *Australian Aboriginal Studies*, vol. 2, pp.3-18, <https://search.informit.com.au/documentSummary;dn=807372348968731;res=IELIND>

⁸³ Gilroy, J (2019), op cit.

⁸⁴ Revindran, S., Brentnall, J., Gilroy, J. (2017). Conceptualising disability: A critical comparison between Indigenous people in Australia and New South Wales disability service agencies. *Australian Journal of Social Issues*, article in press.

⁸⁵ Ferdinand, A, Massey, L, Cullen, J, Temple, J, Meiselbach, J, Paradies, Y, Baynam, G, Savarirayan, R and Kelaher, M, (2021) Culturally competent communication in Indigenous disability assessment: a qualitative study Ferdinand et al. *International Journal for Equity in Health* (2021) 20:68 <https://doi.org/10.1186/s12939-021-01402-9>

⁸⁶ Gilroy J, Donnelly M, Colmar S, Parmenter T (2016) Twelve factors that can influence the participation of Aboriginal people in disability services. *Australian Indigenous Health Bulletin* 16(1).

What we heard

Aboriginal and Torres Strait Islander people need to be involved in the design, development, and delivery of support to enable cultural safety.

- “We need to employ more Indigenous staff.”
- “We need to build cultural competence in the NDIS and disability services.”
- “Cultural competency is too easy to tick and flick. Deep structural change is required.”
- “Diversity of voices needs to be respected.”
- “Not all Aboriginal people want to access Aboriginal services: the Twin Tracks model is an essential UN approach in which mainstream services are required to be inclusive and targeted investments are developed to speak to the specific needs of excluded groups and redress historic imbalance. Aboriginal services are not always disability sensitive.”
- “Problems happen because programs are developed without First Australian’s contribution. Deciding what areas should have programs and what success looks like should be done with and by the community.”
- “The NDIA needs a Research Strategy that incorporates Aboriginal research morals, ethics and methodology. The community are experts, not people with PhDs. We need community informed outcomes. Research has to be either in partnership with the Aboriginal community, preferably Aboriginal led, or just straight led by the Aboriginal community.”

What we know

“Not all services can be delivered by a community-controlled organisation. Mainstream organisations get lots of money to provide services to Aboriginal and Torres Strait Islander people so should be doing more to improve outcomes for our people. They need to change the way they work, putting more effort into tackling systemic racism and promoting cultural safety.... We need measures such as ensuring Aboriginal and Torres Strait Islander people play a key role in decision making in these institutions if there is to be long term change.”⁸⁷

This view is consistent with literature related to eliminating indigenous and ethnic health inequities that focuses on addressing the determinants of health inequities including institutionalised racism and ensuring a health care system that delivers appropriate and equitable care. There is growing recognition of the importance of cultural competency and cultural safety at both individual health practitioner and organisational levels to achieve equitable health care. Some jurisdictions have included cultural competency in health

⁸⁷ Coalition of Aboriginal and Torres Strait Islander Peak Organisations (2019) op cit

professional licensing legislation, health professional accreditation standards, and pre-service and in-service training programmes.⁸⁸

Aboriginal and Torres Strait Islander scholars emphasise that cultural competence is not a skill-set competency/attribute or a training course. For Aboriginal and Torres Strait Islander people, cultural competence requires the moral-value of “*cultural humility – a life-long process of self-reflection and self-critique that an individual engages to examine his/her own cultural identity and beliefs when learning about another culture*”.⁸⁹

Australian literature outlines the challenges of developing curricula that seeks to build cultural competence in graduates of large student cohorts. The development of a mandatory unit of study in initial teacher education emphasised the multi-layered and complex nature of the task of building a future teacher workforce that is engaging in the continuous process of becoming culturally competent in an ever-increasing diverse world.⁹⁰

Building cultural competence in dentistry education was found to require stringent governance, adequate faculty resources and effective educational strategies, in order to increase students’ knowledge, understanding and skills to achieve a minimum cultural competence standard upon graduation.⁹¹

A review of literature exploring cultural competence and cultural safety⁹² preferred the goal of cultural safety to achieve health equity because cultural safety requires practitioners to critique the ‘taken for granted’ power structures and to be prepared to challenge their own culture and cultural systems rather than prioritise becoming ‘competent’ in the cultures of others. The review urged that the objective of cultural safety activities be clearly linked to achieving health equity with healthcare organisations held accountable for providing culturally safe care, as defined by patients and their communities, and as measured through progress towards achieving health equity.

Cultural safety is a basic human right and a legislative requirement of public agencies to provide safety in the workplace. The Victorian Department of Health describes cultural safety as creating an environment that is safe for Aboriginal and Torres Strait Islander people. This means there is no assault, challenge or denial of their identity and experience and is seen in:

- Shared respect, shared meaning and shared knowledge.

⁸⁸ Curtis, E., Jones, R., Tipene-Leach, D. *et al.* Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. *Int J Equity Health* **18**, 174 (2019). <https://doi.org/10.1186/s12939-019-1082-3>

⁸⁹ Tervalon, M., & Murray-Garcia, J. (1998). Cultural Humility Versus Cultural Competence: A Critical Distinction in Defining Physician Training Outcomes in Multicultural Education. *Journal of Health Care for the Poor and Underserved* **9**(2), 117-125. Doi:10.1353/hpu.2010.0233

⁹⁰ Daniels-Mayes, S, Deconstructing and Embedding Cultural Competence in Initial Teacher Education: Responding to University Graduate Qualities for Undergraduate Students Transforming Lives and Systems, 39-49

⁹¹ Forsyth, C., Short, S., Gilroy, J., Tennant, M., & Irving, M. (2020). An Indigenous cultural competence model for dentistry education. *British Dental Journal*, **228**(9), 719-725. doi:10.1038/s41415-020-1480-3

⁹² Curtis, E., *et al.* (2019) op cit.

- The experience of learning together with dignity and truly listening.
- Strategic and institutional reform to remove barriers to the optimal health, wellbeing and safety of Aboriginal people. This includes addressing unconscious bias, racism and discrimination, and supporting Aboriginal self-determination.
- Individuals, organisations and systems ensuring:
 - their cultural values do not negatively impact on Aboriginal peoples, including addressing the potential for unconscious bias, racism and discrimination.
 - self-determination for Aboriginal people. This includes sharing power (decision-making and governance) and resources with Aboriginal communities, especially in relation to the design, delivery and evaluation of services for Aboriginal people.

Ensuring the NDIA, Partners in the Community and service providers work with Aboriginal and Torres Strait Islander people in respectful ways requires a process of continual improvement to create culturally safe environments, services and workplaces. Each community requires its own nuanced approach that is Co-Designed with the community.

Many Aboriginal people with disability living in rural and remote areas are faced with the dilemma of having to leave their Country and family to access disability services thus trading off “better access to services in a metropolitan location with the detrimental health and well-being consequences of leaving Country and community”.⁹³ Numerous studies illustrate that a greater sense of identity, social cohesion and control is experienced by Aboriginal people who maintain a connection to Country and significantly poorer mental and physical health for those disconnected from their Country.⁹⁴ This is highlighted in research with Aboriginal people (Anangu) with disability and family carers from remote Central Australian communities finding that connection to their Lands, being with family and engaging in cultural activities identified as essential to living a good life. Workers' support for a good life involves “Proper Way” help and an understanding of Anangu culture.

Alternate ways of planning have been developed and would be of value in assisting the NDIA and Partners in the Community to engage with Aboriginal and Torres Strait Islander people with disability and their families in planning in culturally respectful ways. The approach⁹⁵ is collaborative between Aboriginal led and non-Aboriginal led organisations and at the participant level includes a family, community and culture focus based on how the

⁹³ Avery, S, (2019) op cit.

⁹⁴ Dew, A, Barton, R., Gilroy, J., Ryall, L., Lincoln, M., Jensen, H., Flood, V., Taylor, K., McCrae, K (2019), Importance of Land, family and culture for a good life: Remote Aboriginal people with disability and carers, Australian Journal on Social Issues, <https://doi.org/10.1002/ajs4.96>

⁹⁵ Dew, A., McEntyre, E., Vaughan, P., Cooney, E., Dillon Savage, I., & Dowse, L., UNSW (2018). *No More Waiting: A Guide for Organisations to Plan with Aboriginal People with Disability*. UNSW: Sydney.

person views him or herself as well as how they are viewed by others, including family, community, and broader social and cultural connections.⁹⁶

Culturally competent elements of communication in Aboriginal and Torres Strait Islander disability assessment and planning have also been identified. Elements that provide a solid base for participant understanding of the NDIS include the use of culturally safe and appropriate interpreters, trusted individuals (including existing service providers), Community Connectors and family members.⁹⁷

Planners need communication skills and sufficient time to engage and build rapport, but NDIS practice often prevents this happening. Engaging with a person who has no carer or advocate, is disengaged or suspicious of governments and service providers, or has little idea of what potential support options may exist presents further challenges.⁹⁸

National Aboriginal Community Controlled Organisation⁹⁹ called for integrated holistic service response to better serve many Aboriginal and Torres Strait Islander people to engage in multiple service systems that have not had a history of working well together. This has implications for adjustment of the interface principles to enable case management across the interface on behalf of indigenous people with disability.

Finally, significantly more Aboriginal and Torres Strait Islander people report having a disability compared to the general population (SDAC, 2015). ILC services especially delivered by Aboriginal and Torres Strait Islander community organisations could be an important bridge to improving equity for indigenous people with disability. Their established relationships of trust within communities could be harnessed to improve service engagement of indigenous people and build the cultural competence of non-indigenous organisations.

What success looks like

The NDIA, Partners in Community and support providers are culturally competent organisations that embed cultural humility so that Aboriginal and Torres Strait Islander people with disability, their families and communities can experience cultural safety.

The requirements and approach to cultural competence and cultural safety are Co-Designed with the Aboriginal and Torres Strait Islander disability community and are monitored with its chosen representatives.

In the NDIA, Partners in the Community and support providers this is seen in:

- relationships of trust and respect with Aboriginal and Torres Strait Islander staff, clients and local Aboriginal communities based on behaviours, attitudes and policies

⁹⁶ Dew A; Vaughan P; McEntyre E; Dowse L, (2019), op cit

⁹⁷ Ferdinand, A, et al, (2021) op cit

⁹⁸ Collings, S, Dew, A and Dowse, L (2016), Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme, Journal of Intellectual and Developmental Disability, v41, no 3, p272-276

⁹⁹ National Aboriginal Community Controlled Organisation (NACCHO). (2020). Submission in response to the Productivity Commission draft report – Mental health inquiry.

https://www.pc.gov.au/__data/assets/pdf_file/0020/252128/sub1226-mental-health.pdf

that support and sustain Aboriginal self-determination, human rights, culturally safe systems, ongoing learning and reflection, accountability and transparency.

- policies, processes, and practices that enable participants to experience cultural safety.
- training and development, time, and opportunities for reflection to enable staff to be culturally humble.
- participants receiving equitable support based on their functional impairment and their personal and environmental circumstances and
- participants enjoying their best possible lives.

Specifically, Aboriginal and Torres Strait Islander leaders want:

- adjustment to the NDIA outreach, access and planning and plan implementation processes
- increased employment of Aboriginal and Torres Strait Islander people
- funding for interpreters
- the provision of navigational and planning support through ACCOs
- longer contracts in recognition that it takes time to build trust with and for people with disability from Indigenous communities.
- mechanisms in place to support place-based solution such as collective quotable funding for in community support
- adjustment of interface principles to enable case management across the interfaces between the NDIS, health, justice, and child protection systems for and on behalf of indigenous people with disability.
- a research Strategy that incorporates Aboriginal research morals, ethics, and methodology.
- partnerships with Aboriginal and Torres Strait Islander community organisations.
- processes that monitor culturally safe practice.

19 Strengthening Aboriginal and Torres Strait Islander community sector to deliver supports

Strengthening Aboriginal and Torres Strait Islander community services sector to deliver supports so that Aboriginal and Torres Strait Islander people with disability have

opportunities and choice to use Aboriginal and Torres Strait Islander services that are disability safe.

What we heard

Trust is an important element of cultural safety and takes time to build

- “We didn’t want to do a community connector contract for 12 months, but we ultimately took it because we wanted to support our community – we need a longer funding cycle. These short contracts must stop.”
- “People need to work in their communities, not in communities in which they have no connection.”
- “If families reach out for help, family services are all over us and the children are taken away. If you want families to come forward to get help for their children, the services need to be Aboriginal controlled.”

We need solutions tailored to each community

- “Each community is different. You can’t have one size fits all.”
- “We need to employ people in their own communities.”
- “Community based solutions run by black fellas for black fellas will build trust.”

If we are to have choice, we must build up an Aboriginal and Torres Strait Islander disability sector so we can deliver services ourselves

- “Our mob needs to be skilled up about the NDIS.”
- “Super important to have community connectors because they are mob.”
- “We need a pathway in the Agency for approvals of innovative approaches.”
- “We don’t want “ad hoc solutions” that are not nationally recognized.”
- “Aboriginal RTOs (Registered Training Organisations) can provide the training.
- “We need more programs like the Nugel Program run by the Victorian Aboriginal Child Care Agency. The Nugel Program is the first of its kind in Australia where an Aboriginal organisation is taking full responsibility for Aboriginal children and young people on Children’s Court Orders.”

What we know

A lack of Aboriginal and Torres Strait Islander disability service providers and culturally competent services is one of the main drivers for poor access to services and poorer outcomes for Aboriginal and Torres Strait Islander people.¹⁰⁰

The Twin Tracks approach is essential to provide opportunities, choice and control. Aboriginal and Torres Strait Islander people with disability need Aboriginal services that are disability friendly and disability services that are culturally safe. In addition, an Indigenous disability workforce strategy based on community-centred principles and incorporating cultural training and Indigenous disability workforce development is important to attract and retain Aboriginal workers.¹⁰¹

Government working with and strengthening the Aboriginal and Torres Strait Islander community-controlled services sector is mainstream government policy. The Australian Department of Health works in partnership with Aboriginal and Torres Strait Islander people to develop and implement strategies, programs, and initiatives to improve health and wellbeing. It funds Aboriginal Community Controlled Health Organisations¹⁰² to better deliver support to Aboriginal and Torres Strait Islander people through their healthcare journey. Policy work in health is undertaken in line with the National Closing the Gap commitments.

