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Which Way? Experiences of Aboriginal and Torres Strait Islander People Who Are Deaf or Hard of Hearing Attaining Supports to Meet Their Interwoven Socio-Cultural, Health and Disability-Related Needs and Aspirations Within the Context of Australia's National Disability Insurance Scheme

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Which Way? Experiences of Aboriginal and Torres Strait Islander People Who Are Deaf or Hard of Hearing Attaining Supports to Meet Their Interwoven Socio-Cultural, Health and Disability-Related Needs and Aspirations Within the Context of Australia’s National Disability Insurance Scheme

Abstract

The life experiences of Aboriginal and Torres Strait Islander people who are Deaf or Hard of Hearing are often more complex than for Aboriginal and Torres Strait Islander people who are hearing, or non-Aboriginal Australians who are Deaf or Hard of Hearing. In turn, this can make engaging with and benefiting from policies and programs such as Australia’s National Disability Insurance Scheme (NDIS) more complex, particularly for individuals living in remote settings. To understand more about these complexities, yarnings were held with 15 Aboriginal and Torres Strait Islander NDIS participants who are Deaf or Hard of Hearing living in rural and remote communities in the Northern Territory. Alongside analysis of the emerging narratives, we analysed NDIS quantitative data to examine how NDIS plan budgets were being utilised by this group in comparison to the wider NDIS population. This paper’s focus is on yarning participants’ experiences navigating the NDIS to gain supports that meet their interwoven socio-cultural, health and disability-related needs and aspirations. We highlight that with sufficient cultural and communication supports, some yarning participants were able to effectively utilise their NDIS plan to attain supports to achieve positive socio-cultural, health and disability-related outcomes. However, the NDIS must enhance collaboration with participants, local communities and Aboriginal Community Controlled Organisations, disability service providers, and interfacing systems such as the health system, to develop more locally led solutions that empower Aboriginal and Torres Strait Islander Deaf or Hard of Hearing participants to achieve better outcomes.

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Ethics Approval Statement

Ethical approval to implement the project was granted through the University of Melbourne’s Human Research Ethics Committee (Ethics ID number: 13317.2.4).

Keywords

Deaf or Hard of Hearing, National Disability Insurance Scheme, Disability, Health Systems interface

Compounding Challenges of Unaddressed Hearing Loss

Improving ear health and access to supports for people experiencing hearing loss has long been identified as critical to closing the gap in health and social inequities experienced by many Aboriginal and Torres Strait Islander communities (Harkus et al., 2023; Parliament of the Commonwealth of Australia, 2017). For example, The National Aboriginal and Torres Strait Islander Health Plan (Australian Government Department of Health, 2021) and the National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing (Commonwealth of Australia, 2017) both 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; Commonwealth of Australia, 2017).

While inconsistent data on hearing loss remains a barrier to action, a recent systematic review by Pender et al., (2022) estimated that between 43-50% of Aboriginal and Torres Strait Islander people aged 15 years and older experience hearing loss (i.e., they are Hard of Hearing). Their review includes data identified in the 2018-2019 National Aboriginal and Torres Strait Islander Health Survey (NATSIHS), which for the first time offered a voluntary hearing test to those over seven years of age without a cochlear implant. Screening found 79% with a measured hearing loss (43% aged over seven years to 82% aged over 55 years) did not report having it long term (Australian Institute of Health and Welfare, 2022). The high prevalence of - often undiagnosed - hearing loss can largely be attributed to social determinants of poor health, which contribute to both endemic childhood middle ear infections and insufficient access to appropriate diagnostic and treatment services (Australian Institute of Health and Welfare, 2022; Parliament of the Commonwealth of Australia, 2017). While the exact number of Aboriginal and Torres Strait Islander people who are Deaf (i.e., severe or profound hearing loss, often since birth or early childhood) is not known, comparing data between the NATSIHS 2018-2019 and the National Health Survey 2017-2018 (adjusting for differences in the age structure), the Australian Bureau of Statistics (ABS) identified the rate of deafness to be 1.5 times the rate of deafness in non-

Indigenous Australians (14% and 9%) (ABS, 2019), for whom the condition is more likely to be attributed to aging and occupational sound hazards (Department of Health and Aged Care, 2023). Compared to non-Indigenous Deaf Australians, fewer Aboriginal and Torres Strait Islander people who are Deaf use Auslan. Instead, they may use a mix of culturally derived signing systems (Howard & Barney, 2017). Their communication with people unfamiliar with these systems is therefore very dependent on family and cultural connections (Bone et al., 2022; Green, 2018).

