HEY
HEAR ME OUT!

Voices of Deaf
& Hard of Hearing Mob
on the NDIS in the NT



Deaf Indigenous Community Consultancy©

THE UNIVERSITY OF MELBOURNE

Phoenix Consulting

Suggested citation

Barney, J., Devine, A., Howard, D., Huska, M., Yang, Y., Disney, G., Summers, P., McAllister, A. (2022). *Hey! Hear me out. Voices of Deaf and Hard of Hearing Mob on the National Disability Insurance Scheme in the Northern Territory*. Melbourne: The University of Melbourne. https://doi.org/10.26188/21985496

Published February 2023

ISBN 978 0 7340 5700 6

© Deaf Indigenous Community Consultancy, Phoenix Consulting and The University of Melbourne

© Cover art by Kristy Day-Robertson https://kristyday.design/

Contact us

Jody Barney, Deaf Indigenous Community Consultancy, jody@deaficc.com.au

Alexandra Devine, The University of Melbourne, alexandra.devine@unimelb.edu.au

Damien Howard, Phoenix Consulting, damienatphoenix@gmail.com

We acknowledge the Traditional Owners of the lands and nations on which this project was implemented and pay our respects to the Elders past, present and future. We acknowledge all Aboriginal and Torres Strait Islander peoples who were involved in this project and pay respects to their families, kin and country across Australia.

This project was funded by the National Disability Research Partnership. The contents presented however are of the participants and project team and do not necessarily reflect the views of the funder.

Table of Contents

Executive Summary **4**
Introduction **6**
Contextual background **7**
Interplay of culture and communication 7
Caring and receiving care within collective First Nations cultures 8
Complex life trajectories for those within insufficient supports 9
First Nations people and the NDIS 10
Methods **11**
Yarnings **12**
Community engagement and dissemination **12**
Quantitative methods **12**
Limitations **12**
Findings **13**
Quantitative results **13**
Yarning narratives **18**
Life circumstances of First Nations people who are Deaf or Hard of Hearing 18
Perceptions on whether interwoven cultural and disability related needs and aspirations are currently being met through NDIS plan utilisation 23
Barriers to more effective utilisation 25
Moving towards 'Proper way' engagement for more effective outcomes 34
Reflections on key findings **35**
Policy and practice considerations **39**
References **43**

Executive Summary

The life experiences of First Nations people who are Deaf or Hard of Hearing are often more complex than First Nations people who are hearing, or non-Indigenous people who are Deaf or Hard of Hearing. This complexity can influence how they engage with and benefit from policies and programs such as Australia's National Disability Insurance Scheme (NDIS). This project, funded by the National Disability Research Partnership, aimed to develop co-design approaches to explore factors influencing effective NDIS plan utilisation among First Nations participants who are Deaf or Hard of Hearing, living in rural and remote communities in the Northern Territory. Yarnings were held with 15 individuals between October and November in 2021. Yarnings included some family members or key supports where appropriate and only with permission.

This report outlines key factors participants highlighted as influencing their experiences within the NDIS, in particular the utilisation of their NDIS plans. We propose potential policy and practice considerations that – when led, co-designed and progressively delivered by First Nations communities - may help improve opportunities for First Nations people who are Deaf or Hard of Hearing to engage with and benefit from the NDIS.

Overarching findings

- Our quantitative analysis demonstrates First Nations NDIS participants in the Northern Territory generally received higher plan sizes compared to the generalised population. Yet those who were primarily Deaf or Hard of Hearing received smaller NDIS budgets and their utilisation was lower than their non-Indigenous and/or non-Deaf counterparts.
- Capabilities to engage with and benefit from the NDIS were contextualised within complex life trajectories. Lives were impacted by persistent structural disadvantage associated with colonisation and challenges in accessing required services and supports to improve inclusion and participation in the context of hearing loss.
- A mistrust in 'white fella' systems has negated trust and engagement with new systems such as the NDIS. This was compounded by limited recognition and understanding within the NDIS of the circumstances, needs and aspirations of First Nations people who are Deaf or Hard of Hearing.
- Insufficient cultural and communication supports undermined participants understanding of the NDIS and capacity to advocate for plans that met individual and collective needs and aspirations. Plans that were not reflective of these needs often went unutilised.
- Utilisation was further undermined by limited availability of culturally safe and communication responsive service and supports, particularly when not available on Country.
- Having to move off Country and away from family and culturally aligned supports to access services such as Specialist Disability Accommodation and/or Supported Independent Living was commonly found to be extremely distressing.
- Culturally unsafe service provision within these settings were often harmful and distressing to participants and their families. Expressions of distress were often misinterpreted as 'behaviours of concern', increasing exposure to restrictive practices and further exacerbating existing complex experiences of trauma.
- Progress towards better engagement, plan utilisation and outcomes were possible when participants were provided with sufficient and relevant cultural and communication supports.
- Crucially, when skilled NDIS staff and service providers made a concerted effort in relation to 'Proper way' engagement with families, cultural guardians and advocates, more culturally supportive and communication enabling services were provided.

- The NDIS – in interaction with interfacing systems - is still falling short in enabling First Nations people who are Deaf or Hard of Hearing to live better lives in connection with Country, family, culture and community.
- While broader policy and social change remain critical in closing the gap in disability inequities experienced across many First Nations communities, the NDIS has the opportunity to work with local communities to develop locally-led solutions to improve experiences and outcomes for First Nations participants who are Deaf or Hard of Hearing.

Policy and practice considerations

Eight key policy and practice considerations emerged from the project. Any action taken to further develop these considerations must be led by and co-designed with First Nations people who are Deaf or Hard of Hearing. Further details on potential responsibilities and strategies aligning with the following policy and practice considerations can be found in Table 5. at the end of the report.

1. Enhance awareness and understanding within community, the NDIS and interfacing systems of the importance of addressing hearing loss and the need to better respond to the experiences of First Nations people who are Deaf or Hard of Hearing.
2. Enable and appropriately resource 'Proper way' engagement between the NDIS, individuals, families, communities and services and supports.
3. Position the importance of connection to Country, family, community and culture for First Nations people who are Deaf or Hard of Hearing at the centre of processes and decision making.
4. Recognising the diversity of local sign languages and ways of communicating, resource the provision of sufficient cultural and hearing loss responsive communication training and supports within participants engagement with NDIS.
5. Promote First Nations led, localised solutions, services and supports.
6. Where First Nations led services and supports are not yet available, improve access to culturally safe, communication responsive and trauma informed services and supports.
7. Ensure shared intersectoral collaboration and responsibility to improve the way the NDIS interfaces with other systems.
8. Ensure that the needs of First Nations individuals who are Deaf or Hard of Hearing or are at risk of hearing loss are better considered within all strategies to close the gap in inequalities experienced by First Nations communities.



Introduction

Improving ear health and access to supports for people experiencing hearing loss has been identified as critical to closing the gap in health and social inequities experienced by First Nations peoples (House of Representatives Standing Committee on Health, 2017, p. 29). Both the National Aboriginal and Torres Strait Islander Health Plan (2021-2031) and National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing (2017-2023) identify key strategies to improve ear health whilst also addressing the physical, social and emotional impacts of hearing loss (Australian Government Department of Health, 2021; Australian Health Ministers' Advisory Council., 2017).

When hearing loss – combined with contextual circumstances – contributes to more disabling experiences, individuals, families and communities often require additional services and supports. Australia's National Disability Insurance Scheme (NDIS) is a key program that should ideally provide such supports. Introduced in 2013, the NDIS aims to facilitate the full participation of people with disabilities within their communities. The National Disability Insurance Agency (NDIA) – responsible for the administration of the NDIS – released the Aboriginal and Torres Strait Islander Engagement Strategy in 2017. As part of their commitment to work with First Nations communities, the Strategy ensures the NDIS draws on local solutions to meet the diverse needs of First Nations individuals, their families, carers and communities (NDIS, 2017; NDIS, 2021).

Despite the high prevalence and impact of hearing loss among First Nations communities, the Strategy remains silent on the experiences of First Nations people who are Deaf or Hard of Hearing. While we acknowledge the Strategy deliberately doesn't focus on any one disability, the lack of reference to the significant issue of hearing loss among First Nations communities is of great concern, particularly given the life experiences of First Nations people who are Deaf or Hard of Hearing are often more complex than First Nations people who are hearing, or non-Indigenous people who are Deaf or Hard of Hearing (Howard & Saxton Barney, 2010; Howard & Barney, 2021a, Howard & Barney, 2021b). Understanding the current NDIS perspectives and experiences of First Nations NDIS participants who are Deaf or Hard of Hearing is critical to addressing this gap.

This report documents our research project: Hey! Hear me out. Voices of Deaf and Hard of Hearing Mob on the National Disability Insurance Scheme in the Northern Territory. Funded through the National Disability Research Partnership (NDRP), the aim of this research was to co-design approaches to explore factors influencing effective NDIS plan utilisation among First Nations participants who are Deaf or Hard of Hearing living in rural and remote communities in the Northern Territory.

In this report, we start with a contextual background of key cultural and communication elements relevant to understanding the NDIS experiences of First Nations people who are Deaf or Hard of Hearing. We then provide an overview of the complex life trajectories that can emerge when these elements are insufficiently recognised or disrupted. An overview of the projects yarning methods is then followed by presentation of the findings under four key themes:

1. Life circumstances of First Nations people who are Deaf or Hard of Hearing
2. Perceptions on whether interwoven disability and cultural needs and aspirations are currently being met through NDIS plan utilisation
3. Barriers to more effective utilisation
4. Moving towards 'Proper way' engagement for more effective outcomes.

We conclude the report with potential policy and practice considerations that – when led and co-designed by First Nations communities - may help improve opportunities for First Nations people who are Deaf or Hard of Hearing to engage with and benefit from the NDIS.

Contextual background

Hearing loss associated with the high incidence of Otitis media (middle-ear) infection has long been recognised as a major public health issue inequitably impacting First Nations communities (Morris, 1998). Acknowledging challenges within the collection and reporting of relevant data, estimates range from 18 to 40 per cent within urban and rural settings and 30 to 90 per cent in remote communities (Australian Government, 2017; Avery, 2020; Department of Social Services, 2020; Howard & Barney, 2021b; Howard & Saxton Barney, 2010). It is further recognised that in contexts of limited supports and existing socio-economic disadvantage, hearing loss can significantly contribute to disabling experiences particularly within First Nations communities. Communication difficulties can undermine access and inclusion across all life domains (e.g., education, health, employment, community and social inclusion), and influence interactions with police, justice and child protection systems (Australian Government Department of Health, 2021; Australian Health Ministers' Advisory Council., 2017; Howard & Barney, 2021b; Howard & Saxton Barney, 2010). These issues are further compounded because many First Nations people with hearing loss are not aware of their condition or remain undiagnosed and/or without appropriate supports (Avery, 2020; Howard & Barney, 2021b). Below, we outline some of the factors which can contribute to the more complex life trajectories experienced by First Nations people who are Deaf or Hard of Hearing. We provide this overview to help position our own project findings within the broader context of the lived experiences of First Nations people who are Deaf or Hard of Hearing.

Interplay of culture and communication

Communication systems among First Nations Deaf or Hard of Hearing people, their families and communities, have long drawn on linguistic structures of local oral languages, cultural signs, hand talk and gestures, and facial and body expressions linked to knowledge of Country, history, family, storytelling and lore, ceremonies, customs and performances (Howard & Saxton Barney, 2010; Power, 2013). Given these linkages, the use of local sign languages off Country or in other parts of the country is often prohibited or considered disrespectful and may be punishable by cultural lore: for example, people may experience shaming or exclusion from their communities (Howard & Saxton Barney, 2010; Power, 2013).

While First Nations Deaf people from different communities do communicate with each other - using diverse modes of communication which may include Auslan for the few who are proficient in its use - trying to develop a unified First Nations sign language is linguistically problematic for many individuals and communities. It is also culturally problematic as many First Nations Deaf people are more closely linked (and prefer to remain so) to the culture of their family and community (Howard & Saxton Barney, 2010). This can, however, make it much harder for First Nations people who are Deaf or Hard of Hearing to access and navigate services and systems without adequate communication and cultural supports.

In contrast, the use of Auslan particularly for non-Indigenous - Deaf Australians, provides a cultural and communication link that enables most people to communicate, engage and mobilise with each other, no matter where they are from. Many share a strong 'Deaf identity'. Advocacy on a national level is enabled. The availability of Auslan Interpreters - whilst far from sufficient - also enables access to information and communication between Deaf and non-Deaf individuals and facilitates their access to services and systems (Howard & Saxton Barney, 2010). For example, allied health workers and other professionals involved in assessment processes to determine and document evidence on needs and to demonstrate eligibility for

programs such as the NDIS, have access to existing testing protocols they can draw on when assessing individuals who communicate using Auslan. This is not the case when individuals and families do not use Auslan but local sign languages. It is therefore not uncommon for individuals and families to lack formal documentation of their disabilities and needs, making it more difficult to access and engage with systems such as the NDIS.

First Nations Deaf community members prime identification is with their local community, family and culture. Some First Nations Deaf people do access - and benefit from - specialist educational settings off Country. Such options often involve people learning Auslan and/or oral communication and other communication skills, with many people valuing the different connections, opportunities and access to services and supports these skills may help facilitate. However, for others, being moved off Country to pursue education and Auslan skills has the consequence of being disconnected from family and local sign language capacity which can have devastating consequences if they later return home. It is not a desired or appropriate option for many individuals or families.