Aboriginal peak bodies, scholars and advocates present strong evidence that Aboriginal Community Controlled Organisations play a large part in fostering social inclusion for Aboriginal and Torres Strait Islander people with disability. Community control is described as “an act of self-determination for Aboriginal and Torres Strait Islander people. No other way of delivering and governing services guarantees Aboriginal and Torres Strait Islander empowerment and protects our identity and culture for the long term. ACCOs employ more Aboriginal and Torres Strait Islander people than do mainstream services, result in communities taking responsibility for services that can be a cultural match to their needs¹⁰³ and play an important role in forming relationships and referral pathways to disability services. They have been described as the “social glue” between Indigenous communities, and disability and community organisations.¹⁰⁴

There are already successful, formal sectors of community-controlled services for land, native title, health, legal aid, and media. However, community-controlled sectors are still developing in other areas such as housing, aged care, and disability support, despite these service areas including some well-established Aboriginal and Torres Strait Islander community-controlled organisations. NDIS readiness grants are assisting Aboriginal

¹⁰⁰ NACCHO (2021) Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with disability Accessed <https://disability.royalcommission.gov.au/system/files/submission/ISS.001.00443.PDF> 10 March 2022

¹⁰¹ Gilroy, J, Dew, A, Lincoln, M, & Hines, M, (2017) Need for an Australian Indigenous disability workforce strategy: review of the literature, *Disability and Rehabilitation*, 39:16, 1664-1673, DOI: 10.1080/09638288.2016.1201151

¹⁰² that came into being because of the inability of mainstream health services to effectively engage Aboriginal communities with their services

¹⁰³ NACCHO (2019)

¹⁰⁴ Gilroy, J & Smith-Merry, J (2017) NDIS must promote and support community-based programs to meet Indigenous people's needs, Croakey

Community Controlled Health Organisations (ACCHOs) to transition into the NDIS with the main aim, articulated by National Aboriginal Community Controlled Health Organisation (NACCHO) as to ensure *all Aboriginal and Torres Strait Islander people can access culturally appropriate services and supports no matter where they live in Australia.*¹⁰⁵ All acknowledge that capacity building is necessary to ensure regulatory and service delivery requirements can be met.

Consistent with the National Agreement on Closing the Gap, NACCHO argues that Aboriginal Community Controlled Organisations must be the preferred providers of disability programs and services within communities. In areas where there are no ACCHOs, Aboriginal community-controlled organisations (ACCOs) should be prioritised. In instances where funding is unable to be provided to a community-controlled organisation, governments and Primary Health Networks must ensure that funded organisations are held accountable for providing culturally competent services to Aboriginal and Torres Strait Islander people. These services must prioritise shared decision-making and service delivery with Aboriginal and Torres Strait Islander organisations.¹⁰⁶

The community-led research undertaken with Aboriginal people with disability and their family members and workers in five communities in NSW provides insights into possible partnerships that could build the disability knowledge in Aboriginal organisations and cultural competence in non-Aboriginal led organisations. The research aimed to learn about the experiences of Aboriginal people with disability and their families regarding planning and access to services. The participants in five communities were all able to identify at least one Aboriginal-led organisation in their community with which they had an established relationship and would feel comfortable working through, to plan for disability-related supports and services. These organisations were all local and could be supported to take on a coordinating role employing Aboriginal workers, providing information and advocacy and delivering cultural training for non-Aboriginal workers, thus enhancing people's choice in service provider.¹⁰⁷

This work will be furthered through an Australian Research Council funded project investigating how planning is occurring for Aboriginal and non-Aboriginal people, including those with intellectual disability, in regional, rural, and remote areas of Central Australia and Western NSW.¹⁰⁸

What success looks like

The NDIS has identified Aboriginal and Torres Strait Islander navigation and planning support

The NDIA has an Aboriginal and Torres Strait Islander systems navigation and planning function Co-Designed, developed and implemented with Aboriginal and Torres Strait

¹⁰⁵ NACCHO QoN Senate hearing NDIS workforce p2

¹⁰⁶ NACCHO (2021) Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with disability Accessed <https://disability.royalcommission.gov.au/system/files/submission/ISS.001.00443.PDF> 10 March 2022

¹⁰⁷ Dew A; et al (2019)

¹⁰⁸ Gilroy, J., Lincoln, M., Dew, A., Jensen, H., Bulkeley (2020) Planning for a better life in regional , rural, and remote areas under the NDIS, Vol 2(3), pp 3-8

Islander communities. The Aboriginal and Torres Strait Islander staff employed have functions similar to that of Local Area Coordinators, community connectors and Evidence, Access and Coordination of Planning (EACP) staff.

Disability friendly Aboriginal community-controlled services provide an increasing proportion of services and supports to Aboriginal and Torres Strait Islander people with disability

Aboriginal and Torres Strait Islander people with disability have increased access to community-controlled services and supports.

- The NDIA partners with Aboriginal Community Controlled Organisations in the delivery of LAC services.
- There is significant funding in ILC to reflect the fact that prevalence of disability in Indigenous people is twice that of non-indigenous people.
- Priority is given to Aboriginal community-controlled organisations for ILC funding.
- The NDIA plays its part in the Disability Sector Strengthening Plan aimed at supporting:
 - increased capacity of ACCOs to provide disability support
 - non-Aboriginal and Torres Strait Islander organisations to work in partnership with Aboriginal and Torres Strait Islander groups to build the capacity of both organisations.
 - a preferred model of support that recruits, trains, and supports Aboriginal people living in the community to ensure their retention in direct disability service roles within the community.

20 Shared access to data and information

Shared access to data and information (including the Co-Designed identification of data needs, methods of collection, analysis and utilisation) for the design, delivery, and evaluation of supports for Aboriginal and Torres Strait Islander people.

What we heard

- Aboriginal and community-led scholarly research are essential to the disability advocacy human-rights movement. Research must embody good ethical conduct relating to both Aboriginal and Torres Strait Islander research and disability research as stipulated by the NHMRC and the United Nations.
- Aboriginal and Torres Strait Islander researchers want the NDIA to engage in data sovereignty.

- Data sets have not been developed by Aboriginal people – we know the priority areas, but we can't get the right data or get access to aggregate and interrogate existing datasets.

What we know

There are multiple sources of statistics on prevalence of disability among Aboriginal and Torres Strait Islander (Indigenous) people in Australia. Official statistics are used to allocate resources; in particular, to and within the National Disability Insurance Scheme. These need to be accurate to ensure Indigenous people's health needs are met.¹⁰⁹

Data is critical for effective decision making. It helps to build shared understanding of the issues, to target action, to assess progress, to inform the public and to hold decision makers to account.

Historical disability research has disempowered Indigenous people. It is imperative that disability research privileges Indigenous experiences and cultures. Partnerships between Aboriginal community organisations and researchers is a recent practice in disability research in Australia.¹¹⁰

Indigenous community-controlled research must originate from local communities to address problems identified by those communities. Research should privilege the voices of Indigenous people and should involve Indigenous researchers, sometimes alongside non-Indigenous. In this way, communities and researchers 'walk together' identifying, understanding and finding ways to address barriers to Indigenous self-determination.¹¹¹

What success looks like

Aboriginal and Torres Strait Islander people with disability and their representatives are partners in all elements of data including the identification of data needs, methods of collection, analysis, and utilisation.

The NDIA works with the academic community to create research scholarships (Masters and PHD) to grow the pool of Aboriginal and Torres Strait Islander researchers in disability scholarship.

¹⁰⁹ Coleman, C., Wingman, N., **Gilroy, J.**, Madden, R (2X018) "Aboriginal and Torres Strait Islander disability prevalence: making sense of multiple estimates and definitions", Australian & New Zealand Journal of Public Health, doi10.1111/1753-6405.12838.

¹¹⁰ Gilroy, J., Lincoln, M., Taylor, K., Flood, V., Dew, A., Jensen, H., Barton, R., Ryall, L., and McRae, K. Walykumunu nyinaratjaku: To live a good life. 2018, Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation: Alice Springs, Northern Territory

¹¹¹ Gilroy, J, Dew, A, Lincoln, M, Ryall, L, Jensen, H, Taylor, K, Barton, R, McRae, K, & Flood, V (2018a) Indigenous persons with disability in remote Australia: research methodology and Indigenous community control, Disability & Society, 33:7, 1025-1045, DOI: 10.1080/09687599.2018.1478802

21 Assisted Council with development of Advice

Jody Barney, Certified Aboriginal Disability Cultural Consultant.

Dr Leda Barnett, The Hopkins Centre Griffith University.

Jake Briggs, Managing Director, Culture Connex Pty Ltd.

Dr John Gilroy, ARC Indigenous Research Fellow (DAATSIA) The University Of Sydney.

Catherine Liddle, CEO SNAICC – National Voice for our Children.

Adele Cox, National Sector Development Manager SNAICC – National Voice for our Children.

Nadia Lindop, CEO MJD Foundation.

Jess Styles, Director of Programs NACCHO.

The Independent Advisory Council also asked Mr Damien Griffis, Chief Executive Officer of First Peoples Disability Network (Australia) to be involved the development of the Advice. The Council respectfully acknowledges that Mr Griffis declined and will only be in a position to consider involvement when the NDIA, together with DSS, is ready to genuinely and respectfully engage with FPDN in a Co-Design power sharing way.

Discussion with Leaders in the CALD disability community

22 Executive Summary

This report outlines discussion with leaders of the CALD disability community who participated in discussion with the Equity and Inclusion Reference Group of the Independent Advisory Council of the NDIS (Council). The discussion focused on what the NDIA can do to improve equity for participants of CALD background. It will form part of Council Advice to the NDIA Board and will be provided to the Ministerial Council with a statement from the NDIA Management about what has been done, or is to be done, in response to the Advice.

The report and Advice are underpinned by frameworks related to human rights, intersectionality, creating cultural safety and strengthening empowerment and self-determination.

Three aims to achieve equity and related indicators of success are outlined including aims related to:

- achieving equitable access and participation for participants of CALD background
- achieving equitable outcomes for participants of CALD background
- ensuring the NDIS has the competence and capacity to enable people with disability and their families of CALD background to feel culturally safe.

The report combines the wisdom of leaders of the CALD disability community (What we heard) with research and literature (What we know) to explore the reasons for the inequities and approaches to redress inequities.

What we heard in relation to data

- “The NDIS does not even count all people of CALD background.”
- “We know what the issues are, but we can’t get the right data.”

What we know: Data is critical for effective decision making. It helps to build shared understanding of the issues, to target action, to assess progress, to inform the public and to hold decision makers to account.

What we heard in relation to people’s experiences

- “People are struggling with challenges that are perceived to lie in individuals rather than in systems.”

What we know: Case studies at the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability demonstrate the depth and breadth of challenges faced by many people with disability of CALD background.

What we heard about NDIS design

- “NDIS is designed without considering diversity and intersectionality.”
- “NDIA processes leave some people behind.”

What we know:

- Navigation of the NDIS relies on people being fluent in English and having sociocultural literacy and informal support.
- Many services have entrenched ways of working that were informed from times where the cultural mix in any given society was different.
- A significant group of CALD participants face intersectional challenges. Many distrust governments, many are part of the 300 language groups that are not represented by the 12 community languages favoured by the NDIS, many face cultural barriers.
- There is a difference between cultural diversity and linguistic diversity and at best NDIA data captures linguistic diversity.

What we heard about cultural competence and cultural safety:

- “You can’t take a simplistic approach to cultural competence.”

What we know

- Equity requires a change to the way mainstream services work, including tackling systemic racism to eliminate inequities and deliver appropriate support.
- Equity requires we aim for cultural safety as defined by people with disability from CALD communities.
- Settlement Services International identified organisational or sector-wide strategies that are effective in building capacity to work better with CALD participants in human services.
- NDIS access, planning and plan implementation leave some people behind with barriers including not identifying with a disability label, distrust of government, lack knowledge of Australian entitlements, challenges with access online and by phone or experiencing other characteristics related to disadvantage.
- CALD community navigators are favoured for their ability to support people of CALD communities to build trust in services and assist services to become more culturally competent.

What we heard about providers

- “Many providers are not responsive.”

What we know: There are two distinct groups of potential NDIS service providers facing CALD-related challenges: CALD community service providers seeking to develop NDIS expertise; and mainstream disability service providers seeking to develop CALD expertise. The challenges each group face have many overlaps as well as some unique differences.

What we heard about what is required

- “The NDIS needs additional measures to achieve equity.”

What we know

- The literature supports approaches that are strongly grounded in communities both to understand the language and culture of the people they serve and to develop, incubate and deliver culturally responsive services in the NDIS environment.
- Well-established relationships with CALD communities ensure the appropriate sourcing of alternative communication to manage language and cultural barriers.
- A study from Logan, Queensland reported that the use of community navigators improved access to health services for people with disability of CALD background.

The report concludes with strategies to

- improve the competence and capacity of the service system
- improve the competence and capacity of services
- strengthen the capacity of individuals and families of CALD background
- strengthen communities to welcome people with disability of CALD background.

23 Background

This report provides feedback to leaders of the CALD disability community who participated in discussion with the Equity and Inclusion Reference Group of the Independent Advisory Council of the NDIS (Council). The discussion focused on what the NDIA can do to improve equity for participants for whom the benefits of the NDIS are less evident with reference to improving equity for Aboriginal and Torres Strait Islander participants, CALD participants and LGBTIQ+ participants.

Feedback reported in this paper will form part of Council Advice to the NDIA Board and under S145 of the *NDIS Act, 2013*, will be provided to the Ministerial Council with a statement from the NDIA Management about what has been done, or is to be done, in response to the Advice.

In seeking equity in the NDIS, the Independent Advisory Council (Council) is seeking systems, information, services and supports that deliver outcomes that are fair for all, and that the allocation of resources is based on disability support need and personal and

environmental factors. The NDIS aims to ensure all people with disability, irrespective of their gender, class, religion, cultural heritage etc have equal opportunity to its benefits. This is not currently the case. The NDIA commitment to data analysis and targeted Strategies is testimony to its discomfort with the inequities. The approaches have made some difference, but key metrics demonstrate inequities continue to exist for some groups.

This report is part of the Advice of the Equity and Inclusion Reference Group of Council as to what is required to improve equity in the NDIS. The report and Advice are underpinned by:

- A) Human Rights Framework
- B) Intersectional framework
- C) Requirements for cultural safety and empowerment of individuals and communities, namely:
 - a. Shared access to data and information
 - b. Co-Design
 - c. Shared decision making
 - d. Transforming organisations to enable cultural safety
 - e. Valuing diversity and strengthening empowerment and self-determination.

23.1 Human rights framework

The NDIS Act, 2013 strongly affirms the obligations of the NDIS to give effect to Australia's obligations under international rights conventions, namely the Convention on the Rights of Persons with Disabilities (2006), the International Covenant on Civil and Political Rights (1966), the International Covenant on Economic, Social and Cultural Rights (1966), the Convention on the Rights of the Child (1989), the Convention on the Elimination of All Forms of Discrimination Against Women (1979) and the Convention on the Elimination of All Forms of Racial Discrimination (1965).

Council is confident that the Board and the Agency are mindful of these obligations and are alert to guidance as to ways to strengthen commitment to equity.

23.2 An intersectional lens

Like Australia's Disability Strategy 2021-2031, the Advice uses an intersectional approach as a framework to understand the complex systems and structures that privilege some people and create barriers for others.

Some of the overlapping characteristics that create barriers and marginalise people include Aboriginality, gender, sex, sexual orientation, gender identity, ethnicity, colour, nationality, refugee or asylum seeker background, migration or visa status, language, religion, ability,

age, mental health, socioeconomic status, housing status, geographic location, medical record or criminal record.

Some of the attitudes, systems and structures in society and organisations that interact to create inequality and result in exclusion include sexism, racism, homophobia, biphobia, transphobia, intersex discrimination, ableism, ageism and stigma.¹¹²

An intersectional framework acknowledges the dynamics of power and social inequality in society and facilitates an understanding of the multiple forms of discrimination and disadvantage arising from the overlapping characteristics that are not privileged by society. An intersectional framework will thereby assist the NDIA to better understand and respond to complexity and work towards creating and sustaining an NDIS that is inclusive, safe, responsive, and accountable for all.