Hearing loss - combined with contextual circumstances associated with colonisation and limited access to culturally appropriate supports – significantly contributes to more disabling experiences and the subsequent higher prevalence of disability within Aboriginal and Torres Strait Islander communities in comparison to non-Aboriginal Australians (ABS, 2019; Puszka et al., 2022). Communication barriers, for example, can undermine participation across all life domains (e.g., education, health, employment, community participation, interpersonal violence) and influence interactions with social services such as the child protection and Criminal Justice Systems (Australian Government Department of Health, 2021; Australian Health Ministers' Advisory Council, 2017; Howard & Barney, 2021; Howard & Saxton Barney, 2010). Indeed, a high proportion (up to 90% in some settings) of Aboriginal and Torres Strait Islander people who are in custody are thought to experience hearing loss (Parliament of the Commonwealth of Australia, 2017; Vanderpoll & Howard, 2012).

Responding to the Impact of Hearing Loss Within the NDIS

Despite the high prevalence and the disabling impact of hearing loss among Aboriginal and Torres Strait Islander communities, Australia's National Disability Insurance Scheme (NDIS) policy and practice environment – including the NDIS Aboriginal and Torres Strait Islander Strategy - is all but silent on this issue (Gordon et al., 2019; National Disability Insurance Agency, 2017, 2021). Introduced in 2013, the NDIS aims to facilitate the full participation of people with disabilities within their communities and achieve their self-determined goals. Approximately 49,000 Aboriginal and Torres Strait Islander people currently receive NDIS individualised budgets (National Disability Insurance Agency, 2023), which in theory they can use to purchase services and supports that align with their needs and aspirations. For some, access to services and supports through the NDIS has improved over time and contributed to positive outcomes across various life domains (Ferdinand et al., 2021). For others, however, the limited supply of appropriate language interpreters and support to navigate through the complexity of NDIS processes can substantially limit access to choice and participation within the Scheme (Avery, 2018; Bailey & Arciuli, 2020; Howard & Barney, 2021; Phuong, 2017; Puszka et al., 2022; Trounson et al., 2022). Experiences and outcomes can be further complicated by the limited availability of culturally safe services, particularly for those living in very remote areas. This can force individuals to choose between remaining on Country or re-locating to access the services they need (Puszka et al., 2022; Trounson et al., 2022).

While there is a dearth of research on the NDIS experiences of Aboriginal and Torres Strait Islander people who are Deaf or Hard of Hearing, research on the experiences of non-Aboriginal Australian adults who are Deaf or Hard of Hearing highlights significant barriers to accessing information and navigating NDIS access and planning processes (Treloar, 2023). Limited recognition of the disability-specific needs of Deaf participants and their subsequent insufficient and sometimes inappropriate NDIS support has similarly been raised as a concern (Treloar, 2023).

Navigating Complexity of the NDIS and its Interfacing Systems

More broadly, NDIS participants must also navigate the complex boundaries of where the NDIS interacts with several federal, state and territory systems, including the health system (Foster, Hummel et al., 2022; Foster, Bowley et al., 2022; Yates et al., 2022). How effectively these interfacing systems function and interact with each other can positively or negatively impact individual outcomes (Yates et al., 2022). While the roles and responsibilities of each mainstream system and the NDIS have been determined and articulated within the Applied Principles and Table of Supports (Department of Social Services, 2015), confusion at the interface of these systems persists (Foster, Bowley et al., 2022; Yates et al., 2022). Within the health system, for example, health workers have a significant role in supporting individuals to access the NDIS, identifying and documenting eligibility criteria (e.g. including in diagnosing hearing loss and co-occurring conditions) and support needs whilst also ensuring these individuals gain and maintain access to health services and supports that fall outside of the remit of the NDIS (Gordon et al., 2019; Harkus et al., 2023). The administration associated with these responsibilities have been reported as both confusing and burdensome (Foster, Hummel et al., 2022; Gordon et al., 2019; McAllister et al., 2022). Disruption to, and the insufficient availability of, community services and supports since the roll-out of the NDIS has also been reported as undermining health pathways (e.g., delayed hospital discharge) (Foster, Borg et al., 2022; Gordon et al., 2019; McAllister et al., 2022). Further, poor integration and coordination of interfacing services and system have made it particularly difficult for Aboriginal and Torres Strait Islander NDIS participants - who often require interaction with multi-sectoral supports to address their complex needs - to access appropriate supports (Trounson et al., 2022). Yet the impact of these issues on NDIS participants who are also Deaf or Hard of Hearing remains poorly understood. Our paper aims to contribute to responding to this research gap. We present findings from a co-designed project exploring the experiences of Aboriginal and Torres Strait Islander NDIS participants who are Deaf or Hard of Hearing connected to rural and remote areas of the Northern Territory. This paper shares findings focused on their challenges and facilitators in navigating the NDIS and its interface with health systems to gain support to meet their interwoven socio-cultural, health and disability-related needs.