Differences in communication and culture can also make it harder for the non-Indigenous Deaf sector or other mainstream disability organisations to understand and represent the needs and aspirations of First Nations Deaf people. The notion that this divide can be bridged by more First Nations Deaf people learning Auslan so that they can also be more readily accepted into mainstream Deaf and speaking/hearing communities, negates important cultural and linguistic connections interwoven with local sign languages. It can also be seen as perpetuating 'assimilationist' agendas not dissimilar to the attitude of 'oralist' demands that Deaf people should learn to speak, or that First Nations peoples should assimilate into Western normative cultures as a way of addressing poverty and disadvantage arising from colonialism and structural discrimination (Hollinsworth, 2013; Howard & Saxton Barney, 2010; King et al., 2014; Mathews, 1997; Puszka et al., 2022). The necessity to leave family and community to access training in Auslan also replicates the situation of those of the stolen generation. However, with the additional consequence of when returning home, people are often communicatively isolated by having lost or not acquired local community signing.

Caring and receiving care within collective First Nations cultures

First Nations holistic conceptualisations and experiences of health, well-being and collective ways of functioning and reciprocal caring are often in stark contrast to western conceptualisations of health, ill-health, functionality and disability. As such, a key feature of wellbeing and cultural connectedness for First Nations people, including those with a disability, is being able to continue to reciprocally care for and be cared for by others on and by Country (Green, 2017). The often siloed and fragmented way that State, Territory and Federal health, disability and broader social systems are designed, function and interact with each other, are also generally at odds with First Nations preferences for holistic, joined-up services that are provided by First Nations led organisations and/or those with well-established and trusted relationships and that recognise and support First Nations reciprocal ways of caring and being cared for (Green, 2017).

The ability of First Nations people who are Deaf or Hard of Hearing – and indeed individuals with and without other conditions such as cognitive disabilities - to communicate and have needs met and to facilitate participation, is often highly reliant on responsible family members who know them well and can be relied on to provide regular supports. This is often nurtured within culturally collectivist First Nations communities through proactive responsiveness: i.e., children are taught and expected from a very young age to closely observe and monitor those around them and be responsive to their needs, often without a person having to directly ask. As such, a family member can observe, from very nuanced facial expressions

or expressions of emotions, that a person may be hungry or thirsty and respond by providing food or water (Howard & Barney, 2021b).

Key family members or people within community who have specific capacity to understand and respond to the needs of certain individuals, may be responsible for supporting several people with diverse needs. However, regularly required supports may be difficult to sustain due to poor availability of culturally informed shared-care arrangement supports in community, their own poor health or aging and financial constraints.

In such circumstances, and when services and supports are not available in community to meet current or changing needs of individuals and families, people are often forced to move off Country. As discussed throughout this report, this is far from an ideal situation, as remaining on and connected to Country is of vital importance to First Nations holistic physical, mental, emotional and spiritual well-being. For First Nations people who are Deaf or Hard of Hearing this can be additionally challenging, as they are often separated from the family and/or cultural guardians who they have relied upon to recognise and respond to their needs. This issue is often compounded:

- in the absence of culturally safe services with an understanding of the complexity of the interplay of culture and communication.
- if individuals do not have other ways of communicating their needs with services and supports, yet services have unrealistic expectations that individuals can and will communicate their needs in a way that workers are accustomed to.
- if individuals don't realise that the services or support staff they are interacting with are not able to understand their ways of communicating needs and appropriately responding (Howard & Barney, 2021b).

Within many First Nations collectivist communities, caring and receiving care is also embedded within cultural obligations and responsibilities. Therefore, there is an expectation that any external supports will support families as a whole and care for all family members requiring supports: directly contrasting the individualised nature of systems such as the NDIS (Deaf Indigenous Community Consultancy, 2015).

Complex life trajectories for those within insufficient supports

For First Nations people who are Deaf or Hard of Hearing growing up and living in contexts of limited family/community support – including to learn ways of communicating - communication difficulties can significantly exacerbate social and educational exclusion. Such circumstances can compound the persistent disadvantage experienced across many First Nations communities associated with the ongoing impact of colonisation (i.e., cultural genocide, stolen generations, disrupted ways of living, discrimination, marginalisation from services and systems, poverty) (Avery, 2018; Gilroy et al., 2013; Mathews, 1997). It can also further undermine access to adequate housing, healthcare, employment, and appropriate supports to help address underlying issues that contribute to experiences of complex trauma and subsequent high-risk behaviours (Atkinson, 2013, Atkinson et al., 2014). These issues may be further exacerbated for people with co-occurring conditions (e.g., cognitive difficulties); with intersectional experiences (e.g., in relation to gender, sexuality, ethnicity); and/or for those living in more remote geographical locations.

Further, in the absence of supportive family members and/or cultural guardians, alongside the strong desire of individuals who are Deaf or Hard of Hearing to be accepted within their community and fulfil cultural obligations (e.g., sharing of resources), First Nations Deaf or Hard of Hearing people are often more vulnerable to exploitation and abuse (Howard & Barney, 2021b). This may include giving away more of their

money than they can afford or would be culturally expected of them (e.g., targeted for humbugging[1]), or, being blamed for the actions of others. This issue can be exacerbated in communities where the needs across community are great but only some people receive supports such as the Disability Support Pension or the NDIS, alongside the impacts of poverty, trauma and addiction that result in some members of the community trying to take advantage of those deemed to have more (Howard & Barney, 2021a; Howard & Barney, 2021b; Howard & Saxton Barney, 2010).

The totality of these factors can contribute to increased risk of interaction with an often inaccessible and unaccommodating police and Criminal Justice System (CJS). Incarceration – again a setting where peoples' complex communication and other support needs are poorly resourced - can in turn intensify the complexity of support needs and create further barriers to accessing and benefitting from services and systems upon release, including in relation to disability (Howard & Barney, 2021b).

First Nations people and the NDIS

The above experiences make engagement with the NDIS - a system that has not been sufficiently resourced to respond to the diverse needs of First Nations people living across diverse communities, let alone for those who are Deaf or Hard of Hearing – extraordinarily complicated from the outset. For some, their interface with NDIS processes and supports may improve over time, enabling achievement of desired outcomes (Ferdinand et al., 2019). However, for others, the intersection of multifaceted challenges, at the individual, community, broader systems and societal levels, in interaction with the NDIS can make desired outcomes difficult to achieve or sustain. Indeed, in these conditions, NDIS processes and culturally unsafe services and supports can accelerate and compound disconnection from Country, family, community and culture, and negatively exacerbate experiences of disability. Again, this is particularly so when individuals and their families are not provided with sufficient communication, language and cultural supports to facilitate relational understanding of the NDIS and family engagement within it (Bailey & Arciuli, 2020; Howard & Barney, 2021b).

Indeed, the lack of cultural safety, including in relation to excluding relational input to planning and receiving of supports, is considered one of the largest factors of disempowerment for First Nations families across their engagement with the NDIS (Bailey & Arciuli, 2020; Deaf Indigenous Community Consultancy, 2015). In contrast, cultural pride is one of the greatest needs for First Nations people with disabilities, and one of the greatest aspirations that individuals, families and communities hope for within and external to the NDIS (Deaf Indigenous Community Consultancy, 2015).

More broadly, the 2018 Evaluation of the NDIS, which incorporated a focus on the Barkly Region (a trial site in the Northern Territory) and therefore examined the experiences of rural and remote First Nations communities, found: "that both its [NDIS] approach and implementation were ineffective…" (Mavromaras et al., 2018, p. 252). This evaluation, however, did not identify issues specific to those who are Deaf or Hard of Hearing, despite the known incidence of hearing loss in First Nations communities. Similarly, while Ferdinand et al (2019.) examination of progress made against the NDIA's 2017 Aboriginal and Torres Strait Islander Strategy, identified specific issues and made recommendations around ensuring community 'buy-in' and increasing and expanding the use of interpreters of Aboriginal languages, the report did not specify challenges experienced by or interpreters for people who are Deaf or Hard of hearing. Finally, the absence

[1] Humbugging refers to being persistently accosted to give to others. The expectation of being able to make demands on people to accommodate to these demands is based on expectations of sharing that is at the heart of First Nations Identity. In impoverished First Nations communities those with disabilities have access to regular income stream and resources that make them 'rich' in the eyes of others. This means they may be often 'humbugged' for resources and want to share to be accepted and valued.

of any focus on First Nations people who are Deaf or Hard of Hearing within the 2021 NDIS Aboriginal and Torres Strait Islander Strategy (2017) progress update report, again reflects the urgency of the NDIS to further understand and address the specific experiences, needs and challenges of this cohort.

Methods

The aim of this research project was to understand factors influencing effective NDIS plan utilisation among First Nations people who are Deaf or Hard of Hearing living in rural and remote communities in the Northern Territory. The research aimed to understand these factors from the perspective of participants themselves. The questions guiding the project were:

1. How does the experience of being First Nations Deaf or Hard of Hearing influence NDIS access and engagement?
2. How are participants currently utilising their plans, and how does this compare to their aspirations for plan use?
3. What are the facilitators and barriers in utilising plans in a way that meets disability and cultural needs and aspirations?
4. How has NDIS plan utilisation impacted on the lives of participants and communities?

Co-design of approaches

The project was co-designed and led by Co-Investigator (CI) Jody Barney, herself a proud Deaf Birri-Gubba and Urangan woman with more than 35 years' experience working with linguistically and culturally diverse First Nations people with disabilities. Jody's lived experience, expertise and connection to community were fundamental to the co-design approach adopted in this project and to gaining cultural and community permissions to engage with individuals and their families.

The approach adopted throughout this project aligned with key elements of Gilroy and colleagues' conceptual framework for research on disability with Indigenous communities (Gilroy et al., 2013) including the project:

- was co-led by a First Nations researcher (CI Barney) with lived experience and deep connections to diverse First Nations individuals with disabilities, their families and communities
- recognised the impact of colonisation as a social determinant of both hearing loss and disability as central to this project and a driver of our efforts to address these impacts
- had an explicit focus on the interface of culture, language, communication, Deafness and hearing loss and co-occurring disabilities is explicit
- utilised CI Barney's ability to communicate using multiple local sign languages that enabled individuals from diverse language groups to participate using their local and preferred languages (Gilroy et al., 2013).

The first phase of the project involved the co-design and adaption of linguistically accessible and culturally sensitive research approaches to ensure alignment with cultural protocols and to meet the accessibility needs of yarning participants. This phase also involved negotiations with communities to gain cultural and community approvals to implement the project. Subsequent phases, in terms of framing of the analysis and findings, were also validated amongst the project team and through ongoing consultation with participants and their communities.

Yarnings

Yarnings were led by CI Barney who travelled to communities across the Northern Territory where she has long-standing connections. Areas included Mparntwe (Alice Springs), Jawoyn/Dagoman/Wardaman Country (Katherine), Larrakia (Darwin), Waramungu Patta Country (Tennant Creek, Barkly) and Jabiru (Kakadu). Engagement with the 15 participants also drew upon Jody's connections with community and her ability to have culturally safe 'yarns' with participants using their own language and modes of communication. Yarning within the context of this research enabled mutually respectful and reciprocal sharing of stories and experiences in relation to the NDIS (Bessarab & Ng'Andu, 2010). In some cases, and with appropriate permissions, further yarning was conducted with family members of participants. Yarnings were conducted between October and November in 2021.

Yarning sessions were recorded, translated, transcribed and then summarised by CI Barney for qualitative data analysis. Qualitative team members then began the analysis process by reading all transcript summaries to identify key themes. Key themes were then discussed as a team to help develop a thematic analysis framework, to then finalise a more in-depth analysis and drafting of findings. Key themes identified included life circumstances; importance of connections to Country, family, community and culture; how plans were currently being utilised to meet needs and aspirations; access to cultural and communication supports; barriers to navigating the NDIS, services and interfacing systems; and factors supporting 'Proper way' engagement and better NDIS outcomes.

Community engagement and dissemination

CI Barney continued to engage with individuals and communities to cross-check our interpretation of findings and to support the development of accessible materials for the dissemination of key findings back to community. This included working with interpreters skilled in supporting knowledge translation through development of linguistically accessible and culturally sensitive dissemination video materials. CI Barney travels frequently to the NT through her work. This enables ongoing opportunities to share the findings directly with participants, families and communities.

Quantitative methods

Alongside the yarnings, we analysed a tailored dataset that was provided under a research agreement between the NDIA and The University of Melbourne's Melbourne Disability Institute (MDI). This dataset contains de-identified individual-level information on NDIS participants on 31 August 2022 and information on participant plan budgets and spending on services and supports. To summarise the socio-demographic profile of the active NDIS participants in the Northern Territory, we present basic summary statistics, including counts and percentages. We also provide national summary statistics for comparison. To summarise data on plan budgets, we used medians and interquartile ranges of plan size, spending, and utilisation (proportion of plan spent). Data summarised reflect participants' most recent plans completed before 31 August 2022.

Limitations

This was a relatively small study and cannot be seen as representative of the experiences of all First Nations NDIS participants who are Deaf or Hard of Hearing. Nonetheless, yarnings elicited rich data on the complexities that can be experienced by this cohort within and external to the NDIS. We do note that we spoke to more individuals who are Deaf than who were Hard of Hearing. The research team want to acknowledge that the experiences of First Nations people who are Hard of Hearing can differ from those

who are Deaf. Many people who are Hard of Hearing are not aware they have hearing loss: neither are the many service providers and practitioners who they interact with (Australian Bureau of Statistics, 2019). This invisibility of hearing loss can lead to misunderstanding of circumstances, needs and behaviours, contributing to unmet need across various domains including health, disability and justice. Further research is needed to better understand NDIS experiences more specifically for First Nations people who are Hard of Hearing.