23.3 Framework for making diversity and cultural safety core Scheme values

One of the major barriers for people with disability from CALD backgrounds accessing and utilising NDIS services and supports that can make a difference to their lives is that they report not feeling safe in interaction with the services. In addition, the social construction of minority groups as less powerful and their accepting that position, consolidates their disenfranchised and marginalised status, tarnishing the potential for their significant contribution on the basis of the richness of culture and experience.¹¹³

Empowering individuals and enabling them to have confidence in the cultural safety of the service system is pivotal to achieving equity. Hence Council proposes that all work to achieve equity focus on what is required to remove barriers and enhance opportunities and must:

- be based on shared access to data and information
- be Co-designed with representatives of CALD communities including the data and information on which progress will be monitored and reported
- share decision making
- work toward achieving cultural competence at the organisational and staff levels to enable people of CALD background to feel and be culturally safe
- value diversity and strengthen the empowerment and self-determination of people of CALD backgrounds and their families and of CALD communities.

¹¹² Victorian Government, *Understanding Intersectionality*, Accessed 18 November 2021 at <https://www.vic.gov.au/understanding-intersectionality>

¹¹³ Kenning (2017) in Awata, M, (2018), *Facilitators of successful service engagement of people with disabilities from culturally and linguistically diverse backgrounds*, Thesis submitted for the degree of Graduate Diploma in Research methods, College of Education, Psychology and Social Work, Flinders University, South Australia.

23.4 Cultural and Linguistic Diversity Strategy Refresh

In 2018, the NDIA launched its Cultural and Linguistic Diversity Strategy. In July 2021, the NDIA published the Progress Update announcing that it will commence engagement with the stakeholders from CALD backgrounds to develop the refreshed Strategy that will be completed in 2022.

It is anticipated that the work of Council will contribute to the Strategy refresh.

24 Aim

Leaders in the CALD disability community identified 3 foci for the improvement of equity with the aims of:

24.1 Achieving equitable access and participation for participants of CALD background

With success seen in

- match between number of participants of CALD background and estimates from ABS and other sources of Commonwealth Government data
- match between interpreter utilisation and estimates of need for interpreters derived from data above
- little or no differentiation between participants of CALD background and those of non-CALD background in measures of:
 - social and economic participation
 - plan size, plan utilisation
 - choice and control including confidence to change services, use of non-Agency managed plan management options
 - choosing who they live with
 - who make most of the decision in their lives
 - who have difficulty in accessing health services
 - who have family and friends outside their home to call on for practical, emotional support and when they are sick
 - who work in open employment
 - who are involved in a community group
 - reports that “NIDS has helped” (NDIS Outcomes data)

24.2 Achieving equitable outcomes for participants of CALD background

With success seen in little or no differentiation between participants of CALD background and those of non-CALD background in measures of:

- outcomes in life domains for participant
- outcomes for families
- quality of life measures for participants and families.

24.3 Ensure the NDIS¹¹⁴ has the competence and capacity to enable people with disability and their families of CALD background to feel culturally safe

With success seen in people of CALD background:

- being able to request a planer/ LAC who is from their own culture/ speak their language where available
- seeing themselves represented in the NDIS as both participants and workers
- being offered an interpreter
- reporting feeling safe to use the NDIS including at access, in planning, plan implementation and connecting to mainstream and community services and supports
- using mainstream, disability or CALD specific services that are culturally and disability safe.

25 Understanding the basis for inequities

This section brings together messages from leaders in the CALD disability community (What we heard) with literature and research (What we know).

What we heard about data

- The NDIS does even count all CALD people. Children and many second-generation adults with disability experience similar barriers to overseas born people with disability.
- The data sets have not been developed by people with disability of CALD background: we know what the issues are, but we can't get the right data.

¹¹⁴NDIA, LAC and ECEI Partners (PiTC) and support providers

What we know

Data is critical for effective decision making. It helps to build shared understanding of the issues, to target action, to assess progress, to inform the public and to hold decision makers to account.

What we heard people's experiences

People struggling with challenges that are perceived to lie in individuals rather than in systems

- “The NDIS has a pretence of being individualised, but my cultural background is not considered. I want my kitchen modified so I can cook (traditional Chinese food). The NDIA rejects my request, offering just a benchtop to make sandwiches. I don't eat sandwiches.”
- “Most families of children with disability from CALD backgrounds are isolated even from their ethnic communities and, in most cases, do not have the informal support of the extended family as they would be living outside of Australia.”
- “Many LGBTIQ+ people with disability feel excluded from their CALD community as well as from disability and LGBTIQ+ communities.”
- “Even participants who are competent and experienced in their lives struggle with NDIA processes.”
- “The way the NDIS works, people need assistance end to end: with pre-planning, planning, understanding and implementing their plan. If they don't have strong informal support or paid advocacy, vulnerable people just don't get a good deal. They don't have the information needed and don't know the right things to say. They are streamed incorrectly so don't get the level of skilled guidance they need.”
- “Many favour the approach of tailored participant pathways designed to support specific cohorts of participants such as those of CALD and other disadvantaged groups.”¹¹⁵

What we know

Case studies presented in the joint submission of NEDA, PWDA and FECCA to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability demonstrate the depth and breadth of challenges faced by many people with disability of CALD background. The submission recommended a systems navigation function that leverages existing social infrastructure and CALD service capacity.

What we heard about NDIS design

NDIS is designed without considering diversity and intersectionality

¹¹⁵ Also supported by the Joint Standing Committee on the NDIS, 2018. *Market readiness for the provision of services under the NDIS*

- “We need to frame the discussion to understand the structural inequality and what we can do to do fix it. If we want better outcomes, there must be a willingness to make structural changes. Fluffing around the edges will mean opportunities are lost for the Agency as well as people with disability.”
- “The NDIA lacks cultural competence. A culturally competent NDIS would not have barriers to participation associated with English proficiency or digital literacy, different understandings of disability, different cultural expectations, or different world view.”
- “Low uptake of the NDIS results from its rigid nature that does not reflect the diversity that is Australia. If you address issues of the cultural competence of the NDIA and the NDIS, people will flock to it.”

NDIA processes leave some people behind

- “LACs are not doing what it takes to support access. The National Community Connector Program (NCCP) clearly demonstrated that LACs were not up to the task of supporting people with barriers to accessing the NDIA. We see this in all government systems, not just the NDIA.”
- “I have never met or spoken to the people who made decisions that have significant consequences for me and my family. I’ve asked repeatedly for the delegates to discuss my application with me before rejecting it, but no one has ever made contact.”
- “After my application was rejected, I was sent a survey seeking feedback on my recent interaction with the Agency. The online survey disadvantages people who don’t have access to technology. In addition, both the email and survey were in English only and made no mention of any language support should it be required. The survey questions were misleading and poorly designed. They asked for my view on the Scheme, not the Agency. Such evaluation measures not only exclude people with English language barriers but are also ineffective in gathering genuine views from participants and nominees. At worst, people’s support of the Scheme is being construed to support for the Agency.”
- “Participants can access TIS (Translating and Interpreting Service) to implement their plan but it’s only possible if they use registered providers. This creates inequity between people with and without English language barriers. So even though people with English language barriers managed to get on the NDIS bus, they are still being made to sit at the back of the bus.”

What we know

Many services have entrenched ways of working that were informed from times where the cultural mix in any given society was different. Even though many frontline workers are of CALD background, many services lack the connection and nuanced understanding of ways

to enable people from CALD backgrounds to feel safe that use of the service will not undermine cultural obligations to family, community and religion.¹¹⁶

The NDIS relies on individuals being willing and able to self-advocate and make choices and decisions to secure the full benefit of the Scheme. This includes proving eligibility and engaging with services and supports designed to ultimately reduce dependence on formal support. These are foreign concepts for some and require fluency in English, sociocultural literacy, and informal support necessary to navigate mainstream systems.¹¹⁷

A significant group of CALD participants however face intersectional challenges arising from their ethnicity, colour, nationality, refugee or asylum seeker background, migration or visa status, language, religion, ability, age, gender, sex, sexual orientation, gender identity, mental health, socioeconomic status, housing status, geographic location, medical or criminal record.

Many distrust governments because of persecution or mental and physical trauma they experienced prior to arriving in Australia. Others are part of the 300 language groups that are not represented by the 12 community languages favoured by the NDIS. Many face cultural barriers arising from the lack of recognition of the significance of cultural, social networks and religious affiliations in shaping gender and age-based family and community expectations. In many non-western societies, values such as being part of the family, accepting other people's decisions and honouring the family and community are more important than independence. And for some, the ways in which disability services are delivered conflicts with the inner emotional and spiritual life of a potential service user resulting in a significant mismatch and likely service disengagement.

It is the view of the three key disability representative organisations (DROs) in the CALD disability community¹¹⁸ that many agencies have presumed that linguistic diversity and cultural diversity are the same. They argue that it is essential to distinguish between cultural diversity and linguistic diversity indicating that NDIA data at best captures linguistic diversity. Cultural diversity would be measured by indicators such as cultural, ethnic and religious background.

The three DROs describe the 2018 CALD Strategy as a high-level aspirational document that did not even have an implementation plan. They lament squandered opportunities and urge that greater efforts will be required to ensure the inclusion of the voices of CALD people in the development and, importantly, in the implementation of the refreshed strategy.¹¹⁹

¹¹⁶ Mortimer, P, & McMahon, T, (2018) Still outside the tent: cultural diversity and disability in a time of reform – a rapid review of evidence, Settlement Services International Occasional Paper 2

¹¹⁷ Soldatic, K, van Toorn, G, Dowse, L & Muir, K, (2014) Intellectual Disability and Complex Intersections: Marginalisation under the National Disability Insurance Scheme, Research and Practice in Intellectual and Developmental Disabilities, 1:1, 6-16, DOI: 10.1080/23297018.2014.906050

¹¹⁸ People with Disability Australia (PWDA), National Ethnic Disability Alliance (NEDA) and Federation of Ethnic Community Associations (FECCA)

¹¹⁹ <https://www.neda.org.au/disability-royal-commission-information> p70

What we heard about cultural competence and cultural safety

You can't take a simplistic approach to cultural competence

- “We need to look at the capacity of the NDIA to be responsive to cultural diversity.”
- “Caution against a simplistic view of culture: Cultural competence is often translated into cultural awareness training and employing more staff of CALD background. When done badly, cultural awareness training can create stereotypes and present cultures as homogenous. Coming from a CALD background is not a qualification for cultural competence.”
- “Different understandings of data contribute to a breakdown of trust. Even within agreed data, its interpretation requires cultural nuance: I might rate something high, and my mum would rate the same thing low, wondering why I pay someone to provide support when she can.”
- “We know that effective communication can foster trust, connections, and empathy. Yet, this can't be achieved when the decision makers are often so far removed from participants.”

What we know

Eliminating indigenous and ethnic health inequities requires addressing the determinants of health inequities which includes institutionalised racism and ensuring a health care system that delivers appropriate and equitable care. There is growing recognition of the importance of cultural competency and cultural safety at both individual health practitioner and organisational levels to achieve equitable health care. Some jurisdictions have included cultural competency in health professional licensing legislation, health professional accreditation standards, and pre-service and in-service training programmes.¹²⁰

Cultural competence¹²¹ refers to a set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals enabling that system agency or those professionals to work effectively in cross cultural situations and support the people who use their services to feel cultural safety. The conceptual framework and model of achieving cultural competence¹²² uses a continuum of six stages including: 1) *cultural destructiveness*, 2) *cultural incapacity*, 3) *cultural blindness*, 4) *cultural pre-competence*, 5) *cultural competency* and 6) *cultural proficiency*. Systems and organizations are encouraged to conduct self-assessment and use the results to set goals and plan for meaningful growth.

¹²⁰ Curtis, E., Jones, R., Tipene-Leach, D. *et al.* Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. *Int J Equity Health* **18**, 174 (2019). <https://doi.org/10.1186/s12939-019-1082-3>

¹²¹ Cross, T., Bazron, B., Dennis, K., & Isaacs, M. (1989). *Towards a Culturally Competent System of Care, Volume 1*. Washington, DC: CASSP Technical Assistance Centre, Centre for Child Health and Mental Health Policy, Georgetown University Child Development Centre

¹²² Cross, T et al, (1989) op cit.

A review of literature by Curtis et al¹²³ indicated that to achieve health equity requires the goal of cultural safety (as defined by patients and their community) rather than cultural competence because cultural safety requires practitioners to critique the ‘taken for granted’ power structures and to be prepared to challenge their own culture and cultural systems rather than prioritise becoming ‘competent’ in the cultures of others.¹²⁴

Settlement Services International¹²⁵ identified organisational or sector-wide strategies that are effective in building capacity to work better with CALD participants in human services. These include: recruiting culturally diverse staff who are competent to work across cultures, recruiting staff with targeted language skills and cultural knowledge, providing training for staff in culturally responsive practice, developing standards and resources to include culturally responsive practices, providing interpreter services and training staff on the use of interpreters, providing translated information and resources and using multicultural marketing strategies to reach CALD participants, creating a business unit that is responsible for coordinating multicultural strategies, partnering with CALD community organisations and using intermediaries to assist CALD participants to navigate service systems. The National Community Connector Program provided an NDIS systems navigation function that was highly valued by CALD communities.

NDIS access, planning and plan implementation leave some people behind

Studies of NDIS experiences suggest that people are struggling with NDIA processes that have been built on underlying assumptions that do not reflect the diversity and complexity of participants. Successful navigation of the administrative systems of the Scheme requires a specific set of skills and resources. Dependent on one’s access to such skills and resources, people may fare better or worse than others in terms of both how onerous the experience is but also whether they get the ‘personalised’ supports the scheme was designed to deliver.¹²⁶ Challenges appear to be exacerbated for already vulnerable or disadvantaged groups.

Outreach and Access

Many who distrust government will not seek out services that may assist. They require active outreach by trusted sources to help them to balance the benefits of engagement with the perceived risks.

To determine eligibility for individualised funding, the NDIS relies on proof that impairments that are permanent or likely to be permanent and result in substantially reduced functional capacity in a range of activities. Barriers to access for some people from CALD backgrounds include not identifying with a disability label, distrust of government, lack knowledge of Australian entitlements, challenges with access online and by phone or experiencing other characteristics related to disadvantage.

¹²³ Curtis, E., (2019) op cit

¹²⁴ Curtis, E., (2019) op cit

¹²⁵ Mortimer, P, & McMahon, T, (2018) op cit

¹²⁶ Carey, G, Malbon, E, Blackwell, J (2021) Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals Centre for Social Impact, University of New South Wales, Sydney, New South Wales, Australia

Responses recommended in the literature include flexible and 'soft' entry points in community-based settings and a 'soft' touch approach to support that maximises the opportunity for establishing rapport and trust.¹²⁷ CALD community navigators are favoured for their ability to support people of CALD communities to build trust in services and assist services to become more culturally competent.¹²⁸ It is important to note however that CALD services are not always disability sensitive and not all people from CALD communities want to use CALD services. The Twin Tracks model favoured by the UN is essential whereby mainstream services are required to be inclusive and targeted investments are developed to speak to the specific needs of excluded groups and redress historic imbalance.