We had thought we may also need to engage with service providers if we were not able to engage with enough NDIS participants. Given we were able to yarn with a larger than anticipated number of NDIS participants, the time frame, limited resources and logistical challenges of conducting research across the NT, we decided that service provider interviews were not required to respond to the key research questions at this point in time. However, this is an area for future research. Indeed, future research that engages with a broader range of stakeholders from within (e.g., planners and frontline workers, policy makers, service providers) and external to the NDIS (e.g., interfacing systems and service providers) will also improve much needed understanding of issues identified by yarning participants. Further research to unpack the interplay of communication and culture may also help inform strategies to better support First Nations NDIS participants who are Deaf or Hard of Hearing in their engagement with the NDIS and services. Finally, as demonstrated within the below findings, barriers to plan development and utilisation are complex. Nonetheless, research to further examine factors contributing to more effective utilisation and how to support the growing emergence of First Nations led services and solutions are critical next steps.

Findings

We start this section with an overview of the results from the quantitative data analysis. Findings emerging from the yarnings are then presented across four key areas:

1. Life circumstances of First Nations people who are Deaf or Hard of Hearing
2. Perceptions on whether interwoven disability and cultural needs and aspirations are currently being met through NDIS plan utilisation
3. Barriers to more effective NDIS plan utilisation
4. Moving towards 'Proper way' engagement for more effective outcomes.

Each area contains several sub-themes describing the different ways factors such as connection to Country, culture, communication and access to services and supports may influence life trajectories, engagement with the NDIS and interfacing systems, and plan utilisation outcomes. Throughout, we have interwoven vignettes drawn from the yarnings with participants to ensure their voices and perspectives are central to the interpretation of findings and inform understanding of their experiences.

Quantitative results

As of the 31 August 2022, there were 5112 active participants whose place of residence was in the Northern Territory: 2571 of whom were First Nations. Of the 2571 First Nations participants, close to 210 had 'hearing impairment' recorded as their primary or secondary disability (herein referred to as Hard of Hearing or hearing loss within some tables), and close to 290 had spent some of their funding on hearing- or speech-related services. This latter group were included as they may be indicative of participants who experience hearing loss as a co-occurring condition that has not been formally recorded as their primary or secondary disability. Given the high prevalence of undiagnosed/underreported hearing loss among many First Nations communities, we also note that these numbers are likely to be an underestimate of the

number of First Nations NDIS participants who experience hearing loss, or of the number of First Nations Deaf or Hard of Hearing individuals that may be eligible for the NDIS but are not currently accessing it.

Tables 1 and 2 summarise the characteristics of NDIS participants residing in the Northern Territory and across Australia, respectively. The group of First Nations participants who were Hard of Hearing recorded as their primary or secondary disability had proportionately more women compared with non-First Nations participants or First Nations participants including other disability types. In the Northern Territory, many of the participants were living in socioeconomically disadvantaged areas (58%) and did not have any disability support prior to the NDIS (55%). First Nations participants with spending on hearing- or speech-related services had a younger age profile (51% in the Northern Territory and 69% nationally aged 14 years or younger). They were mainly children whose primary or secondary condition was recorded as autism, intellectual disability, or developmental delay.

Table 1. Socio-demographic and disability-related profiles of active participants in the Northern Territory on 31 August 2022

The Northern Territory (N=5112)				
	Non-First Nations	**First Nations**	**First Nations Hard of Hearing or Deaf #**	**First Nations with hearing or speech spending +**
Number of participants	N=2541	N=2571	N<210	N<290
Age at data extraction, N (%)				
0 to 6	598 (23.5)	321 (12.5)	15 (7.2)	45 (15.7)
07 to 14	733 (28.8)	531 (20.7)	35 (16.8)	101 (35.2)
15 to 18	182 (7.2)	186 (7.2)	19 (9.1)	31 (10.8)
19 to 24	148 (5.8)	211 (8.2)	18 (8.7)	16 (5.6)
25 to 34	170 (6.7)	259 (10.1)	30 (14.4)	<15
35 to 44	182 (7.2)	350 (13.6)	23 (11.1)	25 (8.7)
45 to 54	196 (7.7)	358 (13.9)	29 (13.9)	25 (8.7)
55 to 64	245 (9.6)	292 (11.4)	32 (15.4)	24 (8.4)
65+	87 (3.4)	63 (2.5)	<15	<15
Women, N (%)	862 (33.9)	901 (35.0)	107 (51.4)	97 (33.8)
Living in socioeconomically disadvantaged areas *, N (%)	218 (8.6)	1069 (41.6)	121 (58.2)	76 (26.5)
Days enrolled in the NDIS prior to current plan, median (IQR)	574 (0,1047)	708 (0,1175)	955 (495,1385)	846 (391,1211)
Pre-NDIS source of support, N (%)				
Commonwealth	209 (8.2)	208 (8.1)	16 (7.7)	22 (7.7)
New to disability support	1558 (61.3)	1466 (57.0)	115 (55.3)	133 (46.3)
State	774 (30.5)	897 (34.9)	77 (37.0)	132 (46.0)
Severity score ^, N (%)				
1 to 5	958 (37.7)	833 (32.4)	68 (32.7)	108 (37.6)
6 to 10	1065 (41.9)	1178 (45.8)	97 (46.6)	91 (31.7)
11 to 15	517 (20.4)	559 (21.8)	43 (20.7)	88 (30.7)

Abbreviations: N-numbers; IQR-interquartile range. Values generated based on fewer than 15 individuals are omitted because of confidentiality requirement. *Areas in the lowest three deciles indicated by the Index of Relative Socio-economic Disadvantage. ^NDIA normalised severity score. +Most had autism, intellectual disability, or developmental delay as primary disability. # Had "hearing impairment" recorded as primary or secondary disability by the NDIS.

Table 2. Socio-demographic and disability-related profiles of active participants in Australia on 31 August 2022

National (N=548487)				
	Non-First Nations	**First Nations**	**First Nations Hard of Hearing or Deaf [#]**	**First Nations with hearing or speech spending [+]**
Number of participants	N=508309	N=40178	N=1913	N=5634
Age at data extraction, N (%)				
0 to 6	79223 (15.6)	7915 (19.7)	274 (14.3)	1015 (18.0)
07 to 14	130964 (25.8)	11346 (28.2)	447 (23.4)	2857 (50.7)
15 to 18	41591 (8.2)	3711 (9.2)	190 (9.9)	559 (9.9)
19 to 24	41245 (8.1)	3808 (9.5)	199 (10.4)	312 (5.5)
25 to 34	44406 (8.7)	3772 (9.4)	216 (11.3)	267 (4.7)
35 to 44	40671 (8.0)	3181 (7.9)	141 (7.4)	179 (3.2)
45 to 54	48774 (9.6)	3243 (8.1)	187 (9.8)	206 (3.7)
55 to 64	59151 (11.6)	2589 (6.4)	195 (10.2)	195 (3.5)
65+	22284 (4.4)	613 (1.5)	64 (3.3)	44 (0.8)
Women, N (%)	190507 (37.5)	14156 (35.2)	941 (49.2)	1834 (32.6)
Living in socioeconomically disadvantaged areas *, N (%)	146224 (28.8)	17845 (44.4)	861 (45.0)	2314 (41.1)
Days enrolled in the NDIS prior to current plan, median (IQR)	801 (364,1358)	713 (225,1180)	778 (371,1246)	890 (382,1412)
Received pre-NDIS support from, N (%)				
Commonwealth	38944 (7.7)	2489 (6.2)	164 (8.6)	344 (6.1)
New to disability support	302073 (59.4)	25926 (64.5)	1145 (59.9)	3471 (61.6)
State	167292 (32.9)	11763 (29.3)	604 (31.6)	1819 (32.3)
Severity score ^, N (%)				
1 to 5	144653 (28.5)	13022 (32.4)	939 (49.1)	1902 (33.8)
6 to 10	233304 (45.9)	18328 (45.6)	679 (35.5)	2207 (39.2)
11 to 15	130121 (25.6)	8806 (21.9)	295 (15.4)	1523 (27.0)

Abbreviations: N-numbers; IQR-interquartile range.
*Areas in the lowest three deciles indicated by the Index of Relative Socio-economic Disadvantage. ^NDIA normalised severity score. [+]Most had autism, intellectual disability, or developmental delay as primary disability. [#] Had "hearing impairment" recorded as primary or secondary disability by the NDIS.

Table 3 presents an overview of the distributions of total plan size, spending, and utilisation in the Northern Territory and across Australia. First Nations participants in the Northern Territory had larger plans in general relative to the national figure, but utilisations were lower. Within this, those who are Hard of Hearing had comparatively lower plan size. Utilisation was particularly low for First Nations with primary or secondary hearing loss (medians are 29% in the Northern Territory and 32% nationally).

Table 3. Total plan size and spending (annualised) of participants in the Northern Territory and across Australia

	Median plan size (IQR)	Median spending (IQR)	Median utilisation (IQR)
The Northern Territory			
All participants	48.2k (23.0k, 130.5k)	20.6k (8.7k, 70.2k)	52.9 (29.1, 80.4)
Non-First Nations	32.0k (19.2k, 85.0k)	15.9k (7.4k, 48.5k)	55.2 (32.6, 78.9)
First Nations	70.5k (31.5k, 172.0k)	28.4k (10.5k, 97.5k)	50.8 (26.5, 82.0)
First Nations with any primary/secondary hearing loss or hearing/speech service spending	55.3k (26.7k, 167.3k)	23.0k (10.0k, 124.1k)	55.8 (29.8, 86.2)
First Nations with primary hearing loss	32.2k (21.7k, 58.3k)	8.5k (4.5k, 16.3k)	28.6 (16.9, 52.2)
First Nations with primary/secondary hearing loss	55.5k (29.3k, 151.4k)	17.8k (8.2k, 111.7k)	48.8 (23.1, 80.8)
First Nations with hearing/speech service spending	51.1k (26.0k, 177.6k)	24.6k (10.4k, 168.4k)	63.7 (35.6, 88.8)
National			
All participants	32.6k (17.1k, 78.1k)	17.9k (7.9k, 49.0k)	63.1 (38.3, 84.3)
Non-First Nations	32.6k (17.0k, 78.4k)	18.0k (8.0k, 49.6k)	63.6 (39.0, 84.6)
First Nations	32.6k (18.4k, 74.6k)	15.6k (6.8k, 41.2k)	55.5 (29.2, 80.0)
First Nations with any primary/secondary hearing loss or hearing/speech service spending	26.7k (16.9k, 60.2k)	14.9k (7.7k, 36.1k)	61.0 (38.0, 81.9)
First Nations with primary hearing loss	16.4k (9.2k, 28.2k)	5.3k (1.3k, 11.6k)	31.8 (10.7, 58.6)
First Nations with primary/secondary hearing loss	26.5k (13.6k, 59.9k)	10.7k (3.3k, 32.9k)	46.0 (19.3, 74.3)
First Nations with hearing/speech service spending	26.8k (17.5k, 59.9k)	15.9k (8.9k, 37.0k)	63.8 (42.7, 83.3)

Abbreviation(s): IQR-interquartile range, k-thousands. To ensure plans are material plans, we included those with annualised values of $500 AUD or higher and lasted for at least 180 days.
The median is the middle value in the dataset that holds 50% of the values below it (and 50% above it). The first quartile holds 25% of the values below it. The third quartile holds 25% above it.

Table 4 provides a more detailed summary of plan size, spending, and utilisation for each class and category of support funded to First Nations participants in the Northern Territory who are Hard of Hearing recorded as their primary or secondary disability or had spent on hearing- or speech-related services. Core support plans funded for assistance with daily life (including Supported Independent Living or Specialist Disability Accommodation) were almost fully spent (median utilisations > 95%), while utilisations for other core support categories were relatively low. Capacity building plans for intermediaries such as support coordination (the "Support Coordination" category) or plan management (the "Improved Life Choices" category) were well spent (median utilisations were 78% and 94%, respectively). Other capacity building supports were either rarely funded or had low utilisation. Utilisation of capital support was low in general, with half of participants funded spending lower than 5% of their allocated budget.

Table 4. Plans and spending (annualised) of specific support types for First Nations in the Northern Territory with primary or secondary hearing loss, or spending on hearing or speech related services

	N (%) funded	Median plan size (IQR)	Median spending (IQR)	Median utilisation (IQR)
Core	**370 (96.6)**	**21.5k (1.6k, 125.1k)**	**7.2k (0.0k, 107.7k)**	**52.7 (0.0, 92.8)**
Assistance with Daily Life	220 (57.4)	60.1k (13.5k, 261.5k)	38.7k (2.4k, 271.0k)	95.3 (29.2, 100.0)
Supported Independent Living or Specialist Disability Accommodation	62 (16.2)	337.5k (252.5k, 477.1k)	323.3k (247.7k, 448.4k)	95.6 (89.2, 98.7)
Assistance with Social & Community Participation	220 (57.4)	29.4k (9.7k, 56.9k)	12.4k (1.3k, 35.0k)	61.6 (13.3, 98.1)
Transport	166 (43.3)	2.1k (1.8k, 2.7k)	0.0k (0.0k, 1.8k)	2.1 (0.0, 96.3)
Consumables	326 (85.1)	1.1k (0.5k, 3.3k)	0.0k (0.0k, 0.9k)	1.0 (0.0, 70.5)
Capacity building	**383 (100.0)**	**27.9k (21.1k, 39.7k)**	**13.5k (7.7k, 21.2k)**	**48.8 (31.1, 72.8)**
Improved Daily Living	381 (99.5)	14.6k (9.6k, 21.0k)	5.2k (2.8k, 10.1k)	38.9 (19.2, 75.4)
Support Coordination	349 (91.1)	8.3k (5.3k, 12.0k)	4.9k (3.0k, 8.5k)	77.7 (47.1, 99.4)
Improved Relationships	65 (17.0)	14.1k (9.5k, 20.3k)	8.7k (0.0k, 14.1k)	61.8 (0.0, 96.0)
Improved Life Choices	233 (60.8)	2.1k (1.6k, 2.2k)	1.7k (1.5k, 2.1k)	93.7 (82.8, 100.0)
Increased Social & Community Participation	105 (27.4)	7.5k (4.3k, 11.1k)	0.0k (0.0k, 3.2k)	0.0 (0.0, 39.5)
Improved Health & Wellbeing	<15	-	-	-
Finding & Keeping a Job	29 (7.6)	-	-	-
Improved Living Arrangements	<15	-	-	-
Improved Learning	<15	-	-	-
Capital	**118 (30.8)**	**8.7k (1.2k, 16.1k)**	**0.3k (0.0k, 6.7k)**	**4.9 (0.0, 56.0)**
Assistive Technology	105 (27.4)	3.3k (0.9k, 12.8k)	0.1k (0.0k, 4.0k)	4.2 (0.0, 53.7)
Home Modification	36 (9.4)	12.2k	0.0k	0.0

Abbreviation(s): N-number; IQR-interquartile range; k-Thousands.
To ensure plans are material plans, we included those with values of $100 AUD for each class and category (annualised) or higher and lasted for at least 180 days. Values generated based on fewer than 15 individuals are omitted because of confidentiality requirement. The median is the middle value in the dataset that holds 50% of the values below it (and 50% above it). The first quartile holds 25% of the values below it. The third quartile holds 25% above it. Only median is presented when quartiles hold fewer than 15 individuals.

Yarning narratives

Life circumstances of First Nations people who are Deaf or Hard of Hearing

The life circumstances of yarning participants were overwhelmingly contextualised within broader structural discrimination and subsequent intergenerational disadvantage across many life domains. Challenges experienced in one domain, such as overcrowded housing and limited access to health services, often compounded challenges in other domains, such as education. Life trajectories were further impacted when people were dislocated from family and Country, the trauma of which often contributed to complex circumstances and increased risk of interacting with police and CJS as further unpacked below.

Limited supports to address challenges associated with early onset of hearing loss

Repeated early childhood ear infections were reported by many participants. Lack of access to appropriate ear/health interventions was then reported as contributing to absent or delayed treatment. In turn, this contributed to longer-term hearing loss and reduced access to hearing supports such as hearing aids or other communication enhancing strategies, including development of use of sign language.

For all but one participant, delayed identification of hearing loss also impacted access to education. This was partly because of disrupted communication development (oral and/or sign), but also due to challenges accessing culturally safe and accessible education for students who are Deaf or Hard of Hearing (e.g., lack of visiting teachers) or to meet other disability-related learning supports and amidst the fear of removal. This contributed to a history of poor regular access to school within communities. In turn, most participants reported low literacy levels which subsequently contributed to difficulties in being able to find and keep a job later in life, but also more complex life trajectories.

> *Albert was born and raised in Jay Creek. Receiving limited supports for his diagnosed hearing loss in childhood, social participation and schooling was challenging. Albert had no hearing aids until he attended secondary school in Mparntwe/Alice Springs. Receiving devices at this time actually increased his isolation and increased bullying from others. Albert didn't have any spoken language until the school set up the visiting teacher services. Yet the presence of these supports also exacerbated the family's concern that Albert was at risk of being removed from them and his school attendance was limited. Albert continued to struggle with communication as it was acquired later than others. He got into trouble with 'white fella' law and ended up in youth detention. At 18 he pleaded guilty so he could stay with family in prison and spent much of the next few decades inside. Upon release Albert moved back on Country with family.*

Some participants who received Deaf education outside of their communities developed sign language and English literacy skills. This also allowed them to communicate their needs and goals through an Auslan interpreter at NDIS planning meetings. While some considered this education useful in gaining employment and communication skills, others were so distressed by their removal from their communities that they became alienated from education systems altogether. Alongside difficulties with literacy, disrupted education also contributed to persistent challenges with communication, social inclusion and participation, including in relation to engagement with the NDIS. With time, some participants were able to gain appropriate cultural and linguistic supports to help them overcome some of the communication barriers that previously prevented them from obtaining NDIS services and supports that were more reflective of their needs and aspirations.

Albert attended his first NDIS meeting with an interpreter that didn't understand his local language. He didn't understand any of it but saw others doing it, so he followed. He didn't know what the "purple money" did and his first plan wasn't used except to move him into a Supported Independent Living (SIL) setting in town. During subsequent meetings, he was supported by his younger brother and an Aboriginal Liaison Worker, enabling him to communicate in his own language that he was ok to stay in the SIL, but wanted to spend more time on Country and do more Men's only programs. Albert expressed that he is now happier with his "purple money". He has been doing more Men's art programs and this has reduced his isolation. He goes on visits to be with family on Country. He takes out gifts and supplies and participates in hunting, all of which bring him much joy. Photos of these trips are on the wall in the SIL. He asked if his money will "nothing - empty" soon. Albert is hoping his next plan will help him visit his children as his previous plans didn't enable this.



Impact of dislocation from family and Country on life trajectories prior to the NDIS

Several participants reported that their family had been forced to relocate off Country into regional or urban communities during or subsequent to their childhood. Others had been separated or removed from family by child protection and placed into extended family care or non-Indigenous care arrangements. Experiences of abuse or neglect (within community and/or in out-of-home care) were often cited by services as the rationale for separation.

Elsie was born in a remote community. Following a childhood illness that caused hearing loss, Elsie was deemed vulnerable by Territory Families and placed in extended family care. Experiences of abuse within this care saw Elsie placed in non-Aboriginal foster-care. Her mother died young, but Elsie remained in contact with her father throughout childhood, creating happy memories.

The resulting dislocation from Country and family – the latter of which often meant disruption or loss of communication supports – alongside experiences of trauma, contributed to ongoing challenges and interaction with other systems across the life course. As such, feelings of isolation and traumatic experiences, particularly throughout adolescence contributed to the development of risk-taking behaviours (e.g., alcohol and drug use, sexual coercion, fighting). Homelessness during these periods was not uncommon. While lack of affordable, accessible and safe housing options was clearly an issue – especially for gender diverse participants who struggled to access gender segregated crisis accommodation for example –some identified 'opting' to live in town camps, the 'long grass' or even prison due to not feeling safe, connected or supported in alternative housing that was available.

Elsie acquired a brain injury through a violent altercation in her youth. In her early teens she was raped. She struggled with police processes and was not provided with an appropriate interpreter to support her. Elsie has no recollection of the outcome of the case. The following years were

traumatic. She started drinking heavily and was coerced into exchanging sex for alcohol by people transiting through town (e.g., truck drivers). A forced termination of pregnancy contributed to her removal from foster-care into homelessness.

Homelessness in combination with risk-taking behaviours often exposed participants to further disabling injury, violence and trauma, and also put them in contact with police and the CJS. Ultimately, underservicing in areas such as health and housing, alongside an absence of appropriate disability services and communication and cultural supports, was paralleled by overservicing through police and CJS; often acting as 'alternative disability service providers'. In effect, this results in a 'cost shifting' of potential disability and mainstream systems support (e.g., health, housing) costs to the police and CJS, which also comes with a terrible human cost.

During this time, Elsie was charged with various offences but again without sufficient supports found it hard to understand the court orders, so was placed in custody and spent two years in prison. Elsie was not provided with an interpreter and found it difficult to communicate with staff and other inmates. Elsie spent long periods of time alone in her cell. She is now very scared of police as she associates them with being in jail.

Too often, yarning participants reported having been incarcerated as a young adolescent. Incarceration for many happened on multiple occasions, frequently for minor offences. Most went on to report experiencing beatings, mocking, taunting from both fellow inmates and prison guards about their communication difficulties, all of which compounded further their feelings of isolation and loneliness. Often the cycle of incarceration persisted into adult life and contributed to more disabling conditions. For some, there were perceived benefits to being incarcerated including access to accommodation, health services, and being able to connect with members of family and their community. In some circumstances, this contributed to participants opting to remain in prison (i.e., pleading guilty for something instead of going to trial, even when they might not have fully understood the charges against them or knowing they were innocent).

Elsie's access to the NDIS was requested by her Guardian. In her first planning meeting, with interpreter support, Elsie requested safe accommodation, technology to keep her safe, and supports to help her find a job. She also requested support to visit family on Country and participate in community. But Elsie struggled to stay engage with NDIS supports. Her risk behaviours escalated and she was hospitalised with chronic illnesses. Her plan remained underutilised.

Increasing complexity of life circumstances including interactions with multiple systems, and a perception of services that participants or communities were at heightened risk, often resulted in the appointment of a public guardian. In some circumstances – particularly when a kinship guardian was in place alongside a more formal guardianship arrangement – more culturally informed decision-making processes and outcomes were achieved. For others, however, being placed under guardianship often felt like a further blow to their sense of connection, independence and decision-making authority over their lives. Public guardians were also often unable to support participants to better navigate the NDIS and other systems (as discussed further in the following section on barriers to effective utilisation).

At the time of her third NDIS plan, Elsie was in custody. She was not provided with an interpreter, nor consistent access to appropriate NDIS supports. A cognitive assessment of documentary evidence (no direct in-person assessment) was being undertaken to determine Elsie's fitness to plead. The ongoing inconsistent access to culturally safe support and specialist sign language interpreters across these systems has amplified her reduced capacity. Without appropriate communication support and access to NDIS funded supports, Elsie is likely to face a longer period of

incarceration. When asked about how the NDIS could support her, she replied: "NDIS did shit, they didn't give me a job, didn't help me with interpreter, didn't help me find a safer home, didn't give me support to go see dying [family] … all them white workers don't know my ways."

Cycle of mistrust of 'white fella' systems

Yarnings consistently illustrated past, present and future fear of engagement with 'white fella' systems that justifiably lead to mistrust of new systems such as the NDIS. Participants often reflected they had little understanding of the NDIS, and that the NDIS had little understanding of their experiences and circumstances. As such, participants highlighted that First Nations people who are Deaf or Hard of Hearing, their families and communities had not really been engaged to develop a shared understanding of how the NDIS might work for them. This contributed to the limited understanding of the NDIS in relation to:

- lived experience of being a First Nations Deaf or Hard of Hearing person and how this may interact with experiences related to other identities, co-occurring conditions and complex life circumstances.
- diverse ways that First Nations people who are Deaf or Hard of Hearing communicate (on and off Country).
- essential cultural obligations that often sit alongside or take precedence over individual needs and aspirations.

Prior to accessing the NDIS, very few participants described their perception of the NDIS as a culturally safe system or one that they believed would help them. Instead, participants often described hearing about others who had entered the NDIS but not received the supports they had been promised in meetings. This often led to negative perceptions of the NDIS before and subsequent to engagement with the NDIS.

Levin comes from an outstation near Tennant Creek. He received a few years of Deaf education where he learnt to sign the alphabet and some English. He is currently on remand. Levin was referred to the NDIS through a local Arts program. He stated there were many in the town camp that had the "white people" come and promise help but they were still waiting. Levin's NDIS interview was his first exposure to the disability sector. He wasn't sure what the paper would make him do. Levin asked if it was for court and the "white person" told him that the "paper was the truth." He wasn't sure if they were only getting his information and going to tell the police.

Participants and their families also reflected that in a rush to ensure First Nations people were gaining access to the NDIS, many were quickly signed up to it. Yet - particularly for those who are Deaf or Hard of Hearing - they were generally not provided with culturally safe and accessible information or support to help them understand the NDIS and what the implications, challenges and benefits may be of accessing it.

Levin's reaction to that meeting was that they didn't know how to work with him and with all the "white talk" he didn't understand the interpreters. Levin explained that he was promised a lot of things. He had asked for help to find employment and wanted to work with other men and have friendships. He didn't know that they were called goals and was overwhelmed and confused during the meeting. Levin didn't know what the paperwork was and that he had signed it. His family stated that Levin's plan was "done in same way as many at the time and was to get Levin into the system". The plan wasn't right for Levin and his funding never utilised. He was subsequently incarcerated.

Without sufficient cultural and communication supports, inaccurate assumptions were often made about individuals and family capabilities to 'care' for individuals with disabilities. Families subsequently felt pressured to engage with the NDIS, despite their lack of trust that the NDIS was needed or that it would be of benefit. Indeed, some participants expressed their serious doubts that a "white system" would be able

to provide appropriate or safe care for First Nations people. Of greater concern, some participants were apprehensive about the NDIS being staffed by "bad people" that may cause further harm, and perpetuate a legacy of individuals being removed from families. For participants, this situation had troubling parallels with other policies and systems that continue to contribute to the separation of First Nations people from family, Country, community and culture.

> *The uncertainty of how Levin's NDIS plan would be utilised impacted on decisions around his release from prison, as his release was dependent on orders that his living arrangements and supports are within proximity to legal services such as parole. Levin still believes that the NDIS will help him live a more quiet and easy life away from bad things and that he has learnt that prison is not a place to die: "If the NDIS help me in my new life away from prison, I will die on Country in the quiet. If I die here in the prison then NDIS has fail me." When asked why he thought this he stated: "Because if NDIS was better I would of had more support and understanding and not get into this trouble in the first place, but they left me without helpers and now I made bad decision because I didn't understand".*

Many participants expressed they did not understand essential aspects of NDIS processes such as eligibility and access, planning meetings, the plans themselves or the purpose of their goals, or how their plan could be implemented. This was exacerbated for participants for whom the NDIS was applied for on their behalf, or those with limited prior experience of the disability service system. These challenges were often compounded by the limited availability of culturally safe health and disability services and supports in regional and remote areas prior to the NDIS. This makes it difficult for potentially eligible participants to acquire evidence of need to access the NDIS or highlight what their specific needs are, creating further tangible yet often invisible institutionalised barriers within the operationalisation of the NDIS.