Planning

Personalisation schemes put unprecedented emphasis on participants to be able to clearly articulate their goals, needs, and then access services/supports to achieve these.¹²⁹ The individualised person-centred approach of the NDIS is incompatible with the collectivist worldview held by many people, in which identity is inextricably bound with extended family ties, community and culture.^{130 131}

Planners need communication skills and sufficient time to engage and build rapport, but NDIS practice often prevents this happening. Engaging with a person who has no carer or advocate, is disengaged or suspicious of governments and service providers, or has little idea of what potential support options may exist presents further challenges.¹³² For some, planning would be more effective if it had a family, community and culture focus, based on how the person views him or herself as well as how the person is viewed by others.¹³³

Plan implementation

Participatory strategies and collaboration between mainstream service organisations and CALD communities is required to enable some people to connect to services. Whilst people with disability of CALD background have a right to expect cultural safety when using disability services, they also have a right to expect a good life on their own terms, even where this is in tension with cultural expectations of their community. CALD community organisations need to reflect contemporary understandings of disability and disability

¹²⁷ Mortimer, P, & McMahon, T, (2018) op cit.

¹²⁸ Mortimer, P, & McMahon, T, (2018) op cit.

¹²⁹ Collings, S, Dew, A and Dowse, L (2016), Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme, *Journal of Intellectual and Developmental Disability*, v41, no 3, p272-276

¹³⁰ Avery, S. (2018) *Culture is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability*, Sydney, Australia, First People's Disability Network (Australia).

¹³¹ Dew A; Vaughan P; McEntyre E; Dowse L, 2019, 'Our ways to planning': Preparing organisations to plan with Aboriginal and Torres Strait Islander people with disability', *Australian Aboriginal Studies*, vol. 2, pp. 3 -

18, <https://search.informit.com.au/documentSummary;dn=807372348968731;res=IELIND>

¹³² Collings, S, Dew, A and Dowse, L (2016), Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme, *Journal of Intellectual and Developmental Disability*, v41, no 3, p272-276

¹³³ Dew A; Vaughan P; McEntyre E; Dowse L, 2019, 'op cit.

providers need to be open to the cultural explanatory models and intersectional characteristics of some service users.

What we heard about providers

Many providers are not responsive

- “The competition model of the NDIS does not seem to deliver what people want and need. Are cooperative options where individuals pool their funding the way to go where market fails?”
- “Large providers are the antithesis of culturally safe services. Cultural safety needs to be built on relationships and trust. People need to feel understood, cared for and have a sense of belonging.”
- “CALD services do not necessarily provide better support. There is not enough capacity building to help communities establish good services. Many CALD services are not respectful to LGBTIQ+ people and many are not equipped to support people’s complex needs. Unfortunately, we see LACs and planners connecting participants to these services with no due diligence.”

What we know

There are two distinct groups of potential NDIS service providers facing CALD-related challenges: CALD community service providers seeking to develop NDIS expertise; and mainstream disability service providers seeking to develop CALD expertise. The challenges each group face have many overlaps as well as some unique differences.¹³⁴

What we heard about what is required

The NDIS needs additional measures to achieve equity for different people

- “I don’t know how you get people into the room if you haven’t got people they trust to usher them into the room. We have to go to people, not expect them all to come to the NDIS.”
- “The National Community Connector Program (NCCP) clearly demonstrated that LACs were not up to the task of supporting people with barriers to accessing the NDIS. We see this in all government systems, not just the NDIA.”
- “People need support to build agency in their lives – they don’t have to be dependent.”
- “The NDIS has to take responsibility for its incompetence: if you look at the under-representation of people with disability of CALD background, the NDIA should give the money to CALD communities to bridge the gap, to build the capacity of our communities to do better.”

¹³⁴ Settlement Services International, (2018) FutureAbility Project Report Stage 2, CALD access to NDIS services in NSW, Accessed https://www.ssi.org.au/images/FutureAbility_Stage_2_2017_18_Project_Report.pdf 26 November 2021

- “We need to think about the resources required to create dedicated services to support CALD people.”
- “Peer led support is especially important in communities where people distrust government. Speaking to someone that might understand can be significant bridge for connection and inspiration.”
- “Without a well-resourced systems navigation function, people with disability of CALD communities will be underrepresented in accessing the NDIS and other support services.”
- “Community connectors helped gain trust and build rapport with the clients trying to navigate the NDIS. The coordinators did this by having open and transparent conversations with clients, keeping them informed throughout the process, being culturally responsive and closing the communication gap. Many people with disability reported that they felt heard, supported, and informed about the application process, and felt that they had a better chance of accessing the NDIS.”
- The Community Connector program was good but:
 - “It takes time to build trust and relationships. In the initial months, considerable time was spent on facilitating information sessions on disability awareness, NDIS and the NCCP, so the community felt comfortable to reach out to Community Connectors. Its short-term nature made people feel abandoned.”
 - “By the time we finished the NCCP contract, many people had not yet been able to provide information required at access because of the long wait lists for specialists to get a diagnosis and assessment. When we finished, there were 132 people in X and Y who still didn’t have access to the Scheme. LACs continue to prove they are not doing what it takes to get people access.”
 - “Community connectors are helpful to get people into the NDIS, but people also need assistance to develop self-advocacy skills and through pre-planning, planning, connection to services and support to implement their plan.”

What we know

The literature supports approaches that are strongly grounded in communities both to understand the language and culture of the people they serve and to develop, incubate and deliver culturally responsive services in the NDIS environment.

Well-established relationships with CALD communities ensure the appropriate sourcing of alternative communication to manage language and cultural barriers. Strategies such as developing partnerships with local community organisations and engaging through existing community mechanisms and ethnic media enhance the cultural competence of mainstream organisations and the disability knowledge of CALD informal and formal supports.

The contribution of community navigators derives from their knowledge of the history, experience, cultural etiquette and understanding of traditional wellness and healing networks within the diverse communities they serve. They are well placed to provide Advice on strategies for community members to navigate healthcare and other social support systems within communities.¹³⁵

A study from Logan, Queensland reported that the use of community navigators improved access to health services for people with disability of CALD background.¹³⁶ The improved access was attributed to the navigators creating a positive perception of mainstream services among their community members. The study also showed health care providers' demonstrated commitment to delivering services in a culturally competent manner. This resulted in increased motivation among people with disability from CALD communities in Logan to seek healthcare earlier.

25.2 Summary

The views of leaders in the CALD disability community provide many insights into why and how the CALD Strategy did not succeed. The key view is that the CALD Strategy did not make an impact on the assumptions and infrastructure of the NDIS and hence fell short of what is required to enable people who experience multiple compounding disadvantages to gain the support they needed. Leaders argued that the CALD Strategy resulted in superficial, ad hoc, and inconsistent activities that have not built the cultural competence of the NDIA, PiTC and providers nor given voice and authority to the target groups for whom the Strategy was designed.

Community leaders cautioned against a simplistic view of cultural competence, the view for example, that a CALD background is a qualification for cultural competence or that a cultural awareness training session represents cultural competence. The literature and community leaders agree that significant structural work is required by the NDIA, PiTC and support providers to become culturally competent organisations that enable cultural safety for all participants, cautioning that cultural safety needs to be defined and monitored by participants, their families and communities.

A new approach is required to achieve the vision of the NDIS as inclusive, safe and accountable for all Australians. Progress toward the vision would be built on:

- a deep acknowledgement of the multicultural nature of Australian society where people experience differing levels of trust in government, differing ways of perceiving themselves, differing views of disability and differing value systems.
- human rights and intersectional framework
- a goal of cultural safety

¹³⁵ Awata, M, (2018), Facilitators of successful service engagement of people with disabilities from culturally and linguistically diverse backgrounds, Thesis submitted for the degree of Graduate

¹³⁶ Awata, M, (2018), op cit

- valuing diversity and empowering members of the target communities and
- support for the development of supports and services of and from the community.

26 Strategies to address inequities

Leaders from the CALD disability community recommend the following strategies:

Strategies to improve the competence and capacity of the service system including

- Build on the work of the Co-Design advisory group to plan approaches to improve equity including for the Co-Design of approaches to data and a structural approach to cultural competence and cultural safety
- Partner with organisations trusted by CALD people with disability (LAC commissioning) for all areas of LAC support
- Improve the responsiveness of NDIA processes:
 - reorient outreach to ensure the involvement of organisations trusted by CALD communities
 - change guidance in the availability of interpreter services
 - build cultural competence of NDIA and PiTC processes for planning, plan implementation processes, mainstream interface and connection to community.
- Increase employment of people of CALD background
- Support continuous improvement in cultural competence including through training, opportunities for reflection etc,

Strategies to improve the competence and capacity of services

- Incentivise partnerships between CALD and disability services
- Build the cultural competence of disability services and supports
- Build the disability competence of CALD services and supports
- Make representations to the NDIS Quality and Safeguards Commission in relation to monitoring providers for compliance with practice standards associated with quality.

Strategies to strengthen the capacity of individuals and families of CALD background

- build confidence and competence of participants of CALD background
- actively support participants of CALD backgrounds to negotiate with mainstream services.

Strategies to strengthen communities to welcome people with disability of CALD background

- Make representations to DSS in relation to allocation of ILC grants
- Strengthen role of LACs in building welcoming community

27 Assisted Council with development of Advice

Dwayne Cranfield, CEO, National Ethnic Disability Alliance (NEDA).

Julie Duong, Equity and Inclusion Reference Group, (until 20 January 2022)

Maureen Fordyce, Manager, AMPARO Advocacy.

Dominic Golding, Policy Officer, NEDA.

Melo Kalemkeridis, Plumtree.

Pino Migliorino AM, Managing Director, Cultural Perspectives.

Diana Qian, Disability Advocate.

Alexandra Raphael, Director of Policy and Advocacy, Federation of Ethnic Communities' Councils of Australia.

Wendy Rose, CEO Kin Disability Advocacy.

Dr Dinesh Wadiwel, Senior Lecturer, Socio-Legal Studies and Human Rights, School of Social and Political Sciences, The University of Sydney.

Discussion with leaders of the LGBTIQ+ disability community

28 Executive Summary

This report provides feedback to leaders in the LGBTIQ+¹³⁷ disability community who participated in discussion with the Equity and Inclusion Reference Group of the Independent Advisory Council of the NDIS (Council). The discussion was about what the NDIA can do to improve equity for LGBTIQ+ participants. The report will form part of Council Advice to the NDIA Board and will be provided to the Ministerial Council with a statement from the NDIA Management about what has been done, or is to be done, in response to the Advice.

The report and Advice are underpinned by frameworks related to human rights, intersectionality, creating cultural safety and strengthening empowerment and self-determination.

One of the major barriers faced by LGBTIQ+ people with disability accessing and utilising NDIS services and supports is that they do not feeling safe in interaction with the NDIS system or its services. Empowering individuals and ensuring the LGBTIQ+ cultural safety of the service system is pivotal to achieving equity. Hence Council proposes that all work to achieve equity for LGBTIQ+ people with disability focus on what is required to remove barriers and enhance opportunities and must:

- Be based on shared access to data and information that will provide the basis of monitoring and reporting
- Be Co-Designed and decision making shared with representatives of LGBTIQ+ people with disability
- Work toward achieving LGBTIQ+ cultural competence at the organisational and staff levels to enable LGBTIQ+ people with disability to feel and be culturally safe
- Strengthen the empowerment and self-determination of LGBTIQ+ people with disability.

29 Understanding the basis of inequity

29.1 Data and access to information

What we heard

¹³⁷ LGBTIQ+ is the term preferred in this Advice. Other acronyms are only used when used by studies cited.

- “The NDIA doesn’t even count us – there is no data to see how “LGBTIQA+ people with disability are going.”
- “LGBTIQA+ people with disability know what needs to be measured.”

What we know

- Data is critical for effective decision making. It helps to build shared understanding of the issues, to target action, to assess progress, evaluate effectiveness to inform the public and to hold decision makers to account.
- A consistent data set is required that captures sexuality, sexual orientation, gender, intersex variations and relationships. This must be supported by training and systems development to ensure questions are asked sensitively, and the information treated with appropriate confidentiality and sensitivity.

What success looks like

- LGBTIQA+ people with disability and their representatives are partners in all elements of data including the identification of data needs, methods of collection, analysis, utilisation and review.

Involvement of LGBTIQA+ people with disability in the NDIS

What we heard

- “LGBTIQA+ people with disability need to be in control of the narrative.”

What we know

- LGBTIQ+ people with disability are poorly serviced and under-represented in service approaches.
- Meaningful inclusion means that from design to delivery, LGBTIQA+ people with disability work at all levels of planning and management, in ways which value our expertise and commit to outcomes that offer meaningful transformations in policy and practice.
- Co-Design is essential to embed all voices in all their complexity.

What success looks like

- Co-Design and shared decision-making are used when designing, developing and implementing and evaluating supports for LGBTIQA+ people with disability.

LGBTIQA+ cultural safety of the NDIS

What we heard

- “People do not feel safe in the current system.”
- “The architecture of the Scheme causes violence and denies rights.”

- “The current strategy did nothing to safeguard LGBTIQ+ rights.”
- “The next Strategy must support LGBTIQ+ people with disability to lead their best lives and highlight and adequately deal with any barriers in a robust way.”

What we know

- Many LGBTIQ+ people have difficulty in accessing services and delay seeking treatment due to fear of bias, stigma and discrimination from service providers.
- People who identify as LGBTIQ+ experience greater rates of depression when compared with non LGBTIQ+ people and often lack protective factors such as being in a safe relationship, support from peers, supportive friends and family and a sense of belonging in community.
- Having disability, especially an intellectual disability as well as being LGBTIQ+ compounds disadvantage.
- NDIA processes privilege some and disadvantage others.
- Enabling cultural safety requires a comprehensive strategy for systemic culture change and service system redesign.
- There is a lack of formal protection via existing frameworks.
- Policies and attitudes of disability support staff, community and families deny people their rights.

What success looks like

- The NDIA, LAC providers (Partners in the Community) and support providers are culturally competent and enable cultural safety for LGBTIQ+ people with disability.
- The requirements and approach to cultural competence and cultural safety are Co-Designed with the LGBTIQ+ disability community and are monitored with its chosen representatives. Specific requirements of leaders in the LGBTIQ+ disability community are documented in the report.

Empowerment of LGBTIQ+ people with disability

What we heard

- “People don’t know their rights.”
- “People feel isolated.”

What we know

- LGBTIQ+ people with disability report a lack of feeling accepted for their intersectional identities.

- LGBTIQ+ people with disability have difficulty connecting with LGBTIQ+ communities and with disability communities.
- There are higher rates of violence and abuse against LGBTIQ+ people with disability compared with national averages and LGBTIQ+ people without disability.
- Many people have experienced abuse, neglect, violence and discrimination when coming out to support staff and that this is a huge barrier to seeking support.
- It is important people have opportunities to explore and express LGBTIQ+ identities.
- Peer support is an important avenue to provide personal support, assist in service access and facilitate wider community activism in LGBTIQ+ services and disability services.