Perceptions on whether interwoven cultural and disability related needs and aspirations are currently being met through NDIS plan utilisation

First Nations people who are Deaf or Hard of Hearing often have interwoven cultural and disability related needs and aspirations that occur across the levels of the individual, family and community. Central to these needs and aspirations is the importance of connection to family, community and culture. How the NDIS enables – or indeed further disrupts – these connections is central to influencing perceptions on whether or not the NDIS is of benefit to individuals and communities, as further described below.

Importance of NDIS enabling connection to Country, family, community and culture

Overwhelmingly, participants reflected their deep connections to Country, family, community and culture, that they wanted - and indeed are required - to maintain and or enhance. While these connections were at times precarious or disrupted by complex life trajectories, for most participants, engagement with the NDIS was viewed as potentially positive if the NDIS was able to support them to maintain or enhance these connections. With time and sufficient supports, a small number of participants described such connections had been enabled through their NDIS plan utilisation. Key examples of supports that enabled this included Art Therapy and local Men's and Women's groups.

In many cases, however, significant constraints within how the NDIS and services and supports currently engages with First Nations participants who are Deaf or Hard of Hearing, has meant that many have instead experienced further disruptions of these critical connections. This has a detrimental impact on holistic physical, mental, emotional and spiritual well-being.

> *Elijah was born in Mutitjulu before the family were relocated to Katherine after the Northern Territory Intervention. Elijah was removed from his parents after spending time in youth detention where he was exposed to significant and life-threatening trauma. He received his first NDIS plan in 2018 but was then rejected from the NDIS after an assessment conducted during a hospitalisation only focused on one aspect of his functional difficulties. With the support of an advocate, he received a more holistic assessment and was able to re-gain access to the NDIS. A lack of sufficient supports in the community, however, contributed to a decision to move Elijah off Country and into a SIL setting. This was distressing for Elijah and didn't last long. He left the SIL and moved back on Country to be closer to family. His main goal was to fulfil his obligations to help care for family members requiring ongoing support.*

For some, improved access to appropriate cultural and communication supports over time helped them engage with the NDIS system and advocate for more localised solutions that better aligned with individual and family needs and aspirations. This meant that plans actually empowered individuals to remain on Country, fulfil their family and cultural obligations, and achieve more positive outcomes. Nonetheless, unrequested and sometimes requested plan changes often meant these positive outcomes remained precarious. When attained, positive outcomes also led to greater self-direction and ownership of plan and supports, alongside optimism that future positive outcomes were possible. Yet, even when some positive gains had been made these were often difficult to sustain.

With the support of cultural and language interpreters, Elijah was able to receive a plan that helped him get training in how to provide the care his family members required. Alongside these skills and being granted the Disability Support Pension, things stabilised for Elijah and his family. Elijah loves caring for family but also wanted to start using his plan to try other things. But changes made to his recent plan, like employment goals off Country, were not what he wanted: "When they change it, it changes me in a bad way… they make things up because they never talk to me… My family need me. I need NDIS help so I can be part of my family."

Support to navigate complex interactions of cultural expectations, disability and potential exploitation by others

For some participants and their families, there was a recognised issue that when they are the only member of a family or community receiving NDIS supports, they may be exposed to increased and harmful levels of 'humbugging'. (i.e., NDIS participants feeling culturally obliged to concede to kinship requests for money, goods or accommodation). 'Humbugging' can be exacerbated in contexts where there are:

- extreme levels of socio-economic disadvantage and insufficient supports to meet basic and/or disability related needs within communities.
- high levels of community and family dysfunction because of poverty or substance misuse.
- limited number of people receiving supports such as the Disability Support Pension and the NDIS within communities.
- limited participant, family and community awareness around the parameters of the NDIS and what funds can and cannot be used for.
- 'humbugging' perpetrator's function is influenced by their own complex needs and substance misuse.
- people with disabilities are seen as easy targets.

Ivy was bought up by her grandparents, spending time in Darwin for school and in community during the holidays. Ivy was subjected to sexual abuse during visits to community. Ongoing trauma led to increasing risk behaviours and a subsequent Acquired Brain Injury and time in youth detention. Once Ivy was able to link in with appropriate psychological supports, she was then able to engage with supports to help her re-build family relationships, giving her the opportunity to learn from senior women. Ivy expressed that the best part of her plan was the fact that she was no longer alone in her flat every day. But Ivy often struggled to navigate interactions in town.

Navigating an appropriate balance within cultural obligations was a challenging space for individuals and NDIS support workers to traverse, as many participants wanted to be able to fulfil their cultural obligations by sharing their resources. For some, it also gives them joy and helps them feel connected to their communities especially when they may have experienced isolation or exclusion. Having support to learn culturally informed strategies to navigate challenging situations such as 'humbugging' were therefore appreciated by participants, albeit difficult to sustain.

Ivy used her plan to have a support worker help her in town and reduce the likelihood of her being humbugged for money. For a while, Ivy found that the NDIS had saved her life. By identifying that each plan was better than the last in the way that she chose to live her life and what she required to participate in community safely. The complexity of Ivy's trauma and difficulty remaining engaged with supports, however, made it hard to sustain these outcomes and she ended up back in prison. During this time, she felt the NDIS was "just like everyone else, promise lots but when hard to communicate with Deaf mob they make us feel like dog shit." Upon release, she was keen to re-start her NDIS journey with more help to communicate and access the supports she wants.

Barriers to more effective utilisation

Effective utilisation was undermined by multiple and compounding barriers in relation to insufficient access to communication and cultural supports; challenges in having individual and collective needs and aspirations understood; limited availability of culturally safe services and supports; and negative experiences within services and interfacing systems, as discussed in the following sections.

Insufficient communication and cultural supports

Engagement between the NDIS and First Nations participants who are Deaf or Hard of Hearing and their families was often extremely difficult as participants were not provided with appropriate or sufficient cultural and communication supports in their interactions with the NDIS and its processes.

> *Eric grew-up on Larapinta Country where both his parents were respected Elders. Here he was immersed in culture and reflected a very happy childhood. He didn't go to school much due to ear infections and as he was caring for his siblings while his parents were working. He communicates using Arrente and Anangu Pitjantjatjara sign languages. He can spell his name and write a few words of English. An incident in the community saw Eric spend time in prison and he has since spent many years on remand awaiting a fitness to plead hearing. Eric now lives in a town camp outside Mparntwe/Alice Springs. Eric's first NDIS meeting was not supported by any interpreters. He accepted a plan that he didn't understand but that he thought would help him get housing and an interpreter for court. But he couldn't use his plan in these ways and it remained unused.*

Many participants and their families needed more than one interpreter to help translate from local language to Auslan to English and vice-versa. Participants who did not communicate using Auslan or Signed English were particularly disadvantaged in efforts to have their needs and goals heard - despite having proficiency in the local sign languages of their communities. As the use of some local sign languages off Country can be forbidden, meeting the communication and cultural support needs of participants can be challenging but must be addressed in a way that respects cultural protocols.

> *The next NDIS planning meeting was conducted over the phone due to COVID. Eric doesn't have a functioning phone so information was relayed via text message to an Aboriginal consultant who then interpreted it to Eric. Eric couldn't finish the planning session as he was too overwhelmed and fatigued. It was decided that the meeting would be finalised at a later date but was yet to be been done at the time of the yarning.*

Without supports to help communicate and convey cultural overlays embedded within different ways of communicating, it is very difficult for people to have their needs and aspirations accurately understood and reflected in plans and service provision. Similarly, as NDIS staff were not able to effectively communicate with participants and families, many participants had trouble understanding plans and any changes that were made to plans. Again, this undermined people's trust and ability to navigate the NDIS and broader systems.

> *Eric is now due to go to court. On discussing this with Eric, he was confused and maintained a nervous giggle. Eric stated that the police wanted to lock him up and he would be happy because he would get food and it's better than being in the long grasses in the rain. Asking if Eric thinks the NDIS would help him stay out of prison, he replied, "Don't know, they haven't helped me ever".*

Where appropriate interpreters were not available, family members were sometimes able to act as interpreters. Even those who attended meetings with interpreters, cultural and family supports, still highlighted the significant power imbalances between participants and planners. As such, participants

struggled to have their needs and aspirations sufficiently reflected in plans, or to gain plans that enabled culturally safe responses.

Difficulty getting individual and collective needs and aspirations adequately reflected within plans

Once on the NDIS, participants predominantly reported their experiences within the NDIS as overwhelming and confusing. Lack of information and support to engage in NDIS processes often led to suboptimal plans that were difficult to implement. Developing and articulating self-identified goals, needs and aspirations within the parameters of the NDIS is often not straight-forward for First Nations participants who are Deaf or Hard of Hearing for several reasons:

- a preference for relational goals and supports that meet the needs of more than one individual and nurture cultural approaches to caring and receiving care.
- limited recognition by planners of the need for sufficient cultural and communication supports.
- limited recognition and response to co-occurring conditions.
- persistent challenges experienced by individuals, families and communities in meeting basic needs that are not accommodated for within the NDIS, but that nonetheless impact on peoples' ability to utilise plans.

Even when participants did have clear goals and aspirations, were able to articulate them (with or without support), and recognise what supports they needed to achieve them, participants often still met with obstacles to having their goals, needs and aspirations accurately recognised and respected within planning and implementation.

> *Larinda was born and raised on Larrakia lands. She is one of many siblings who were Deaf, in her case due to Rubella. After Larinda completed her education at a specialist school for the Deaf, she worked full time until having her own children. Larinda had been resistant to engaging with the NDIS due to stigma and the perception that "bad people working in community lying about the way the NDIS works." Nonetheless, she went along to a planning meeting and came away with a plan. But the goals were unclear and only allowed for 20 hours a year for an interpreter. Larinda found it difficult to use her first plan and disengaged from the NDIS.*

Further, participants often felt that the goals that were included in their plans didn't reflect their aspirations, but the aspirations of others, including the aspirations of the NDIS and broader societal aspirations for people with disabilities and First Nations communities (e.g., emphasis on living independently out of the family home, engaging with employment programs and employment despite multiple barriers in doing so). Notably, only a few participants felt they were strongly able to self-advocate for their identified goals to be appropriately incorporated within their plans. This was facilitated by longer times in the NDIS, greater proficiency in Auslan (increasing access to interpreter options), higher education levels, and growing up within prominent families in community. Nonetheless, it still took remarkable resilience and support to advocate for plans that met individual and collective needs of participants and their families.

> *Larinda reluctantly went along to her second plan meeting. The provision of an interpreter allowed Larinda to have a voice at the table. She was able to work with the LAC to get a better plan that she was able to use and benefit from. By her third plan, Larinda knew exactly what she needed and how to self-advocate for a plan that was reflective of her needs and aspirations. She has also used these skills to advocate and negotiate for NDIS access for one of her children. Larinda does, however, constantly worry that their plans will be cut, disrupting her family's ability to live a decent life.*

Limited availability of culturally safe quality services and supports particularly where people need them most

Sometimes, individuals and families made informed decisions to access necessary disability and health services and supports that were not available on Country. This meant that they would often have to re-locate into bigger towns or cities, creating an extraordinary tension in their broader need to remain connected to Country. It often felt, however, that individuals and families were denied any choice and control over the decision to remain on Country or re-locate to access services.

> *Derek grew up on Country until moving to Darwin to attend a special school. He enjoyed his time at school and made good friends. After a few years, his parents bought him home for Ceremony. An incident during this time contributed to his disability. Derek remained with family and lived a good life for many years. In 2017, the NDIS was rolled out in Derek's hometown. His parents' instincts were that "If they got him in their white system, he wouldn't be looked after right way". Yet Derek was given an NDIS "goodie bag" and was taken with his parents to an NDIS meeting. The NDIS talked of "big promises" and that his parents should "be relieved that Derek could move into a free home with others like him and that he could do disabled activities". Derek's parents visited the SIL house. They were shown "his space". Derek was confused, the floors were tiled and he didn't like it. His parents asked if he could be in another house where he can lay down on carpet in his room. The response was "there are so many in need he shouldn't be so fussy, he should be grateful." The parents didn't ask for anything else after that. Derek moved into the SIL but it was a very challenging transition.*

While some participants reported positive aspects of being linked in with NDIS services and supports, others experienced distress and deteriorations in health and well-being. Overwhelmingly, negative experiences stemmed from the fundamental issue that, unassisted, service providers and support workers (particularly non-indigenous) did not have:

- the bicultural knowledge and expertise for 'proper-way' engagement with individuals and families, or, the capacity to appropriately communicate with First Nations people who are Deaf or Hard of Hearing.
- The default of 'standard' SIL processes, often involve low pay for a very casual workforce. This results in a constantly changing care support team. Deaf and Hard of Hearing residents however rely on staff to get to know them to have most effective communication. This means the constantly changing staff members cannot develop effective communication skills.

This made it very difficult to ensure that services and supports were designed or delivered in a way that met needs, including in relation to communication needs or cultural safety. Further challenges were incurred when services and supports were not sustained, either due to the high turnover of staff and/or the loss or merging of service providers within the NDIS market. Constant changing of staff made it very difficult for participants to develop effective communication, trusting relationships and adapt to the different ways staff interact and communicate with them.

> *After a while Derek started to learn to communicate with some of the other residents. He enjoyed the art therapy. He liked the BBQs. However, Derek saw less of his family. Derek stopped asking to see them. He had little opportunities to be involved in Ceremony. He was supported to return to Country for Sorry Business of his father. But when he had to return to the SIL, he became very distressed and reclusive.*

Negative experiences within services and supports

Some participants experienced very negative treatment within their NDIS engagement, perpetuating expectation of unfulfilled promises of the past and contributing to a cycle of loss of trust and disengagement in the NDIS and other systems. Once broken, re-building the trust of individuals and communities in any service or system can be very difficult, making effective utilisation very difficult to achieve.

> *Daisy was raised on Country until she was 19 when she was removed after an assault. She didn't see family for five years. She was moved into a group home, attending a day program once a fortnight. During this time, she lost many Elders and has been deeply affected by these losses. Her guardian applied for the NDIS on her behalf in 2018. She was moved into a SIL setting with another woman that she had a poison relationship with. This was very distressing and led to an altercation. Many staff have come and gone. She is glad some are gone as: "They not nice me then, they bad me and this (photo of worker) she hit me lots." Daisy was moved into her own house and family started to visit again, but the visits stopped with COVID. Her constant asking for home escalated concerns for her mental health.*

The most identified settings for negative experiences were within Specialist Disability Accommodation (SDA) and/or SIL settings and services. For many, the issues identified above in relation to limited cultural safety, communication barriers and high turn-over of staff, often intertwined with the feeling of having been coerced to move off Country into non-First Nations led small group disability settings. This disrupted connection to Country and family impacted on participants in several ways including:

- loss of support from people that most understand their ways of communicating and therefore their needs and how to respond to these needs.
- loss of access to receiving and providing kinship care, which was often seen by participants and their families as the only appropriate and desired support.
- decreased capacity to participate in Ceremony, the rich history of practices that shape and give meaning to day-to-day life.
- decreased capacity for services to engage with families and elders to gain required permission to enable cultural protocols to be incorporated within supports provided by non-First Nations people.

Not being able to stay connected on Country and disrupted engagement with culture was often expressed with a deep sense of sadness and distress. Sorry Business practices, for example, were highlighted by participants not only as essential cultural obligation, but core in their expression of kinship and identity. Multiple issues within the NDIS and its market, often meant that participants were not sufficiently supported (within their plans or through service delivery) to engage in 'Proper-Way' grieving and processing of loss. The outcome was often an escalation in distress.

> *Daisy's current plan was decreased in cultural and communication supports. Daisy communicated that she sees less of the interpreter who she thought was her friend. The Support Coordinator stated that "the plan had reduced in the communications access due to a NDIS decrease in many plans". When asked if they felt the decrease of the funds for interpreters was escalating 'behaviours' which were said to have increased since moving to the new SIL, the Support Coordinator attributed this distress as part of "a transition phase." When asked if she was happy? Daisy replied: "No, I go my home to [name of Country]. I no live here [SIL setting] this not my home. I want to go see my family and go to my school, see my friends."*

Misinterpretation and responses to distress and ways of communicating needs

Yarnings highlighted a cycle whereby participants' expressions of distress and/or their nuanced ways of communicating needs were misinterpreted by service providers and support workers and inappropriately labelled as 'behaviours of concern'.

> *Jaida was removed from her family at a young age and put into foster care through Territory Families. She was well cared for until things became challenging in her teenage years and she was moved to an institutionalised setting. During this time, she was locked up inside the house and cars as she would often try to flee the setting. This was very traumatising for Jaida. Jaida was enrolled into the NDIS in 2018. Jaida and her family guardian were not supported to understand the planning process and the plan engagement team didn't assist to explain things to them. Despite requests, the plan was not explained to them in any language that they use to communicate. The plan was not utilised except to move Jaida into a SIL setting with two other women.*

Similarly, culturally ill-equipped service providers and support workers often 'pathologised' culturally mediated expressions of desire for cultural inclusion. For example, across different First Nations modes of communication, it is expected that the 'listener' should proactively considers what a person's behaviourally expressed dissatisfaction is requesting, especially for those with cognitive or communication difficulties. Service providers and support workers do not know they are expected to or know how to understand and respond to these indirect requests.

'Behaviours of concern' may also arise when subtle culturally based non-verbal requests are not understood by carers or the NDIS participant assumes they have been purposely ignored. Reactions that are seen as 'behaviours of concern' in reality are more assertive requests, but are viewed as inexplicable 'behaviours of concern'. Service providers and support workers often responded to these 'behaviours of concern' with harmful reactions including restrictive practices. This is particularly so when workers are not aware of an individual's hearing loss and its impact on communication. This can significantly exacerbate the distress of participants, creating traumatic experiences and contributing to deteriorations in health, mental health and wellbeing, and a further loss of rights.

> *Jaida is now often restrained in her wheelchair to "safeguard her from falling out of the chair." Jaida's family guardian highlights that poorly trained support workers do not understand how to communicate with Jaida. She has become more reclusive and struggles when she sees family when out. She now vocalises her anger and outbursts are increased due to her mobility being reduced. Despite this, Jaida has been exposed to further restrictive practice. During the yarn, Jaida expressed that she is not able to see family, go out or even learn to walk again. She has not seen any support workers who can sign in her language. She expressed that she is left for long periods of time in her room and taken for "sleeps" if she expresses she doesn't like something.*

When separated from family and without cultural advocates or linguistic and communication supports, individuals and families found it very difficult to raise their concerns and advocate for more appropriate responses and options. When family is engaged, and with the right supports, better options can be identified and should be supported.

Jaida doesn't know who the NDIS is. She doesn't know why there are none of her people looking after her. When asked, the SIL staff stated that Jaida 'doesn't talk much'. However Jaida can articulate her needs and aspirations very clearly when communicating with someone who understands her language. A cultural advocate was bought on board, enabling Jaida to see her family and clearly state she wants to be cared for on Country without the use of restricted practices. This should be possible, as there is a First-Nations led SIL service now available in her community.

Challenges at the interface of the NDIS and other systems

It was particularly difficult for participants to engage with or sustain benefits through the NDIS when challenging life circumstances are not sufficiently addressed. While NDIS system-level factors certainly influenced these journeys, these were often in interaction with individual-level and broader systems level complexities. Though the responsibilities of each mainstream system and the NDIS have been identified (NDIA 2015), how effectively these systems function and interact with each other in the delivery of these responsibilities, can positively or negatively impact individual outcomes. To demonstrate some of these challenges at the interface of the NDIS and other systems, experiences of the NDIS, Health and CJS interface are described below.

Health system interface

Chronic and co-occurring significant unmet health and disability needs were commonly reported (e.g., diabetes, mental health, acquired brain injury, complex trauma). Though complex health profiles required contact with health practitioners, access to culturally safe practitioners and interpreters was reported as either absent or irregular. Access barriers were multifaceted and often involved issues with transport, discrimination, and fear of services due to previous negative experiences. The more remote individuals were located, the less access they had to culturally safe and trauma-informed health care. This contributed to more disabling conditions and inappropriate system responses. Participants requiring higher levels of, or episodic, support through the health system, often described the challenges of maintaining sufficient access to NDIS supports and the disruption this had on the provision of cultural/kinship caring and supports. This was even more complex for people experiencing discrimination on account of additional layers of intersectional factors such as gender and sexuality.

Ruby grew up on Larrakia Country. She communicates through Larrakia and Yolngu Matha sign languages and English. Experiences of discrimination and violence on account of her hearing difficulties and LGBTIQ status, however, led Ruby to leave her community and head to Sydney. Living on the streets of Sydney was hard and she worked as a sex worker for many years. Ruby was accepted back by the community after the death of her parents. However, her family found it difficult to have her living full time with them and challenging to meet her chronic health related support needs. Ruby was enrolled in the NDIS in 2017 but received little support to meet her goals of safe housing, employment, and communication supports to help attend medical appointments and engage with family. Limited support workers or interpreters made navigating the discrimination she experienced within the NDIS, housing, health and employment systems too difficult. At this point, Ruby felt the NDIS caused more harm than good.

Many First Nations communities' approaches to caring and the receiving of care are deeply entwined within kinship and cultural obligations and are an important component of people's sense of self and belonging within family and community. Individuals rarely consider their care and caregiving needs in isolation from the needs of family and community and their own obligations to care and support others.

Ruby's health took a major hit in 2018 with her access to services undermined by confusion over who would fund interpreters for appointments and be responsible for supports such as OT. Her next plan therefore focused on supports for her health journey. This was difficult due to high turnover of support workers, services merging and their mismanagement of her funds. Things improved with her next plan that enabled help to find housing and home modifications. Ruby declined an option to move into a group home setting as she was happy with her current in-home supports, particularly as they were accessing sign language training to better communicate with her. Secure housing meant that Ruby had more family come to visit. Her Aunty and younger sister had moved into the home to assist in caring for her due to the use of cultural signs that were easier for successful communication. Cultural obligations by others to care for Ruby found a calmer and more appropriate healing for her. Ruby also found that visiting community helped with healing and the increase of wellbeing increased health outcomes.

Yet, these reciprocal approaches to caring are often difficult to reconcile within the individualised underpinning of the NDIS and within the interface of the health system. Participants were often frustrated and confused at the limitations placed on their NDIS plan and how this interacted with their access to health services, which often further disrupted existing reciprocal cultural obligations and arrangements around caring. This issue was exacerbated for individuals with very complex life circumstances, increasing health and disability-related needs, and fluctuating availability of supports. Further, 'payment for care' for external service provision, can also be seen as undermining or undervaluing and therefore disrupting the culturally endorsed care provided by family. This is particularly so when families see themselves as responsible for this care yet can't be paid for it even when costs of care extend beyond the capacity of families to cover.

Ruby's plan was constantly at risk of being reduced due to her increased utilisation of health services. This was very stressful for Ruby. She was offered a guardian. She found this offensive as she said her mind wasn't that bad. She felt that they were trying to "lock her away." Ruby identified that her ability to advocate for herself was getting less and she struggled to keep her independence. Indeed, her next plan was reduced as she was seen to need more medical support rather than disability supports.

Whilst hard to be separated from Country and cultural caring arrangements at any stage of life, being off Country at the end-stage of life was extraordinarily distressing. Whilst the mainstream health system is responsible for end of life and palliative care supports, adequate funding and flexibility of concurrently delivered NDIS disability supports during this stage, are essential to enabling people to return to Country and be culturally cared for.

Ruby stated that this may be her last plan. She didn't want to go into a nursing home or hospital stating: "If I don't get help at home my family would not come visit me in hospital, because they won't want to see dying." The NDIS enabled Ruby to use her plan to engage fulltime nursing support in the home, but she will have to move into care as her health deteriorates. She is being supported to work with family for end-of-life preparations. Whilst these changes are distressing, they are culturally supported by her family and kin. The use of Aboriginal support staff has been crucial during this phase of her NDIS plan.

Criminal Justice System

Participants main concern in relation to the NDIS and the CJS interface was that necessary disability and communication supports that may have been afforded through the NDIS were disrupted or stopped whilst they were in custody/incarcerated - even when these systems have a responsibility to provide supports. For example, almost all participants identified challenges accessing appropriate support to engage with, for example, legal assistance, particularly access to culturally appropriate sign language interpreters, without whom they could not follow police or court information or proceedings, nor adequately participate in these processes.

> *Not much is known about Wirra's early childhood, except that he was born in Daly River, that is where his mother comes from. He describes moving from youth detention to an adult prison but he doesn't know how old he is. Wirra has been living in the long grasses since his release: "I went prison. Lots men there no good. Make me sad. I no live in walls". He feels both freer and safer in the long grasses than moving into more secure disability housing. The NDIS planner says he would qualify for SIL, however, without more evidence (which the prison health service has not released) then his NDIS plan is in a holding pattern. The organisation supporting him have indicated that SIL is required but without funding and reports there is little hope of finding supportive housing options. His risk of self-harm and re-offending is a major concern.*

When people did not receive NDIS services in detention and/or where required supports were not replaced, it was very difficult to escape a cycle of insufficient supports contributing to increased risk of interaction with the CJS. Participants, for example, were often not supported to plan their access to NDIS services upon release to assure courts they will not be a future risk of offending. Subsequently they stayed in jail or returned to jail quickly after release. Similarly, disrupted access to the NDIS due to incarceration, often made it difficult to re-establish access, again leading to further challenges and an increase likelihood of coming into contact with police and CJS.

> *Wirra stated that people like him (people who are Deaf or Hard of Hearing and Aboriginal) don't get help much. They get locked up instead. He shared that he has a worker come look for him and family sometimes tells the worker to go away. He wants to go do things with these workers but he is worried about his family telling them to go away. This has caused some concerns as he has not been able to keep appointments for his health and outstanding legal issues. Wirra shared that "I see less police when I with purple people, but I not like purple people know my stuff". He was given an NDIS hat and water bottle but he doesn't wear them. He doesn't like the purple colour and says that it's no good. When asking his family why he thinks that, they said "that the purple people come and take them away". Wirra has requested his interpreter help him have a conversation about what he wants in his next NDIS planning meeting. His biggest goals are to learn how to ride a bike and learn the road rules so he doesn't get locked up again.*

Some participants had been optimistic the NDIS would support navigation with the CJS: for example, to support navigation of court orders to help prevent further incarcerations. For participants, understanding when and how NDIS disability supports interface with supports which are the responsibility of the CJS proved difficult. Though delivery of NDIS supports may contribute to the prevention of reoffending, it is the CJS responsibility to provide supports during incarceration, navigation of court orders, and for the specific purpose of preventing reoffending. This is a difficult interface. The complexity of participant's circumstances in combination with the challenges within and at the interface of these systems often contributed to disappointing outcomes for participants, leading to further mistrust in 'white fella' systems, including the NDIS.

Impact of COVID on NDIS engagement and access to services and supports

Overwhelmingly, the COVID-19 pandemic and response were extremely challenging for participants and exacerbated existing challenges they experienced in relation to the NDIS. Relevant information (e.g., regarding vaccinations and social distancing) was often not made available to participants in accessible formats, undermining their access to important COVID-19 related services and supports. The widespread use of facemasks restricted the ability to face watch and lipread that are crucial in communication for people who are Deaf or Hard of Hearing. Social distancing and physical barriers used during face-to-face communication further obstructed access to both visual cues and auditory input – making speech more muffled. Even when information was made available through Auslan or written material, this did not help First Nations individuals who do not use Auslan to communicate or because hearing loss had impacted on their acquisition of literacy skills.