What success looks like

- LGBTIQ+ people with disability know their rights and make complaints.
- The NDIA partners with the LGBTIQ+ disability community organisations to Co-Design and deliver opportunities for LGBTIQ+ people with disability to explore and express their LGBTIQ+ identities and live proud LGBTIQ+ lives.
- LGBTIQ+ services are inclusive and accessible.

30 Background

This report provides feedback to leaders of the LGBTIQ+¹³⁸ disability community who participated in discussion with the Equity and Inclusion Reference Group of the Independent Advisory Council of the NDIS (Council). The discussion focused on what the NDIA can do to improve equity for LGBTIQ+ participants as one of a group of participants for whom the benefits of the NDIS are less evident.

Community views, reported in this paper will form part of Council Advice to the NDIA Board and under S145 of the *NDIS Act, 2013*, will be provided to the Ministerial Council with a statement from the NDIA Management about what has been done, or is to be done, in response to the Advice.

In seeking equity in the NDIS, the Independent Advisory Council (Council) is seeking systems, information, services and supports that deliver outcomes that are fair for all, and that the allocation of resources is based on disability support need and personal and environmental factors. The NDIS aims to ensure all people with disability, irrespective of their gender, class, religion, cultural heritage etc have equal opportunity to its benefits. This is not currently the case. The NDIA commitment to data analysis and targeted Strategies is

¹³⁸ LGBTIQ+ is the term preferred in this Advice. Other acronyms are only used when used by studies cited.

testimony to its discomfort with the inequities. The approaches have made some difference, but key metrics demonstrate inequities continue to exist for some groups.

The report and Advice are underpinned by:

- D) Human Rights Framework
- E) Intersectional framework
- F) Requirements for LGBTIQ+ cultural safety and empowerment of people with disability who identify as LGBTIQ+, namely:
 - a. Shared access to data and information
 - b. Co-Design and shared decision making
 - c. Transforming organisations to enable LGBTIQ+ cultural safety
 - d. Strengthening empowerment and self-determination.

30.1 Human rights framework

The NDIS Act, 2013 affirms the obligation of the NDIS to give effect to Australia's obligations under international rights conventions, namely the Convention on the Rights of Persons with Disabilities (2006), the International Covenant on Civil and Political Rights (1966), the International Covenant on Economic, Social and Cultural Rights (1966), the Convention on the Rights of the Child (1989), the Convention on the Elimination of All Forms of Discrimination Against Women (1979) and the Convention on the Elimination of All Forms of Racial Discrimination (1965).

Of specific relevance to LGBTIQ+ people with disability are:

- the Yogyakarta principles (YP+10) that affirm existing international legal standards as they apply to all persons on grounds of their sexual orientation, gender identity, gender expression and sex characteristics. States must comply with these principles both as a legal obligation and as an aspect of their commitment to universal human rights.
- Concluding observations on the Combined Second and Third Periodic Reports of Australia,¹³⁹ in which the Committee on the Rights of Persons with Disabilities identified areas of concern related:
 - Awareness raising (Comment 15 and 16) in relation to the promotion of a positive image and awareness of the rights of all persons with disabilities particularly women, Aboriginal and Torres Strait Islander persons, persons with disabilities from culturally and linguistically diverse backgrounds and

¹³⁹ Committee on the Rights of Persons with Disabilities, Concluding observations on the combined second and third periodic reports of Australia, 15 October 2019. Accessed <https://digitallibrary.un.org/record/3848618?ln=en> 10 February 2022

lesbian, gay, bisexual, transgender, intersex, and queer persons with disabilities, in the development and delivery.

- Freedom from exploitation, violence and abuse (Comments 33 and 34).
- Respect for home and family (Comments 43 and 44).
- Closure of institutions and transition to community living (Comments 37 & 38).

30.2 An intersectional lens

Like Australia's Disability Strategy 2021-2031, the Advice uses an intersectional approach as a framework to understand the complex systems and structures that privilege some people and create barriers for others.

Some of the overlapping characteristics that create barriers and marginalise people include Aboriginality, gender, sex, sexual orientation, gender identity, ethnicity, colour, nationality, refugee or asylum seeker background, migration or visa status, language, religion, ability, age, mental health, socioeconomic status, housing status, geographic location, medical record or criminal record.

Some of the attitudes, systems and structures in society and organisations that interact to create inequality and result in exclusion include sexism, racism, homophobia, biphobia, transphobia, intersex discrimination, ableism, ageism and stigma.¹⁴⁰

An intersectional framework acknowledges the dynamics of power and social inequality in society and facilitates an understanding of the multiple forms of discrimination and disadvantage arising from the overlapping characteristics that are not privileged by society. An intersectional framework will thereby assist the NDIA to better understand and respond to complexity and work towards creating and sustaining an NDIS that is inclusive, safe, responsive, and accountable for all.

30.3 Framework for LGBTIQ+ cultural safety and empowerment

This report uses the concept of cultural safety as described in the Rainbow Tick Standards, drawing on the definition of cultural safety as 'an environment that is safe for people: where there is no assault, challenge or denial of identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience of learning, living and working together with dignity and true listening.'¹⁴¹

The concept of 'cultural safety' was originally developed to apply to health service delivery for Maori communities and then adopted for use by First Nations peoples, including by

¹⁴⁰ Victorian Government, *Understanding Intersectionality*, Accessed 18 November 2021 at <https://www.vic.gov.au/understanding-intersectionality>

¹⁴¹ Australian Human Rights Commission, *Social Justice Report* (October 2011)

Aboriginal and Torres Strait Islander communities. It was later expanded to apply to health and community service delivery for other groups, including LGBTIQ+ communities.

LGBTIQ+ inclusion requires organisations and services to establish universal policies, systems and processes that establish and demonstrate cultural safety. This involves “providing culturally safe services for LGBTIQ people (as) delivering affirmative, responsive, trauma-informed and person-centred care. It requires acknowledging the unique strengths and vulnerabilities of LGBTIQ people and having structures and processes in place that proactively identify and address potential risks to safety and wellbeing. It means challenging heteronormative and cisnormative ideas and assumptions about bodies, genders and sexualities within systems, workplace culture and service delivery.”¹⁴²

One of the major barriers faced by LGBTIQ+ people with disability accessing and utilising NDIS services and supports is that they do not feeling safe in interaction with the NDIS system or its services. Empowering individuals and ensuring the LGBTIQ+ cultural safety of the service system is pivotal to achieving equity. Hence Council proposes that all work to achieve equity for LGBTIQ+ people with disability focus on what is required to remove barriers and enhance opportunities and must:

- Be based on shared access to data and information
- Be Co-Designed with representatives of LGBTIQ+ people with disability including the data and information on which progress will be monitored and reported
- Share decision making
- Work toward achieving LGBTIQ+ cultural competence at the organisational and staff levels to enable LGBTIQ+ people with disability to feel and be culturally safe
- Strengthen the empowerment and self-determination of LGBTIQ+ people with disability.

¹⁴² Jones, J, Fairchild, J, Carman, M, Kennedy, P, Joseph, S, Parsons, M, Rainbow Tick Practice Standards, Rainbow Health Victoria p7

31 Understanding the basis for inequities

31.1 Access to data and information

What we heard

- “The NDIA doesn’t even count LGBTIQ+ people with disability – there is no data to see how LGBTIQ+ people with disability are going.”
- “LGBTIQ+ people with disability know what needs to be measured.”
- “Co-Design of data is important but simply saying data is 'done in Co-Design' would not cover the level of detail necessary to make that data gathering safe and accurate. In my experience it is so rare for us to be asked good questions about who LGBTIQ+ people with disability are in an environment enabling safety; so rare that the average LGBTIQ+ person does not even know what that looks like. "You don't know what you don't know." You know what a safe environment feels like, but most people don't know the specific steps to create an environment for staff to feel enabled and empowered to ask the questions and for LGBTIQ+ people to feel safe to reply.”

What we know

Data is critical for effective decision making. It helps to build shared understanding of the issues, target action, assess progress, evaluate effectiveness, inform the public and hold decision makers to account.

NDIA data is not disaggregated based on LGBTIQ+ status and the existing outcome framework does not measure the experiences of LGBTIQ+ participants.

Information about sexual orientation, gender identity or intersex status can be highly personal, and in some cases, sensitive. Disclosure may pose a risk to an LGBTIQ+ person’s safety, health and wellbeing, and their connections to family and community.¹⁴³

Historically mainstream services and coronial processes have not gathered data that represents the experience of LGBTI people within the mental health and suicide prevention system, and mental health and suicide prevention staff have voiced a lack of confidence and competence in sensitively and appropriately asking these questions (Price Waterhouse Coopers, 2011).¹⁴⁴

A consistent data set is required that captures sexuality, sexual orientation, gender, intersex variations and relationships, and must be also included in suicide registers. This must be

¹⁴³ Rainbow Health Victoria, Rainbow Tick Practice Guide 3rd edition p19

¹⁴⁴ Rainbow Health Victoria and Thorne Harbour Health, (2019)

supported by training and systems development to ensure these questions are asked sensitively, and the information treated with appropriate confidentiality.¹⁴⁵

What success looks like

LGBTIQA+ people with disability and their representatives are partners in all elements of data including the identification of data needs, methods of collection, analysis, utilisation and review for the design, delivery, and evaluation of services for LGBTIQA+ people with disability.

31.2 Involvement of LGBTIQA+ people with disability in the NDIS

What we heard

LGBTIQA+ people with disability need to be in control of the narrative

- “LGBTIQA+ people with disability are not a homogenous community, we have different experiences based on our bodies, our gender identities, our intersex status, our sexualities, our relationships, our impairments, and these differences intersect with our ethnicity, culture, socio-economic status etc and create an individual. All these factors don’t really get a chance to be considered in a holistic way in the NDIS.”
- “There is a lack of coherent understanding of people with intersex characteristics. LGBTIQA+ people with disability feel disrespected. Heterosexual and cisgender people have intersex variations. Parents of children with intersex characteristics are struggling to engage with the NDIS. Understanding everyone who is LGBTIQA+ is important to address the breadth of the community.”
- “LGBTIQA+ people with disability don’t have a way to tell our own success stories, to be in control of the narrative.”
- “Providers are sometimes gatekeepers and substitute decision-makers – they and families make decisions that are ours to make.”
- “LGBTIQA+ people with disability are tired of Band-Aid solutions. They won’t work.”
- “Participatory Action Research Projects is a much better term than ‘Co-Design’.”
- “In the ILC, there are lots of shiny things: seminars, products, but you can tell they have not involved deep conversations with people with disability, especially those who are very marginalised. The outcomes are not out there yet.”
- “The current structure does not support a robust Co-Design process and deep involvement of people with disability. Structural change is needed to the (ILC) grants

¹⁴⁵ Rainbow Health Victoria and Thorne Harbour Health, (2019)

process to enable genuine Co-Design and engagement and drive meaningful and sustainable outcomes for people with disability.”

- “The new strategy must be Co-Designed and co-delivered. They (NDIA) can’t just hold consultations. There must be ongoing commitment to embed people’s voices. And to know it takes a long time. Any strategy needs to cover intersectionality.”
- Participants reported that more positive outcomes are likely when organisations commit to using plain and easy English, embed voices of the community in any work, use a user-led design process, and slow the process to get quality outcomes.

What we know

LGBTIQ+ people with disability are poorly serviced and under-represented in service approaches. As a result of the lack of engagement and visibility within their communities combined with overt and subtle forms of marginalisation and exclusion, LGBTIQ+ people with disability become displaced in their positions as citizens and community members, and are instead constructed as clients, service users, patients and service recipients with little determination or control over the decisions that affect them.¹⁴⁶

Meaningful inclusion means that from design to delivery, LGBTIQ+ people with disability work at all levels of planning and management, in ways which value our expertise and commit to outcomes that offer meaningful transformations in policy and practice People for whom access and accessibility is being planned must be included in the processes of consultation, research, service and policy development.¹⁴⁷

Co-Design is essential to capture all voices in all their complexity. There is less available data on the mental health of people with intersex characteristics. However, some studies have found significant levels of self-harm and suicidality in participants who had an intersex variation. In many cases, participants identified unnecessary medical interventions and other people’s comments and attitudes as drivers of their reduced mental health and wellbeing, rather than the intersex variation itself.¹⁴⁸

The NDIS must strengthen structures to ensure the full involvement of LGBTIQ+ people with disability in Co-Design and decision making.

What success looks like

¹⁴⁶ WWILD-Sexual Violence Prevention Association, (2021) Submission from the Queer and Disability Professionals and Services Network for the Queensland Parliamentary Inquiry into Social Isolation and Loneliness. Accessed <https://documents.parliament.qld.gov.au/com/CSSC-0A12/IQ-DD31/submissions/00000182.pdf> 15 February, 2022

¹⁴⁷ O’Shea, A, Latham, J, McNair, R, Despott, N, Rose, M, Mountford, R and Frawley, P, (2020b) Experiences of LGBTIQ+ People with Disability in Healthcare and Community Services: Towards Embracing Multiple Identities *Int. J. Environ. Res. Public Health* 2020, 17, 8080; doi:10.3390/ijerph17218080 p12

¹⁴⁸ Jones and Leonard, 2019 reported in Rainbow Health Victoria and Thorne Harbour Health, (2019) Royal Commission into Victoria’s Mental Health System, consumer talking points. Accessed. https://cdn.thorneharbour.org/media/documents/MHS_Consumer_Talking_points_20190417.pdf 8 June 2021

The NDIA uses Co-Design processes when designing developing, implementing and evaluating supports for LGBTIQ+ people with disability.

This could mean:

- A Co-Design process in which LGBTIQ+ people have the right to choose which organisations and which people are involved.
- Ensuring everyone has access to the same information and data to support fair and informed decision making and clarity about who is making decisions, how those decisions will be made and what the decisions will be about.

LGBTIQ+ organisations Co-Design supports with LGBTIQ+ people with disability.

31.3 LGBTIQ+ cultural safety of the NDIS

What we heard

LGBTIQ+ people do not feel safe in the current system

- “People seek support workers from the LGBTIQ+ community because LGBTIQ+ people with disability don’t feel safe with faith-based providers, many of which have normalisation at their core. They want to change people to fit into society’s expectations.”
- “People don’t see themselves in NDIS promotional materials and publicity. They don’t see good things and lives changing.”
- “The workforce strategy doesn’t help – it picks up other groups who don’t have social value and turns them into workers for the NDIS.”
- “Short funding contracts in the ILC make in-depth Co-Design and reaching isolated communities practically impossible.”
- “Intersectional training must be trauma informed and mandatory for service providers funded by the NDIS.”

The architecture of the Scheme causes violence and denies rights

The NDIS continues to segregate and marginalise people in ways that create trauma, violence and lead to psychological distress:

- “People are forced to live with homo/transphobic parents, in group homes, aged care facilities, boarding houses and other institutions. Living in these environments makes it almost impossible to live the life you want to live and access to sexual health, intersex peer supports, gender affirming supports and sexuality education.”
- “Practices such as ABA (Applied Behaviour Analysis) and conversion therapies that aim to normalise our queer presentations are funded but following the Minister’s moral judgement, sex supports are not”. It was noted that the high-profile appeal that

the Minister took up to the Federal Court, and lost, was against a lesbian with disability who had sought and was originally granted NDIS supports to access the sex industry. “The Strategy needs to affirm our choices and recognise that ‘reasonable and necessary’ may look different for LGBTIQ+ people with disability.”

The current strategy did nothing to safeguard the rights of LGBTIQ+ people

- “The current Strategy had a silent launch. This is a pattern of addressing our communities, off to the side, anticipating that backlash could be coming. It’s not a controversial topic and LGBTIQ+ people with disability are not a dirty secret.”
- “I feel like it is almost a waste of time focusing on the current NDIA LGBTIQ+ Strategy - the current strategy does nothing to safeguard the rights of LGBTIQ people accessing NDIS providers because it does not reach beyond the NDIA agency itself. This was pointed out to the NDIA at the original consultations on the strategy years ago.”
- “The Strategy is like an internal workforce diversity competency document and even within that, the NDIA reports on what has been done but LGBTIQ+ people with disability have no idea about the quality of the training or the involvement of organisations in the development and delivery of training, or what the survey results showed.”
- “I think it's common knowledge but just in case it isn't, a number of the community members involved in the original LGBTIQ+ Strategy consultation were traumatised by the process and found it extremely dehumanising.”

The next Strategy

For a strategy to make a difference in the lives of LGBTIQ+ people with disability a strategy would need to:

- “Include a human rights and CRPD compliance framework”
- “Lead with a declaration from the NDIA at the highest level that it is their intention to ensure that LGBTQIA+ people with disability are supported to live the lives that they desire, and for any structural impediments or barriers that are in the way of that to be highlighted and adequately dealt with in a robust way.”
- “Centre the voices of LGBTIQ+ people with disability from the start and throughout.”
- “Be transparent and accountable at each layer.”
- “Be trauma informed and through an intersectional framework.”
- “Be directed to NDIS providers including specifics in the practice standards creating obligations to:
 - be LGBTIQ+ inclusive.

- provide information, education, and options about LGBTIQ+ identities and experiences to every person who accesses the NDIS.¹⁴⁹
- fund a capacity building strategy.”
- “Affirm support for our community. Any time a mainstream organisation comes out with an LGBTIQ+ positive strategy they get backlash about promoting ‘the gay/trans agenda’. If the NDIA doesn’t publicly support our community, they support phobia against our community.”

What we know

Many LGBTIQ+ people with disability do not feel safe

Many LGBTIQ+ people have difficulty in accessing services and delay seeking treatment due to fear of bias, stigma and discrimination from service providers.¹⁵⁰

There is an association between poor mental health and disconnection from family or communities, or discrimination and harassment. Despite a legal and social environment that is increasingly supportive of LGBTI people, harassment and discrimination driven by homophobia and transphobia still occurs.¹⁵¹

Many LGBTIQ+ people with disability lack protective factors

People who identify as LGBTIQ experience greater rates of depression when compared with non LGBTIQ+ people (Carman et al., 2021). Three of the noted protective factors for depression in people who identify as LGBTIQ were (a) being in a relationship; (b) social support from peers, friends and family; and (c) a sense of belonging to a community. Further, this review noted an association between discrimination, stigma and depressive symptoms. For people with intellectual disability, the protective factors are often absent regardless of sexual identity with a noted relationship between symptoms of depression, active participation and social inclusion.¹⁵²

Enabling cultural safety requires systemic change

Establishing cultural safety requires more than training and professional development. It requires a comprehensive strategy for systemic culture change and service system redesign. Rainbow Tick Standard 2¹⁵³ recognises the ongoing requirements to achieve and maintain Rainbow Tick accreditation with:

- Standard 2.2 outlining requirements for professional development to the governing body, leadership team, staff and volunteers that includes their legal responsibilities,

¹⁴⁹ LGBTIQ+ advocates argue that there are so many gatekeepers to LGBTIQ people with intellectual disability that a strategy cannot rely on every LGBTIQ person themselves to overcome the many barriers in order to be able to ask for supports that affirm their body autonomy, gender & sexuality.

¹⁵⁰ Rainbow Health Victoria and Thorne Harbour Health, (2019)

¹⁵¹ Rainbow Health Victoria and Thorne Harbour Health, (2019)

¹⁵² Wilson, N, et al (2018)

¹⁵³ Jones, J, et al, Rainbow Tick Practice Standards

LGBTIQ cultural safety and a consideration of the impact of employees' attitudes and beliefs on LGBTIQ-inclusive practice.

- Standard 2.3 requiring the organisation keeps up to date with current trends in the field of LGBTIQ-inclusive service provision and uses this information in the ongoing development of staff training and resources; and
- Standard 2.4 requiring the organisation to participate in relevant professional associations and other forums aimed at improving the quality of services provided to LGBTIQ service users."

A number of inclusive practice audit tools and self-assessment tools are available, along with resources and guides to assist organisations in undergoing this change.¹⁵⁴

Lack of explicit formal protection via existing frameworks

Australian and international studies show that LGBTI people underutilise health services and delay seeking treatment due to actual or anticipated bias from service providers. In *Private Lives*, nearly 34% of LGBT Australians reported "usually or occasionally" hiding their sexual orientation or gender identity when accessing services to avoid possible discrimination and abuse (Leonard et al, 2012). This can lead to reduced screening for a range of physical and mental health conditions and an escalation of issues and poorer prognosis.¹⁵⁵

While the rights of LGBTIQ+ people are explicitly defined in international declarations to which Australia is a signatory, this has rarely translated to explicit reference to LGBTIQ+ people with disability in Australian legislation, standards and policy governing the disability support sector. Without explicit affirmative, proactive, and/or preventative measures in every level of legislation, regulation (such as the NDIS Practice Standards and associated guidelines) and policy, an environment is created that enables the regular and systemic violation of the rights of LGBTIQ+ people with disability.

The Victorian State Disability Plan 2017-2020 includes a range of initiatives to promote accessibility and inclusion for LGBTIQ+ people with disability. This is not seen in all state disability plans.

The NDIS LGBTIQ+ Strategy outlines guidelines and plans for engaging LGBTIQ+ participants in the NDIS and engaging NDIA staff. It does not however include guidelines for LGBTIQ+ inclusion in NDIS registered providers and most other contracted bodies.

The NDIS Practice Standards do not explicitly include LGBTIQ+ considerations, although they may be implied in several standards.¹⁵⁶ Any competency standard however needs to be

¹⁵⁴ Thorne Harbour Health & Rainbow Health Victoria (2019) Royal Commission into Victoria's Mental Health System. Accessed https://cdn.thorneharbour.org/media/documents/RHV_THH_SV_RCMH_July_2019.pdf 7 December 2021

¹⁵⁵ Rainbow Health Victoria and Thorne Harbour Health, (2019)

¹⁵⁶ Parsons M, Despott, N and Power R (2021). *Our Rainbow Lives*. Melbourne: Inclusion Melbourne and Rainbow Health Victoria.

connected to audit requirements via the NDIS Quality and Safeguards Commission so that registration can be removed from unsafe organisations.

There are promising developments in amendments to the NDIS Act currently before Parliament that remove the word 'gender' and replace it with 'sex, gender identity, sexual orientation and intersex status'. The Participant Service Charter commits to respectful service, characterised as '*we will recognise your individual experience and acknowledge you are an expert in your own life*'. These steps could be used to authorise the amendment of practice standards and make a difference in policies and attitudes of disability support staff, community and families.

Policies and attitudes of disability support staff, community and families deny people their rights

Many organisations still do not have policies regarding sexuality and relationships, let alone policies for same-sex sexual expression. When policies are non-existent or are not clearly communicated to service providers and service users, or offer unequal rights, there is a risk that staff may deny or negatively influence the service users based on their own attitudes and beliefs. Unclear policies and a lack of education and training may also lead service providers to become hesitant in allowing any same-sex interactions, for fear of breaching their duty of care, or due to fears about the validity of consent of each person.¹⁵⁷

Disability support professionals can inadvertently create barriers to inclusion based on personal attitudes such as inappropriate application of religious frameworks, homophobia, biphobia, transphobia or discrimination against people with intersex characteristics. Some may have insufficient understanding of respectful treatment of transgender people (including use of pronouns) and may make inappropriate or ad hoc assessments of risk based on elevated notions of vulnerability, concerns about organisational reputation or similar concerns. This can lead them to limit choice, education (to explore holistic sexuality and relationships) and supports, including support to participate in LGBTIQ+ events and access to sex workers if the people with intellectual chooses to explore their sexuality in this way.¹⁵⁸ Most LGBTIQ+ people with disability want to express their LGBTIQ+ identity but many are thwarted by disability support staff.

LGBTIQ+ people with disability can also experience barriers to inclusion from the LGBTIQ+ community and civil society as a result of:

- Problematisation and infantilisation of the sexuality of people with intellectual disability in a way that views them as fundamentally incapable of living proud LGBTIQ+ lives.

¹⁵⁷ Wilson, N, Bright, A, MacDonald, J, Frawley, P, Hayman, B, Gallego, G, (2018) A narrative review of the literature about people with intellectual disability who identify as lesbian, gay, bisexual, transgender, intersex or questioning, *Journal of Intellectual Disabilities* 2018, v22(2) 171-196

¹⁵⁸ Parsons M, et al (2021),

- Little or no knowledge of disability support practices that could facilitate inclusion of LGBTIQ+ people with intellectual disability.
- Lack of budget allocation to include intersectional specific supports such as support for LGBTIQ+ people with disability from CALD communities.¹⁵⁹

Families and advocates can further place barriers to inclusion by:

- Employing unbalanced approach to duty of care and dignity of risk due to fear that the person may experience discrimination.
- Discriminatory attitudes such as homophobia, biphobia, transphobia or discrimination against people with intersex characteristics.
- Lack of knowledge of education, referral options and support practice and the person's rights.
- Increased stigma in the community group to which they belong such as a conservative religious group or their diverse cultural background.¹⁶⁰

Having an intellectual disability as well as being LGBTIQ+ compounds disadvantage

“The sexual lives and opportunities for sexual expression for many people with intellectual disability continue to be mediated by family, disability support staff and service policies that tend to be protective in nature and informed from a risk-averse perspective.

These papers demonstrate dual marginalization experienced by people because they are labelled with intellectual disability and also identify as LGBTIQ. They are initially marginalized by their disability and pushed farther from social ‘acceptability’ because of their sexual orientation or gender expression. This position can render some people in this cohort as powerless. Powerlessness can make accessing and negotiating usual social supports more difficult. Relationships, both familial and social (friendships and intimate) relationships, might be affected or influenced/controlled”.¹⁶¹

NDIA processes privilege some and disadvantage others

Studies of NDIS experiences suggest that successfully navigating the administrative systems of the Scheme requires a specific set of skills and resources. Dependent on one's access to such skills and resources, people may fare better or worse than others in terms of both how onerous the experience is but also whether they get the ‘personalised’ supports the Scheme was designed to deliver.¹⁶² Challenges with skills and resources for navigating the NDIS appear to be exacerbated for already vulnerable or disadvantaged groups.

¹⁵⁹ Parsons M, et al (2021)

¹⁶⁰ Parsons M, et al (2021)

¹⁶¹ Wilson, N, et al (2018)

¹⁶² Carey, G, Malbon, E, Blackwell, J (2021) Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals Centre for Social Impact, University of New South Wales, Sydney, New South Wales, Australia

Access

To determine eligibility for individualised funding, the NDIS relies on proof that impairments are permanent or likely to be permanent and result in substantially reduced functional capacity in a range of activities.

LGBTIQ+ people with disability may avoid seeking healthcare and treatment for fear of stigma and discrimination in healthcare and service settings and may not disclose their multiple identities and experiences in those settings. In addition, there is a lack of culturally safe clinicians with a good understanding of disability and affirming care. This creates a combination of factors that prevent LGBTIQ+ people with disability from receiving accurate diagnoses or assessments and prevent them from both accessing the scheme or receiving adequate funding from the NDIS.

Finally, the complexity many LGBTIQ+ people with disability experience can leave people to fall through the cracks between services when eligibility is determined by depth, or severity, in any one area.¹⁶³

Planning

Personalisation schemes put unprecedented emphasis on participants to be able to clearly articulate their goals, needs, and then access services/supports to achieve these. Planners need communication skills and sufficient time to engage and build rapport; however, it appears that current NDIS practices militate against this. Engaging with a person who has no carer or advocate, is disengaged or suspicious of governments and service providers, or has little idea of what potential support options may exist presents further challenges.¹⁶⁴

Many LGBTIQ+ participants need assistance to think about what supports they need to maintain bodily integrity and advocate for themselves when wanting to learn about their body, their gender and their sexuality or to look after their body and mental health. They may want to include a goal that specifically relates to their desire to live as a proud LGBTIQ+ person or experience genuine inclusion in the LGBTIQ+ community.

The NDIA must ensure that the NDIA, Partners in the Community and support providers are culturally competent organisations that enable cultural safety LGBTIQ+ people with disability.

What success looks like

The NDIA, Partners in Community and support providers are culturally competent organisations that enable cultural safety for LGBTIQ+ people with disability. Cultural competence is measured by accreditation with the Rainbow Tick standards.

The requirements and approach to cultural competence and cultural safety are Co-Designed with LGBTIQ+ people with disability and are monitored with their chosen representatives.

¹⁶³ Collings, S, Dew, A and Dowse, L (2016), Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme, *Journal of Intellectual and Developmental Disability*, v41, no 3, p272-276

¹⁶⁴Collings, S, et al (2016)

This is reflected in Standard 3, Consumer participation of the Rainbow Tick guide under which LGBTIQ+ service users are required to be consulted about, and participate in the planning, development and review of the service.

In the NDIA, Partners in the Community and support providers this is seen in:

- Relationships of trust and respect with LGBTIQ+ staff, clients and LGBTIQ+ communities based on behaviours, attitudes and policies that support and sustain self-determination, human rights, culturally safe systems, ongoing learning and reflection, accountability and transparency.
- Trauma informed policies, processes and practices that enable participants to experience cultural safety.
- Participants receiving equitable support based on their functional impairment and their personal and environmental circumstances and
- Participants enjoying their best possible lives.

Specifically, leaders from the LGBTIQ+ disability want:

- Strategies to support and empower LGBTIQ+ people to
 - explore and express LGBTIQ+ identity, culture and community
 - engage gatekeepers
 - advocate for themselves
- The use of words, names and pronouns that a person has requested.
- Funded training for paid staff and volunteers, created and delivered by LGBTIQ experts within LGBTIQ lead organisations, covering how to:
 - support people of diverse sexuality, gender, identity, and intersex variations
 - resolve conflict
 - advocate for inclusion within support organisation, health organisations, advocacy groups, families, and wider members of a person's network.
- Practice standards with specific reference to LGBTIQ+ considerations including monitoring for their implementation.
- Regular review of cultural safety.

31.4 Empowerment of LGBTIQ+ people with disability

What we heard

People don't know their rights

- “Documents are not in easy English. People struggle with the Access Request Form.”
- “People don't even know they can report bad things or how to report. They have never heard of the NDIS Quality and Safeguards Commission. It needs to be embedded in the strategy.”
- “Where is the accountability when organisations are not LGBTIQ+ inclusive? There are no consequences. It's not worth the paper it's written on.”