The move to service provision being accessed by phone rather than face-to-face meant these services became unavailable to those who were Deaf or Hard of Hearing. Pre-existing digital poverty (e.g., limited access to technology) meant that some participants had limited capabilities to access services and programs that had moved online or to try and remain engaged with family. This was compounded by limited access to internet due to cost and poor infrastructure. Limited access to technology also made it difficult to upload proof of vaccination, participate in community events or even go shopping in places that required people to use the digital check-in apps.



Access to consistent services and support workers was considerably disrupted, with staff not able to work consistently or not wanting to be vaccinated. Participants also lost access to valued activities (e.g., Men's programs). This was alongside reduced opportunities to go on Country and visit family or have family visit them. This was a particular issue for people in shared SIL settings who often had greater restrictions placed on who could come in and out of these settings. Increased isolation and loss of connections contributed to expressions of distress. As previously highlighted, expressions of distress are often misinterpreted as 'behaviours of concern' and responded to with increased use of restrictive practices. Finally, pandemic related restrictions made it even more difficult for participants to engage with the NDIS. This led to a reduction in their input into planning or plans being rolled-over, even when changes of circumstances were evident.

Moving towards 'Proper way' engagement for more effective outcomes

NDIS processes, plan utilisation and outcomes were more positive when participants were afforded sufficient cultural and communication supports in their engagement with the NDIS, services and supports and interfacing systems. Central to this was 'Proper way' engagement whereby families, cultural guardians and advocates were respectfully involved in helping participants, services and families develop a shared understanding of interwoven cultural needs and aspirations, processes to facilitate communication, and proactive design and delivery of culturally-safe supports that enhanced participants connections with family, Country, community and culture.

Linguistic and communication supports

When available, the provision of both appropriate language interpreters and cultural supports was seen as paramount to the effective relaying and advocating of participant goals and needs to planners and service providers, and, of information from the NDIS regarding access and plans back to the participant and their families.

> *Levin attend his most recent NDIS planning meeting with an interpreter that he had worked with for several years. He found it easy to communicate with the Interpreter using fingerspelling and cultural sign gestures … He was given a better improved plan that was more defined.*

Appropriate interpreters were those who were proficient in the participant's preferred language and were able to communicate with them at the level to which they could use that language. There was also benefit in engaging interpreters that the participant knew and trusted, particularly those with whom they had a long-term relationship.

Involving family to enable more culturally aligned ways of caring and receiving care

Better engagement, plan utilisation and outcomes were possible when skilled NDIS frontline workers (i.e., workers directly engaging with participants and their families or involved in planning and review processes on behalf of the NDIS including Local Area Coordinators, Partners in the Community, planners, plan approvers) and service providers (including Support Coordinators) made a concerted effort to facilitate communication with participants and encouraged positive relationships with families, cultural guardians and advocates to better enable culturally supportive service provision that nurtured connections to family, Country and culture: i.e., 'Proper way' engagement.

> *Tess grew up on an outstation out of Mparntwe/Alice Springs. She was bought up by her Aunties in Mparntwe/Alice Springs after her parents died. Tess communicates using local signing systems. She is a very skilled and keen artist, selling her work to support her immediate and extended families. Her Aunties are getting older and want to return to Country to be at peace. They do worry that when they are not able to provide supports, Tess would be very vulnerable in community. The Aunties were hopeful that the NDIS would help them find some solutions to help them share the care of Tess. During the planning meetings, Tess was not asked at all what she wanted. The Aunties explained Tess was "told" the plan didn't include anything to do with her artwork, or her community engagement or ability to communicate with others. The Aunties left the meeting very frightened and confused. Tess was upset and crying because the Aunties were upset and crying. They never went back to the NDIS. Guardianship was appointed one month after this plan was provided and Tess was moved into a SIL setting. The Aunties were not engaged, not provided with access and could not visit the SIL setting due to COVID restrictions. This was extremely distressing. Tess stopped painting because she felt her spirit was broken.*

'Proper way' engagement was seen as vital to helping individuals and families remain on Country wherever possible, and to providing culturally safe supports when informal supports on Country cannot be sustained (i.e., when informal supports themselves genuinely feel that due to age or other circumstances they are no longer able to provide sufficient support to family members with complex disability). 'Proper way' engagement also enabled permission to incorporate cultural protocols within service delivery.

> *A cultural advocate who has known Tess for a long time, facilitated Tess's family to come into the SIL. Tess communicated with her remaining Aunty and the SIL about what she likes and doesn't like, that she doesn't want to live there but wanted to return home. Her Aunty explained that supports were not available on Country, but that she would visit every few days and that she will help teach workers how to cook her way so Tess can eat right way. It was through this 'Proper way' engagement and appropriate permissions that the cultural protocols to support Tess have been enabled. Her Aunty is now co-guardian and visits regularly to the house and Tess is starting to attend visits to families' homes to help her re-engage with family safely after being away for some time. Tess has started to paint with her Aunty and whilst small pieces of work, it's enough for her to enjoy painting again. There is no money exchanged. The artwork is for the SIL house where Tess lives and is photographed and documented to ensure that it is all accounted for by the SIL and the family. Tess is creating a space for herself to have paintings of her country around her in the home.*

Reflections on key findings

Overall, this project highlights the challenging life circumstances that can be experienced by First Nations people who are Deaf or Hard of Hearing living in rural and remote communities in the Northern Territory. Trajectories can be particularly challenging in circumstances where individuals with hearing loss and their families do not receive sufficient supports to identify and address ear health issues; overcome barriers to communication, social inclusion and participation; or when people have been dislocated from Country, family, community and culture; or when people have experienced significant levels of trauma associated with structural disadvantage; both within communities or in their engagement with multiple systems such as the CJS. Such circumstances can make it very difficult to engage with or benefit from 'white fella' systems such as the NDIS.

Indeed, these significant barriers to engagement help to explain the lower-than-expected number of First Nations NDIS participants who are Deaf or Hard of Hearing in the Northern Territory despite the high prevalence of hearing loss among many First Nations communities. In comparison to mainstream Deaf Australians, First Nations individuals who are Deaf or Hard of Hearing experience numerous barriers to accessing mainstream early childhood and ongoing deaf services and supports to help them address challenges associated with hearing loss, build communication skills and maximise their potential within, for example, the education system. They also experience barriers to maximising support from mainstream services that may then improve access to programs such as the NDIS. This compounds already complex life trajectories. As such, a non-Indigenous Deaf Australian who communicates using Auslan may have appropriate access to allied health assessments and interventions, which in turn facilitates the gathering of evidence to determine eligibility and needs within systems such as education and the NDIS. Whereas a First Nations Deaf individual who does not communicate through Auslan, may find it much more difficult to access allied health services, with the flow on effect of not having needs met or of having sufficient documentation to demonstrate eligibility for the NDIS.

When NDIS frontline workers and planners are not cognisant of the high likelihood that First Nations potential NDIS participants may be experiencing hearing loss, required communication and cultural

supports for meaningful engagement may not be offered, hearing loss may not be factored in as part of determining eligibility, and plans may not be reflective of the impact of hearing loss on functioning and needs. The absolute dearth of trained interpreters who can help individuals and families navigate both interfacing mainstream and NDIS systems then contributes to a likely under-representation of First Nations Deaf or Hard of Hearing participants gaining access to the NDIS.

When yarning participants interacted with the NDIS, they often experienced multifaceted barriers to having their needs and aspirations – individual and collective - recognised and reflected within plans. These issues stemmed from insufficient NDIS understanding of 'Proper ways' to engage with First Nations people who are Deaf or Hard of Hearing and their families, alongside insufficient provision of cultural and communication supports to participants to help them navigate NDIS processes and have their voices heard. This may help explain why First Nations NDIS participants in the Northern Territory generally received higher plan sizes compared to the generalised population, but those who were Deaf or Hard of Hearing received smaller NDIS budgets and their utilisation was lower than their non-Indigenous and/or non-Deaf counterparts.

'Proper way' engagement within the context of the NDIS would ensure that the way information is shared and how planning and implementation processes occur, must also recognise and value the contribution being made by family, cultural guardians and advocates to provide culturally endorsed First Nations ways of caring and receiving care. This does not translate to having an expectation that they do everything, but that plans can be designed and utilised in a way that supports these mechanisms.



While more consultation with First Nations people who are Deaf or Hard of Hearing and their families is required to progress potential approaches to 'Proper way' engagement, the following 'hearing loss responsive service provision' components should be considered. In the first instance, the NDIA in collaboration with communities and Aboriginal Controlled Community Health Organisations could develop strategies to build the awareness of NDIS planners and frontline workers (i.e., people interacting with current or potential NDIS participants, families and communities for or on behalf of the NDIS) of the high level of (often undiagnosed) hearing loss within First Nations communities and the impact this can have on functioning, communication and support needs and preferences.

Alongside increasing awareness of the impact of hearing loss, is the need to afford NDIS frontline workers more time and resources (e.g., resourcing access to cultural advocates and interpreters skilled in working with First Nations individuals who are Deaf or Hard of Hearing) to develop trusting relationships with current or potential participants and their families and opportunities to work together to identify cultural and linguistic communication needs and preferences that will enable 'Proper way' engagement. All efforts should then be made to ensure individuals and their families have access to required and preferred supports to help facilitate their NDIS engagement including within any assessments and gathering of information (noting a need to encourage all professionals engaged in these processes to undertake cultural safety and hearing loss responsive training). Frontline workers must then allow individuals and their families time to yarn in their own way to share information about needs, aspirations and preferences for supports, exploring together what the NDIS may and may not be able to do to respond to these needs.

More time and support (including resourced cultural and communication supports) are then required to work with individuals and their families to develop appropriate plans and understanding of them. Throughout these processes, there is a need for transparent discussions about the challenges that individuals may encounter when trying to access supports within thin markets, as well as opportunities to encourage and enable community-led localised solutions. Similarly, plans should enable individuals and families to work with NDIS services and supports to ensure services can provide culturally safe and hearing loss communication responsive services that align with the needs and preferences of individuals and their families (Howard, 2020).

Plans that are not reflective of the needs and aspirations of individuals and families are all but impossible to implement, let alone implement in a way that respects choice and control and rights of First Nations participants. This was of particular concern for participants and families that could not access appropriate services and supports on Country. While some individuals and families made difficult but informed decisions to access services and supports off Country, others felt coerced towards such options.

Though a broader issue within several areas of services and supports received, inconsistencies within the cultural safety particularly within SDA and/or SIL settings was particularly concerning. Within this, misinterpretation of expressions of distress being responded to as 'behaviours of concern' and through restrictive practices violated rights and compounded existing trauma experiences by many participants. This issue is exacerbated when hearing loss is unidentified, but also by the broader limited recognition of (often undiagnosed) hearing loss within many First Nations communities. When the impact of hearing loss on a person's communication (especially when their familial communication supports are not present or they are in an unfamiliar environment where their needs are not being understood or met) are not recognised or ignored when behaviours are being assessed, behaviours may be misunderstood and perceived and labelled as defiant or of concern (Howard & Hampton, 2006). I.e., when disability support workers or behaviour support practitioners are unaware of an individual's hearing loss and they are seeking to understand the functional purpose of behaviours of concern, their ignorance of the client having hearing loss limits appropriate intervention options, with a result that more coercive restrictive practices are deemed necessary.

Progress towards better NDIS experiences and outcomes for First Nations people who are Deaf or Hard of Hearing requires action across multiple levels and systems. Central to this is developing better understanding and awareness across communities, services and systems of the experiences, needs and aspirations of First Nations people who are Deaf or Hard of Hearing, their families, and communities.

Similarly, there is a clear need to address misconceptions and assumption by NDIS planners, service providers and support staff that First Nations people who are Deaf or Hard of Hearing cannot talk for themselves. This requires far better understanding of the interplay of culture and communication and access to communication and cultural supports for participants to engage with NDIS, alongside capacity building of NDIS and service provider staff.

Investing in bi-cultural training and approaches to mitigate the existing entrenched disconnection between service users, agencies and providers, and helping to bridge the cultural interface between First Nations and non-Indigenous communities, Deaf and hearing communities, and services and systems should be seen as priority (Barney, 2021; Howard & Barney, 2021b; Howard & Lines, 2006).

A common thread throughout yarnings pertained to the ongoing lack of communication, coordination and collaboration between the NDIS and interfacing mainstream systems such as health and the CJS. Federal, state and territory governments have developed and agreed to applying principles to determine the

responsibilities of the NDIS versus other interfacing mainstream systems (Department of Social Services, 2015). Yet our research reflects that participants (and indeed systems) remain unaware or unable able to navigate these systems to have their needs met, and even if individuals are aware of what processes to follow, interfacing systems do not always meet their responsibilities to meet these needs. These issues are particularly complex at the actual points of interface between the NDIS and other systems, undermining participant outcomes. The importance of intersectoral collaboration to try and clarify these roles and responsibilities specifically at the point of interface and particularly in relation to funding of supports, is essential to achieving positive outcomes. A key example of this was the confusion over who was responsible for providing access to appropriate language and sign interpreters and cultural consultants for NDIS participants in their engagement with the NDIS when they are incarcerated, negotiating parole conditions or on remand (e.g., planning for required supports on release so individuals could maintain parole conditions). The absence of intersectoral collaboration in such circumstances resulted in unintended consequences and prolonged interactions with the CJS.

Irrespective of the system or sector being discussed, the evidence overwhelmingly reiterates that the only way to address the challenges experienced by First Nations people who are Deaf or Hard of Hearing in relation to the NDIS and interfacing systems, is to ensure they are included within First Nations led design and delivery of locally responsive solutions. The current limited supply of such solutions not only meant NDIS plans were poorly utilised, but often entrenched or exacerbated disadvantage and risks.