People feel isolated

- “People have difficulty connecting with LGBTIQ+ communities and disability communities.”
- “An insurance scheme must be about empowerment and helping people to discover ways to live the best life as they can.”
- “People feel they are trying to get a toe in the door. LGBTIQ+ people with disability need a collective voice for proud inclusion.”
- “2-year funding contracts in the ILC prevents us reaching the most marginalised people.”

What we know

The Deakin University study of LGBTIQ+ people with disability reported people ‘feeling split’ between different parts of themselves, the stress of constantly coming out in different ways to different people, and the difficulties of making decisions about when, how and to whom they could disclose information, and when they needed to mask parts of themselves in order to feel safe and/or receive services.¹⁶⁵

LGBTIQ+ people with disability have difficulty connecting with LGBTIQ+ communities¹⁶⁶ with a Victorian study¹⁶⁸ finding that a relatively high proportion (48=45%) of respondents did not feel part of the LGBTIQ community, (despite the survey recruitment being largely

¹⁶⁵ O'Shea, A., Latham, J., Beaver, S., Lewis, J., Mountford, R., Rose, M, Trezona, A., Frawley, P. (2020a). More than Ticking a Box: LGBTIQ+ People With Disability Talking About Their Lives. Geelong: Deakin University. P36

¹⁶⁶ Leonard & Mann, (2018) The everyday experience of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability, No.111 GLHV@ARCSHS, La Trobe University: Melbourne.

¹⁶⁷ McNair R and Lewis J. LGBTIQ disability self-advocacy: A report on the results of a survey of LGBTIQ people living with disability in Victoria. Pride Foundation Australia 2020. <https://pridefoundation.org.au/pages/reports/>

¹⁶⁸ McNair R and Lewis J. (2020)

carried out via this community) and under 15% felt that any of the listed LGBTIQ specific areas were very inclusive. The most disability inclusive spaces were online, health services, cultural events and social groups.

LGBTIQA+ people with disability have difficulty connecting with disability communities with very few people reporting that any of the services were very inclusive. Most participants (81%) thought it was important to express their sexual orientation but studies¹⁶⁹ show that LGBT people with disabilities have less freedom to express their sexuality or gender identity. This is even more so for LGB people with intellectual disability or learning difficulty.

Workers are often reluctant, unwilling or lack confidence in addressing the sexuality, sexual expression and gender diverse identities of LGBTI people with disability. Again, this lack of engagement is even more pronounced for LGBTI people with intellectual disability and creates barriers for accessing appropriate information, developing intimate and supportive relations, and connecting to LGBTI and disability community and support groups.¹⁷⁰

There are higher rates of violence and abuse against LGBTI people with disability compared with national averages and LGBTI people without disability.¹⁷¹

Many people have experienced bullying and discrimination when coming out to support staff and that this is a huge barrier to seeking support.¹⁷²

Having the opportunity to explore and express LGBTIQA+ identities

LGBTIQA+ people with disability need to be offered education, counselling and resources about being gender diverse, having relationships, identity, their bodies, their sexuality and the LGBTIQA+ community. They need safe spaces in which to explore their sense of self, how they want to present themselves and their feelings and attractions to others.¹⁷³

Protective strategies such as education and cohort-specific resources are required to promote quality of life including the development of intimate relationships for people who are labelled with intellectual disability and who identify as LGBTIQ.”¹⁷⁴

Peer support

In general, social networks, supportive relationships and a feeling of belonging or connectedness, are recognised as protective factors for mental health. For LGBT people, connection and belonging to LGBT and mainstream communities and family are predictors of improved mental health.¹⁷⁵

The contribution of LGBTI peer relationships and connections appears to have a significant part to play in resilience. Three quarters of respondents in Private Lives rated LGBT friends

¹⁶⁹ Leonard, W. and Mann, R. (2018)

¹⁷⁰ Leonard, W. and Mann, R. (2018)

¹⁷¹ Leonard, W. and Mann, R. (2018)

¹⁷² Parsons M, Despott N and Power R (2021).

¹⁷³ Parsons M, Despott N and Power R (2021), p18

¹⁷⁴ Wilson, N, et al (2018)

¹⁷⁵ Rainbow Health Victoria and Thorne Harbour Health, (2019)

most highly for emotional support (Leonard et al., 2012). Respondents who had participated in LGBT community events had lower rates of psychological distress than those who had not, among all gender identity groupings. For transgender people, having frequent contact with LGBT peers was associated with greater resilience (Bariola, et al 2015).¹⁷⁶

Peer support for LGBTIQ+ people with disability was seen as an important avenue to:

- provide personal support (build relationships, connect to LGBTIQ+ communities, connect to LGBTIQ people with disability, find LGBTIQ+ mentors)
- assist in service access in health services, social services and the NDIS and deal with discrimination, abuse, and violence
- facilitate wider community activism in both LGBTIQ+ services, disability services and general community awareness.^{177 178}

Finally, while there is undoubtedly a role for peer support in disability and LGBTIQ+ communities, peer led service initiatives need to be consistent with the National Lived Experience (Peer) Workforce Development Strategy developed by the National Mental Health Commission.¹⁷⁹ Further engagement is needed to define the similarities and differences between Lived Experience/Peer work, peer support and the mental health/recovery sector approach in disability and LGBTIQ+ contexts and how these can be used for the benefit and wellbeing of LGBTIQ+ people with disability.

The NDIA needs to strengthen empowerment and rights through peer led initiatives.

What success looks like

- LGBTIQ+ people with disability know their rights and make complaints when their rights are not met.
- LGBTIQ+ people with disability use the NDIA.
- The NDIA partnering with LGBTIQ+ disability community to Co-Design and deliver opportunities for people with disability to explore and express their LGBTIQ+ identities and live proud LGBTIQ+ lives.
- LGBTIQ+ services are inclusive and accessible.

¹⁷⁶ Rainbow Health Victoria and Thorne Harbour Health, (2019)

¹⁷⁷ McNair R and Lewis J. (2020)

¹⁷⁸ Hill AO, Lyons A, Jones J, McGowan I, Carman M, Parsons M, Power J, Bourne A (2021) Writing Themselves In 4: The health and wellbeing of LGBTQ+ young people in Australia. National report, monograph series number 124. Australian Research Centre in Sex, Health and Society, La Trobe University: Melbourne. ARCSHS

¹⁷⁹https://www.mentalhealthcommission.gov.au/getmedia/a33cce2a-e7fa-4f90-964d-85dbf1514b6b/NMHC_Lived-Experience-Workforce-Development-Guidelines

32 Assisted Council with development of Advice

Katherine Annear, Developmental Educator.

Cameron Bloomfield Rainbow Rights Self Advocacy Group

Matthew Bowden, Matthew Bowden Consulting

Nathan Despott, Manager, Policy & Projects Inclusion Melbourne

Kaidee Dick, Senior Health Promotion Officer – Disability Family Planning NSW.

Giancarlo de Vera Senior Manager of Policy | People with Disability Australia

Rob Hardy, Director, Training & Capacity Building LGBTIQ+ Health Australia.

Tyler Marks Peer Support Projects Officer Positive Life NSW.

Tess Moodie Policy & Projects Officer | Women With Disabilities Australia (WWDA).

Ruby Mountford, LGBTIQ+ & Disability Advocate & Public Speaker.

Michael Murphy Regional Manager – North Western Pride Disability Services.

Dr Amie O'Shea, Lecturer In Disability And Inclusion Faculty of Health Deakin University.

Matthew Parsons, Manager, Education and Strategic Development Rainbow Health Victoria (formerly GLHV) Australian Research Centre in Sex, Health and Society La Trobe University.

Billie Stimpson WWILD Sexual Violence Prevention Association.

The Independent Advisory Council invited Mr Morgan Carpenter, Executive Director, Intersex Human Rights Australia, to be involved the development of the Advice. The Council respectfully acknowledges that after the first meeting, Mr Carpenter declined to participate further as a result of working material being inappropriate and showing an absence of comprehension of, and research on the needs of, intersex populations.

Section 3: Data appendices

33 Appendix A: Aboriginal and Torres Strait Islander data from ABS and the NDIA

This report draws on data from the Australian Bureau of Statistics National Aboriginal and Torres Strait Islander Social Survey and data about participants from the June 2021 Quarterly Report, from the 2020 deep dive of participants with acquired brain injury, cerebral palsy and spinal cord injury, from the 2020 Participant Outcomes Report, the 2020 Family and Carers Outcome Report, the 2019 Aboriginal and Torres Strait Islander deep dive and from the 2021 Aboriginal and Torres Strait Islander Strategy Update.

NDIS Quarterly Report of December 2021, indicates that 35,733 Aboriginal and Torres Strait Islander people with disability were receiving NDIS support, representing 7.1% of total participants, perceived to be generally in line with estimates from the Census and the Survey of Disability Ageing and Carers (SDAC).

33.1 National Aboriginal and Torres Strait Islander Social Survey (ABS)

Aboriginal and Torres Strait Islander people have been found to have higher incidence of disability compared to the general population. The National Aboriginal and Torres Strait Islander Social Survey, 2018 reported that:

- 23.9% of Indigenous people (excluding those in very remote areas) had disability compared to 18% of non- Indigenous people
- 8.8% of Indigenous people over 15 years had a profound or severe limitation compared to 5.8% of non- Indigenous people
- 11% of Indigenous children aged 0-14 had a profound or severe limitation, up from 5.9% in 2015.

Among Indigenous people with disability:

- Geography had an impact on prevalence with
 - 29.6% of those living in inner regional areas had disability
 - 23.8% of those living in major cities had disability
 - 18.1% of those living in remote areas had disability
- 68.9% needed assistance with at least one activity of daily living and 97.2% receiving assistance

Additional information available for the 2015 Survey of Disability Ageing and Carers (SDAC) indicates that compared to non- Indigenous people with disability, Indigenous people with disability experienced:

- higher rates of disability across all age groups
- discrimination due to disability at almost twice the crude rate
- lower labour force participation (41.7% of Indigenous people with disability participated in the labour force compared to 53% of non- Indigenous people with disability and 83% of people with no reported disability)
- significantly higher rates of physical disability (14.8% compared with 11.4%), psychosocial disability (6.6% compared with 3.8%) intellectual disability (5.9% compared with 2.5%) and head injury, stroke or acquired brain injury (2.1% compared to 1.1%).

33.2 2021 NDIA Aboriginal and Torres Strait Islander Strategy Update reported that after 3 years in the Scheme:

- community and social participation for Indigenous participants aged 25 and over increased from 39% to 48% (compared to 37% to 50% for non-Indigenous participants)
- employment of Indigenous participants aged 15 to 24 increased from 9 to 18% (compared to 13% to 24% for non-Indigenous participants)
- Indigenous participants generally had similar satisfaction rates as non-Indigenous participants with:
 - 78.3% rating their access experience very good or good (and a further 11.7% reporting it as neutral)
 - 73% rating their pre-planning experience very good or good (and a further 13% reporting it as neutral)
 - 84.4% rating their planning experience very good or good (and a further 6.4% reporting it as neutral)
 - 71.5% rating their plan review experience very good or good (and a further 15.2% reporting it as neutral)

33.3 2019 NDIA Deep Dive into Aboriginal and Torres Strait Islander participants

Data about plan utilisation is available from 2019 and indicates that at that time, compared to non-Indigenous participants, Indigenous participants:

- had approximately 1% lower average payments on active plans
- were using slightly less of their plans 60% of their plans compared to 67% for non-indigenous participants
- had a lower complaint rate (5.1%, compared to 6.5% for non-Indigenous participants).

At the point of entering the NDIS, compared to non-Indigenous participants

Indigenous participants aged 0 to 14:

- were more likely to be able to make friends.
- were less likely to participate in social and community activities compared to non-Indigenous participants.
- had lower rates of attending school in a mainstream class and developing skills appropriate to their ability.

Indigenous participants aged 15 and over:

- were less likely be happy with or feel safe in their home compared to non-Indigenous participants.
- generally, reported poorer outcomes in respect to employment, health and wellbeing, and lifelong learning.
- in remote communities had the lowest employment rates for all groups and reported having the least amount of choice and control.

Families and carers of indigenous participants:

- were considerably less likely to have a paid job.
- were more likely to be receiving a Carer Payment.
- were more likely to have friends and family they see as often as they.

After two years in the Scheme, Indigenous participants:

- age 15 to 24 reported a +5% improvement in employment, which was lower than the +9% improvement for non-Indigenous participants.
- age 25 and over, reported a stable rate of paid work, although at a considerably lower rate (12%) compared to non-Indigenous participants (25%).
- aged 15 and over reported a considerable increase in community and social participation from 37% to 46%, which was equivalent to the rate of community participation for non-Indigenous participants.

- Families and carers of participants aged 15+ reported improved perceptions of the NDIS generally and the gap between positive response rates for Indigenous and non-Indigenous participants narrowed.

33.4 NDIA 2020 Deep Dive: Participants with acquired brain injury, cerebral palsy or spinal cord injury

Indigenous people with acquired brain injury, spinal cord injury and cerebral palsy had favourable access decisions at the rate of 2-3% higher for potential Indigenous participants compared to those who are non-Indigenous. This is consistent across the Scheme.

33.5 NDIA 2020 Participant Outcomes Reports (NDIA)

Birth to starting school: after 2 years in the Scheme

- Indigenous status was not strongly associated with longitudinal change with only the only significant difference between indigenous and non-Indigenous children being that indigenous children were reported to have reduced their participation in age-appropriate community, cultural or religious activities.
- Parents/carers of Indigenous participants were more likely to think that the NDIS had not improved their child's access to specialist services.

Starting school to age 14: Compared to non-Indigenous participants,

- Indigenous participants
 - who attend school in a mainstream class were more likely than non-Indigenous participants to move out of mainstream class.
 - were less likely to see that the NDIS has helped.
- Parents/ carers of Indigenous participants who wanted their child to be more involved in activities with other children were more likely to see their child as a barrier to being more involved.

Participants 15-24: Compared to non-Indigenous participants, Indigenous participants:

- were significantly less likely to say that the NDIS has helped improve outcomes across all domains. For the seven domains where significant differences were observed, these were mostly around 8%.
- were more likely to
 - start wanting more choice and control
 - know people in their community
 - say there was something they wanted to do but were prevented from doing

Participants 25+: Compared to non-Indigenous participants, Indigenous participants:

- were less likely to
 - think the NDIS has helped for all domains.
 - get opportunities to learn new things
 - say there was something they wanted to do but were prevented from doing
- were more likely to
 - know people in their community
 - want to see their family more

33.6 NDIA 2020 Family/Carer Outcomes Report

Compared to families and carers of non-Indigenous children under 14, families and carers of Indigenous participants under 14:

- were less likely to think that the NDIS has helped improve their ability to help their child develop and learn.
- were more likely to deteriorate in relation to the level of support available for their family, their health and wellbeing, and being satisfied with the amount of say they had in the implementation of their child's plan.

Families and carers of indigenous participants 25+

- were significantly less likely to say that the NDIS improved the level of support for their families (57.7% compared to 69.8% for non- Indigenous), or that the NDIS helped them access services, programs, and activities in the community (55.1% versus 64.4%).

34 Appendix B: CALD Data from the NDIA

This report draws on data about Culturally and Linguistically Diverse (CALD) participants from the September 2021 Quarterly Report, from the Participant Outcomes Report of June 2020, the Family and Carers Outcome Report of June 2020, the CALD deep dive of June 2019 and from the CALD Strategy of 2018 and its 2021 Update.

NDIS Quarterly Report of December 2021 indicates that 46,191 CALD people with disability were receiving NDIS support, representing 9.2% of total participants. While the proportion of participants who identify as CALD is gradually increasing (8.4% in June 2019), it is below the estimate of around 18.9%.¹⁸⁰ CALD disability advocates would suggest the under-representation is even greater given their different definition¹⁸¹ of who should be considered CALD.

The NDIA has been most concerned about the inequity arising from the under-representation of NDIS participants of CALD background. Accordingly, the Office of the Scheme Actuary has undertaken significant statistical analysis to better understand the reason for this difference – specifically, whether a number of CALD people are yet to join the NDIS, or whether the NDIS is under-reporting the number of CALD participants in the Scheme based on the data collected on country of birth and main language spoken at home.

The analysis, reported in the Quarterly Report of September 2021, implies that it is likely that CALD participants are joining the Scheme but have not been identified as CALD in the data collected. With the introduction of the new ICT system, the opportunity to collect improved data on participants should allow better identification of CALD participants to identify the extent of any inequities in this area.¹⁸² In addition the number of CALD participants now excludes participants who identify as Aboriginal and Torres Strait Islander. In previous reports, Aboriginal and Torres Strait Islander participants were included if their main language spoken at home was not English.

The available evidence indicates that people from CALD backgrounds have rates of disability, and profound or severe disability, similar to the rest of the Australian population, which challenges notions of the so-called ‘healthy migrant effect’.

¹⁸⁰ Expected CALD percentages are derived from the 2016 ABS Census and exclude Indigenous people. Previous results have included Indigenous people (where their language spoken at home was not English)

¹⁸¹ The NDIS identifies a participant as being from a CALD background if their country of birth is not English speaking, (Australia, New Zealand, the United Kingdom, the United States of America, Canada or South Africa) or their primary language spoken at home is not English. This is consistent with the ABS SDAC data for cultural and linguistic diversity. CALD disability advocacy groups however identify CALD background as people who have one or both parents born in a non-English speaking country, arguing that for children and adults with disability, their primary language and cultural identification is that of the parents and hence they experience the same challenges as their parents.

¹⁸² NDIS Quarterly Report September 2021 P21 Accessed <https://www.ndis.gov.au/about-us/publications/quarterly-reports/archived-quarterly-reports-2021-22> 30 March 2022

34.1 NDIA 2021 CALD Strategy Update reported that after 3 years in the Scheme, CALD participants:

- increased their community and social participation
 - o from 35% to 59% for participants aged 15-24 (compared to 31% to 44% for non-CALD participants)
 - o from 39% to 52% for participants aged 25+ (compared to 36% to 49% for non-CALD participants)
- aged 15 to 24 increased their employment participation from 12 to 19% (compared to 13% to 25% for non-CALD participants). Employment participation remained stable for the cohort 25+ in a period in which employment participation for non-CALD participants decreased
- generally, had similar satisfaction rates as non-CALD participants with
 - o 81.3% rating their access experience very good or good (and a further 10.2% reporting it as neutral)
 - o 71.1% rating their pre-planning experience very good or good (and a further 18% reporting it as neutral)
 - o 86.5% rating their planning experience very good or good (and a further 9.3% reporting it as neutral)
 - o 81.3% rating their plan review experience very good or good (and a further 10.4% reporting it as neutral).

34.2 NDIA 2019 CALD Deep Dive

21% of CALD applicants were found to be ineligible for the NDIS compared to 14% of non-CALD applicants.

Compared to non-CALD participants, CALD participants:

- 0-24 and 65+ without SIL had higher committed supports i.e., supports in plans
- 25-64 without SIL had lower committed supports
- were less likely to have SIL in their plans
- had higher committed supports where they have SIL
- were utilising slightly more of their plans (68% for CALD participants compared to 66% for non-CALD participants)
- had a lower complaint rate.

At the point of entering the NDIS, compared to non-CALD participants,

CALD participants aged birth to 14:

- generally, had poorer outcomes.
- were considerably less likely to make friends outside the family, have a genuine say in decisions about themselves and fewer attend school in the mainstream.

CALD participants aged 15 and over:

- were slightly more likely to be involved in a community, cultural or religious group.
- were less likely to have a paid job or have friends other than family or paid staff.

CALD participants aged 15 to 24

- had consistently less choice and control.

CALD participants aged 25 +

- had worse health outcomes.

Families and carers of CALD participants

- had poorer outcomes in general including being less likely to have a paid job or being able to advocate for their child or family member.

After two years in the Scheme, CALD participants:

- age 15 to 24: reported a 18% improvement in social and community participation (compared to a 12% improvement for non-CALD participants). Both CALD and non-CALD participants had a 9% improvement in paid employment.
- age 25 and over: reported similar improvements in social and community participation to non CALD participants, and the percentage of participants in paid work remained broadly stable, although at a lower rate (22%) that for non-CALD participants (25%).
- were more likely to think that the NDIS had helped the longer they had been in the Scheme, however, the perceptions of their families and carers generally remained the same.

34.3 NDIA 2020 Participant Outcomes Reports

Birth to starting school: after 2 years in the Scheme

- CALD participants were less likely to improve in making friends with people outside the family but parents/carers of CALD participants were less likely to indicate they would like their child to be more involved in community activities.
- Parents and carers of CALD participants were more likely to say that the NDIS improved how their child fitted into community life.

Starting school to age 14: Compared to non-CALD participants,

- CALD participants tended to be less likely to improve on a number of the independence indicators, such as having a genuine say in decisions about themselves, spending time away from their parents/carers other than school, having friends that the child enjoys spending time with and moving into a mainstream class at school.
- CALD participants were more likely to improve and less likely to deteriorate in getting along with their siblings.
- Parents and carers of CALD participants were more likely to report that the NDIS improved their child's access to education.

Participants 15-24: Compared to non-CALD participants, CALD participants:

- were less likely to say that the NDIS has helped improve outcomes related to choice and control, daily living activities and social and community participation.
- were more likely to deteriorate in all transitions.

Participants 25+: Compared to non-CALD participants, CALD participants:

- were less likely to say that the NDIS has helped for the domains of choice and control, daily living, home, and work with a gap of 3-4% gap between CALD and non-CALD participants for these domains.

34.4 NDIA 2020 Family/ Carer Outcomes Report

Compared to non-CALD families and carers, families and carers of CALD participants

Birth to school entry

- tended to be more likely to have friends they can see as often as they like, and less likely to rate their health poorly.
- tended to be less likely to improve and/or more likely to deteriorate in relation to helping their child develop and learn and being satisfied with the development and implementation of their child's plan.
- were more likely to say that the NDIS has helped to improve their health and wellbeing (47.6%) compared to those come from a non-CALD background (41.6%), however they were less likely to say that they were satisfied with the amount of say they had in developing (69.8% versus 73.7%) and implementing (62.1% versus 64.8%) their child's plan.

Families and carers of participants 25+

- were less likely to think that their family member with disability gets to the support they need

- were less likely to say that the NDIS helped them understand their rights and to advocate effectively.

35 Appendix C: LGBTIQ+ data

There is very little or no data from the ABS and the NDIA on LGBTIQ+ people with disability. This resource material draws on data derived from studies of LGBTIQ+ people, LGBTIQ+ people with disability and studies that compare LGBTIQ+ people with disability with the general population of people who are LGBTIQ+ and the general population of people with disability.

35.1 LGBTIQ+ people

Research on LGBTI ageing demonstrates the cumulative effects of this marginalisation over the life course, as older LGBTI people have higher rates of disability, depression, anxiety and loneliness than the general community, as well as less social support.¹⁸³

Private Lives 3, a study of 6,835 people who are LGBTIQ+ in Australia¹⁸⁴ found that:

- More than half (57.2%) reported high or very high levels of psychological distress during the past four weeks.
- Over two fifths (41.9%) reported that they had considered attempting suicide in the previous 12 months and almost three quarters (74.8%) had considered attempting suicide at some point during their lives.
- The very vast majority felt that their sexual orientation or gender identity was not respected at mainstream medical clinics.
- Over three quarters (75.3%) reported that they would be more likely to use a service if it has been accredited as LGBTIQ-inclusive.
- More than a third (38.5%) reported a disability or long-term health condition with approximately 11.8% reporting a profound or severe disability. These participants reported:
 - a lower level of acceptance by health and support services than participants not reporting a disability or long-term health condition (29.9% compared to 50.6%).
 - being treated unfairly by others in the past 12 months as a result of their disability or long-term health condition (77.7%).

¹⁸³ O'Shea, A., Latham, J., Beaver, S., Lewis, J., Mountford, R., Rose, M., Trezona, A., Frawley, P. (2020 (a)). More than Ticking a Box: LGBTIQ+ People With Disability Talking About Their Lives. Geelong: Deakin University.

¹⁸⁴ Hill, A. O., Bourne, A., McNair, R., Carman, M. & Lyons, A. (2020). Private Lives 3: The health and wellbeing of LGBTIQ people in Australia. ARCSHS Monograph Series No. 122. Melbourne, Australia: Australian Research Centre in Sex, Health and Society, La Trobe University.

- Overall, a smaller proportion of participants from multicultural backgrounds reported feeling accepted a lot or always in almost all settings compared to those from an Anglo-Celtic background and were more likely to report very high levels of psychological distress (31.7% compared to 26.7% of those from an Anglo-Celtic background).

These results are supported by a 2020 report by the National LGBTI Health Alliance that compared the mental health of LGBTIQ+ people with disability to that of the general population.¹⁸⁵ The report found that the 22.7% of LGBTIQ+ respondents who reported disability or long-term health condition were more likely to report thoughts of suicide, attempt suicide in their lifetime, have engaged in self-harm in their lifetime, experience and be diagnosed with depression and anxiety and experience psychological distress.

35.2 LGBTIQ+ people with disability

LGBTIQ+ people with disability reported ‘feeling split’ between different parts of themselves, the stress of constantly coming out in different ways to different people, and the difficulties of making decisions about when, how and to whom they could disclose information to, and when they needed to mask parts of themselves in order to feel safe and/or receive services.¹⁸⁶

Connection to the LGBTIQ+ community

LGBTIQ+ people with disability have difficulty connecting with LGBTIQ+ communities¹⁸⁷ with a Victorian study¹⁸⁸ finding that a relatively high proportion (48=45%) of respondents did not feel part of the LGBTIQ community, (despite the survey recruitment being largely carried out via this community) and under 15% felt that any of the listed LGBTIQ specific areas were very inclusive. The most disability inclusive spaces were online, health services, cultural events and social groups.

Connection to the disability community

LGBTIQ+ people with disability have difficulty connecting with disability communities with very few people reporting that any of the services were very inclusive. The vast majority of participants (81%) thought it was important to express their sexual orientation. Other studies¹⁸⁹ however show LGBT people with disabilities have less freedom to express their

¹⁸⁵ O’Shea, A., et al (2020 (a))

¹⁸⁶ O’Shea, A., et al (2020 (a))

¹⁸⁷ Leonard, W. and Mann, R. (2018) *The everyday experience of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability*, No.111 GLHV@ARCSHS, La Trobe University: Melbourne.

McNair R and Lewis J. LGBTIQ disability self-advocacy: A report on the results of a survey of LGBTIQ people living with disability in Victoria. Pride Foundation Australia 2020.

<https://pridefoundation.org.au/pages/reports/>

¹⁸⁸ McNair R and Lewis J. (2020) op cit.

¹⁸⁹ Leonard, W. and Mann, R. (2018) op cit.

sexuality or gender identity. This is even more so for LGB people with intellectual disability or learning difficulty.

Workers are often reluctant, unwilling or lack confidence in addressing the sexuality, sexual expression and gender diverse identities of LGBTI people with disability. Again, this lack of engagement is even more pronounced for LGBTI people with intellectual disability and creates barriers for accessing appropriate information, developing intimate and supportive relations, and connecting to LGBTI and disability community and support groups.¹⁹⁰

35.3 LGBTIQ+ people with disability compared to LGBTIQ+ without disability

The recently released Australian study of 6,418 young people (aged 14 to 21) who are LGBTIQ+ (Writing Themselves in 4¹⁹¹ allows for analysis of the lives of LGBTQA+ people with intellectual disability compared to LGBTQA+ people with other disabilities as well as providing insights into the challenges faced by LGBTIQ+ people with disability. The study found that

- 39% of participants reported a disability or long-term health issue, with 5.4% reporting an intellectual disability.
- 15% of LGBTQA+ young people with a disability and 21% of LGBTQA+ young people with intellectual disability have attempted suicide in the past 12 months compared to 6% for LGBTQA+ young people.
- Of the 5.4% who reported having an intellectual disability:
 - 83.3% had disclosed their LGBTQA+ identity to their family but only 55.4% felt supported in their LGBTQA+ identities and bodies by their family.
 - 94.8% reported 'high' or 'very high' levels of psychological distress.
 - 91.3% reported suicidal ideation in their lifetime.
 - there were higher rates of harassment and assault, including verbal, physical and sexual, compared to the broader category of disability.
 - there was a feeling of less acceptance in the LGBTQA+ community and more difficulty in using LGBTQA+ services and venues than LGBTQA+ young people with other disabilities.

¹⁹⁰ Leonard, W. and Mann, R. (2018) op cit.

¹⁹¹ Hill AO, Lyons A, Jones J, McGowan I, Carman M, Parsons M, Power J, Bourne A (2021) Writing Themselves In 4: The health and wellbeing of LGBTQA+ young people in Australia. National report, monograph series number 124. Australian Research Centre in Sex, Health and Society, La Trobe University: Melbourne. ARCSHS

Other studies show that LGBTIQ+ people with disability have twice the rates of anxiety and psychological distress than LGBTIQ+ without disability.¹⁹²

There are very few national surveys comparing rates of violence and discrimination against LGBTI with disabilities versus LGBTI people without or looking at variations in rates of violence among LGBTI people with disabilities. However, the available data suggest that:

- LGBTI people with disability experience higher rates of crime and victimisation than LGBTI people without disability
- The risks of violence are higher for women with disability and for LGBTI people with intellectual disability or learning difficulty.
- Trans and gender diverse people with disability experience even greater discrimination when accessing services than LGB people with disability and, in particular, are less likely to access aged care services due to fear and anticipation of discrimination.
- LGBTI people with disability are subject to higher rates of discrimination and abuse than LGBTI people without disability (unpublished national Australian data)
- people with disability and, in particular, LGBTI people with disability experience restrictions on freedom of sexual expression.¹⁹³(Leonard and Mann, 2018)

¹⁹² O'Shea, A , Latham, J, McNair, R , Despott, N, Rose, M , Mountford, R and Frawley, P, (2020 (b)) Experiences of LGBTIQ+ People with Disability in Healthcare and Community Services: Towards Embracing Multiple Identities *Int. J. Environ. Res. Public Health* 2020, 17, 8080; doi:10.3390/ijerph17218080

¹⁹³ Leonard, W. and Mann, R. (2018) op cit.