To improve NDIS engagement and outcomes for First Nations individuals, families and communities, it is clear that their broader life circumstances and outcomes must simultaneously be improved. Addressing factors that undermine ear health and improving access to appropriate screening and supports for people experiencing hearing loss is paramount. Collaborative, co-designed approaches between First Nations people, the NDIS, Aboriginal Controlled Organisations and Community Health services, and all mainstream systems (e.g., health, ear health, maternal and child health, early intervention, education, housing, CJS) in the development of locally-led policy and programs within the NDIS and across interfacing systems is the only way forward.



Policy and practice considerations

These policy and practice considerations have emerged from the project yarnings and have been contextualised through expertise of key project team members who have extensive experience in working with First Nations people who are Deaf or Hard of Hearing. Any action taken to further develop these policy and practice considerations, however, need to be co-designed with First Nations people who are Deaf or Hard of Hearing.

Table 5. Policy and practice considerations

Policy consideration	Rationale	Potential strategies	Responsibility
Enhance awareness and understanding within community, the NDIS and interfacing systems of the importance of addressing hearing loss and the need to better respond to the experiences of First Nations people who are Deaf or Hard of Hearing.	Limited awareness and under-diagnosis/reporting of hearing loss reduces opportunities for accessing supports, contributing to more complex life trajectories.	Targeted awareness campaigns. Increased access to culturally safe screening and services. All potential First Nations NDIS participants to be offered collaborative team based holistic hearing and communication screening to more accurately identify functioning and needs.	Organisations and services engaged in hearing health, screening, and advocacy (e.g. Hearing Australia, Deaf Australia), Aboriginal Controlled Organisations and Community Health services, Aboriginal Medical Services, Maternal and Child Health NDIA in collaboration with interfacing mainstream systems (e.g., health, education, CJS).
Enable and appropriately resource 'Proper way' engagement between the NDIS, individuals, families, communities and services and supports.	To allow for robust, culturally determined consultations between communities and the NDIS, to develop shared expectations of how the NDIS could be delivered to better meet the needs and aspirations of First Nations communities. Within this, there needs to be a specific focus on 'Proper way' engagement with those who are Deaf and Hard of Hearing and their families.	Incorporate a Deaf and Hard of Hearing lens within the NDIS Aboriginal and Torres Strait Islander Strategy and Complex Support Needs pathway. Bi-cultural training to improve valuing of the knowledge and ways of communicating of individuals and their families, as opposed to a tendency for 'white fella' ways. Resourcing of 'Proper way' engagement within current NDIS Independent Review and any consultations	NDIA in collaboration with First Nations communities.

		relevant to future design and delivery.	
Position the importance of connection to Country, family, community and culture for First Nations people who are Deaf or Hard of Hearing at the center of processes and decision making.	With the right supports, resources and time, First Nations people who are Deaf or Hard of Hearing and their families are best placed to articulate their interrelated needs, aspirations and preferences for how these are best met within the context of the NDIS.	Prioritising these connections within every interaction and decision-making process conducted between individuals, their families, services and the NDIS.	NDIA and interfacing mainstream systems. Disability services and supports.
Recognising the diversity of local sign languages and ways of communicating, resource the provision of sufficient cultural and hearing loss responsive communication training and supports within participants engagement with NDIS.	To enable participants to better communicate their needs, aspirations, preferences, safety and outcomes in relation to how services are delivered.	Provision of culturally safe and communication responsive training for anyone engaging with those who are Deaf and Hard or Hearing within the NDIS and interfacing systems. Increasing availability of and access to cultural and sign language interpreters. Increasing recognition that individuals may have co-occurring conditions that also impact on communication and processing of information and level of support needs.	NDIA in collaboration with NDIS Quality and Safeguards Commission, community and interfacing mainstream systems. Disability services and supports
Promote First Nations led, localised solutions, services and supports.	**To enable supports to be delivered on Country wherever possible and in recognition of cultural obligations and protocols around caring and receiving care.**	Utilise culturally informed and relational approaches to work with individuals, families and communities to determine support needs and how the NDIS can best work with existing cultural and family supports to meet these needs.	NDIA in collaboration with First Nations communities and interfacing mainstream systems.

		Invest in strategies which enable First Nations individuals to gain qualifications that will enable them to deliver services and supports, including in relation to SDA and/or SIL services.	
Where First Nations led services and supports are not yet available, improve access to culturally safe, communication responsive and trauma informed services and supports.	Culturally unsafe services are harmful and risk exacerbating distress and disability.	Bi-cultural training across the NDIS and interfacing systems to enable provision of culturally and trauma informed services specific to the needs of First Nations Deaf or Hard of Hearing. Improve mechanisms to ensure that participants and families are supported to report negative experiences within services.	NDIA in collaboration with NDIS Quality and Safeguards Commission, First Nations communities and interfacing mainstream systems.
Ensure intersectoral collaboration and shared responsibility to improve the way the NDIS interfaces with other systems.	Challenges at these interfaces disrupt access to services and supports, again exacerbating needs and undermining rights.	Collaborative approaches to resource supports such as cultural and language interpreters to help individuals engage with interfacing systems including to understand and reduce the risk of incarceration; enhance legal support/advocacy to understand legal issues and how they interact with the NDIS; and maintain supports during periods of incarceration and when transitioning back into community; address challenges associated with fluctuating levels of	NDIA in collaboration with communities and mainstream systems, specifically education, health and CJS.

		care that require access to both NDIS and health systems, while respecting/maintaining kinship and cultural obligations.	
Ensure that the needs of First Nations individuals who are Deaf or Hard of Hearing or are at risk of hearing loss are better considered within all strategies to close the gap in inequalities experienced by First Nations communities.	Systems and society wide changes are needed to address conditions which contribute to avoidable hearing loss, improving diagnosis and treatment, and mitigate the negative impact that hearing loss can have on participation across social, cultural, educational, health, economic and justice domains.	Invest in strategies that enhance understanding of relationships between structural disadvantage, hearing loss and life trajectories and how to support First Nations led solutions. Law reform to raise the age at which all youth can be legally incarcerated, ensuring access to appropriate assessments, services and supports – including in relation to the NDIS.	First Nations communities with support of whole of government and wider societies.

References

Atkinson, J. (2013). Trauma-informed services and trauma-specific care for Indigenous Australian children. Resource sheet no. 21. Produced for the Closing the Gap Clearinghouse. In *Aifs* (Issue 21, pp. 1–30). https://www.aihw.gov.au/getmedia/e322914f-ac63-44f1-8c2f-4d84938fcd41/ctg-rs21.pdf.aspx?inline=true

Australian Bureau of Statistics. (2019). *National Aboriginal and Torres Strait Islander Health Survey. ABS.* https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/national-aboriginal-and-torres-strait-islander-health-survey/latest-release.

Australian Government. (2017). *Still waiting to be heard … Report on the Inquiry into the Hearing Health and Wellbeing* (Issue September). https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/HearingHealth/Report_1

Australian Government Department of Health. (2021). *National Aboriginal and Torres Strait Islander Health Plan 2021-2031*. https://www.health.gov.au/sites/default/files/documents/2022/06/national-aboriginal-and-torres-strait-islander-health-plan-2021-2031.pdf

Australian Health Ministers' Advisory Council. (2017). *National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017-2023*. https://www.niaa.gov.au/sites/default/files/publications/mhsewb-framework_0.pdf

Avery, S. (2018). *Culture is inclusion: a narrative of Aboriginal and Torres Strait Islander people with disability*. First Peoples Disability Network (Australia).

Avery, S. (2020). *Under-reporting of hearing impairment in the Aboriginal and Torres Strait Islander population*. Australian Bureau of Statistics. https://www.abs.gov.au/articles/under-reporting-hearing-impairment-aboriginal-and-torres-strait-islander-population#potential-under-reporting-of-long-term-hearing-impairment

Bailey, B. & Arciuli, J. (2020). Indigenous Australians with autism: A scoping review. *Autism*, *24*(5), 1031–1046. https://doi.org/10.1177/1362361319894829

Barney, J. (2021). Indigenous Ways of Knowing, Being and Doing, and Responding to NDIS Thin Markets. In M. Cowden & C. McCullagh (Eds.), *The National Disability Insurance Scheme* (pp. 245–255). Springer Singapore. https://doi.org/10.1007/978-981-16-2244-1

Bessarab, D. & Ng'Andu, B. (2010). Yarning About Yarning as a Legitimate Method in Indigenous Research. *International Journal of Critical Indigenous Studies*, *3*(1), 37–50. https://www.academia.edu/50119338/Yarning_About_Yarning_as_a_Legitimate_Method_in_Indigenous_Research

Deaf Indigenous Community Consultancy. (2015). *'Getting it Right' Project REPORT*. https://fdocuments.net/document/getting-it-right-project-report-national.html?page=1

Department of Social Services (2015) Principles to determine the responsibilities of the NDIS and other service systems, (2015). https://www.dss.gov.au/sites/default/files/documents/09_2021/ndis-principles-determine-responsibilities-ndis-and-other-service-1.pdf

Ferdinand, A., Massey, L., Cullen, J., Temple, J., Chamravi, D., Meiselbach, K., Paradies, Y., Baynam, G., Savarirayan, R. & Kelaher, M. (2019). Understanding disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities. In *Melbourne School of Population and Global Health. Centre for Health Policy*. https://www.lowitja.org.au/content/Document/PDF/NDIS_Evaluation_M_Kelaher_v2.pdf

Gilroy, J., Donelly, M., Colmar, S. & Parmenter, T. (2013). Conceptual framework for policy and research development with indigenous people with disabilities. *Australian Aboriginal Studies*, *2*, 42–58. https://doi.org/10.3316/informit.751842945817584

Green, S. (2017). Aboriginal people and caring within a colonised society. In *Critical Ethics of Care in Social Work* (pp. 139–147). Routledge.

Hollinsworth, D. (2013). Decolonizing Indigenous disability in Australia. *Disability and Society*, *28*(5), 601–615. https://doi.org/10.1080/09687599.2012.717879

House of Representatives Standing Committee on Health, A. C. and S. (2017). *Hearing Health and well being in Australia.* (Issue March). Commonwealth of Australia Official Committee Hansard. https://parlinfo.aph.gov.au/parlInfo/download/committees/commrep/cce029dc-6a28-400b-83aa-74ae0633f7b6/toc_pdf/Standing Committee on Health, Aged Care and Sport_2017_03_03_4807_Official.pdf;fileType=application/pdf#search=%22Hearing health and wellbeing in

Howard, D. (2020). The Importance of Physical Health: The Impact of Otitis Media on Hearing Loss and Education Outcomes. In: Midford, R., Nutton, G., Hyndman, B., Silburn, S. (eds) Health and Education Interdependence. Springer, Singapore. https://doi.org/10.1007/978-981-15-3959-6_3

Howard, D. & Barney, J. (2021a). *Cross Cultural Issues in the Work of NT Public Guardians*. This document has been prepared for the NT Guardians Office and by agreement only for use only in that office.

Howard, D. & Barney, J. (2021b). *Submission to Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. First Nations People and the NDIS Those that know mostly can't speak , those that can speak , mostly don't know* .

Howard, D., & Hampton, D. (2006). Ear disease and Aboriginal families. *Aboriginal and Islander Health Worker Journal*, *30*(4), 9-11.

Howard, D. & Lines, D. (2006). *Mixed Messages Cross-sultural managment in Aboriginal community controlled health services*. Phoenix Consulting. https://trove.nla.gov.au/work/34612319?q=Mixed Messages%3A Cross-cultural management in Aboriginal community controlled health services &c=book&versionId=45436373

Howard, D. & Saxton Barney, J. (2010). *Submission No 76 to NT Inquiry into Child Protection*. Northern Territory Government. https://cmc.nt.gov.au/__data/assets/pdf_file/0005/1017869/No76_Damien_Howard_and_Jody_Saxton_Barney.pdf?v=0.1.1

King, J. A., Brough, M. & Knox, M. (2014). Negotiating disability and colonisation: The lived experience of Indigenous Australians with a disability. *Disability and Society*, *29*(5), 738–750. https://doi.org/10.1080/09687599.2013.864257

Mathews, J. D. (1997). *Historical social and biological understanding is needed to improve aboriginal health.* Menzies School of Health Research. http://espace.cdu.edu.au/view/cdu:22068

Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L., Goode, A., Walton, H., Smith, L., Wei, Z. & Flavel, J. (2018). *Evaluation of the ndis final report*. https://apo.org.au/sites/default/files/resource-files/2018/04/apo-nid143516-1215586.pdf

Morris, P. S. (1998). A systematic review of clinical research addressing the prevalence, aetiology, diagnosis, prognosis and therapy of otitis media in Australian Aboriginal children. *Journal of Paediatrics and Child Health*, *34*(6), 487–497. https://doi.org/10.1046/j.1440-1754.1998.00299.x

NDIS. (2017). *Aboriginal and Torres Strait Islander Engagement Strategy*. https://www.ndis.gov.au/about-us/strategies/aboriginal-and-torres-strait-islander-strategy

NDIS. (2021). *Aboriginal and Torres Strait Islander Engagement Strategy, Progress Update*. https://www.ndis.gov.au/about-us/strategies/aboriginal-and-torres-strait-islander-strategy

Power, D. (2013). Australian aboriginal deaf people and aboriginal sign language. *Sign Language Studies*, *13*(2), 264–277. https://doi.org/10.1353/sls.2013.0000

Puszka, S., Walsh, C., Markham, F., Barney, J., Yap, M. & Dreise, T. (2022). Towards the decolonisation of disability: A systematic review of disability conceptualisations, practices and experiences of First Nations people of Australia. *Social Science and Medicine*, *305*(March), 115047. https://doi.org/10.1016/j.socscimed.2022.115047