Situating our Research Team

Our project was co-designed and led by a Birri-Gubba and Urangan woman (Author JB). This lead author is also Deaf and has more than 35 years' experience working with, and has deep connections to, linguistically and culturally diverse Aboriginal and Torres Strait Islander people, their families and communities. These connections were fundamental to working with communities to gain cultural and community permissions to engage with yarning participants. JB's ability to communicate using multiple local sign languages enabled individuals from diverse language groups to participate using their local and preferred languages and share their experiences in a way that respects their ways of knowing (Drawson et al., 2017; Gilroy et al., 2013). Author JB led the resource allocation, design and implementation of the project, strongly guided the analysis and write-up, and leading the dissemination back to communities. The remaining research team members are non-Aboriginal researchers. One co-author (DH) has worked with JB for many years to support Aboriginal and Torres Strait Islander people who are Deaf or Hard of Hearing and the health, justice, education and disability workforces to enhance communication-responsive and culturally safe practices. Two other co-authors (AD and MH) have collaborated with JB and DH for several years on disability-related research with a focus on Aboriginal and Torres Strait Islander peoples. Co-author AD worked with Author JB to manage the project and gain University ethics approval. Three other co-authors (YY, GD, PS) have collaborated with this team on two NDIS-related research projects. Two co-authors (HL and YK) were postgraduate students supervised by research team members in research relevant to this project, as part of their Master of Public Health. The research team have a deep commitment to research that is led by and aligns with the priorities, needs and aspirations of Aboriginal and Torres Strait Islander peoples (National Health and Medical Research Council, 2018).

Methods

The approach adopted throughout this project aligns with the expected ethical national guidelines, as well as the key elements of Gilroy and colleagues' conceptual framework for research on disability with Aboriginal and Torres Strait Islander communities. As such, recognition of the impact of colonisation as a social determinant of both hearing loss and disability was central to our research and ongoing efforts to address these impacts (Gilroy et al., 2013; National Health & Medical Research Council, 2018). Yarnings – as a culturally respectful conversational approach to listening to people's "stories about their lived experiences, feelings, thoughts and ideas" (Bessarab & Ng'andu, 2010, p.38) were central to the project's methods as described below. Ethical approval to implement the project was granted through the University of Melbourne's Human Research Ethics Committee (Ethics ID number: 13317.2.4). The project was funded through the National Disability Research Partnership.

Recruitment

Participants were recruited through the community connections and networks of Author JB. Author JB regularly engages with several communities and individuals within these communities who are Deaf or Hard of Hearing through their work. Depending on each individual case and the relevant cultural protocols, Author JB engaged with individuals, Elders, Traditional Owners, parents, guardians and service providers to gain relevant permissions and consent for potential participants to participate in the project. A total of 15 participants then provided informed consent to participate in the project. While this number provided sufficiently rich data to explore the phenomena, the project team were also limited to this number by time and resourcing constraints.

Yarnings

A communication-responsive and linguistically accessible approach to yarning was adopted by the research team. Author JB led all yarnings, enabling all 15 participants (nine on whom were Deaf and six Hard of Hearing) to use their own language and modes of communication to engage in the mutually respectful and reciprocal sharing of stories and experiences in relation to the NDIS (Bessarab & Ng'Andu, 2010). Participants were recruited through (their) connections of Author JB on the unceded lands of Mparntwe (Alice Springs), Jawoyn/Dagoman/Wardaman Country (Katherine), Larrakia (Darwin), Waramungu Patta Country (Tennant Creek, Barkly) and Jabiru (Kakadu). Yarnings were conducted between October and November 2021. One participant yarned with the support of a family member. In some cases, and with appropriate permissions, further yarning was conducted with family members or close supports of participants to help clarify understanding. Yarning with each participant was organised at their preferred location and time. All yarnings were undertaken face-to-face. Several languages - often in combination - were used during the yarnings including Signed English, Basic Auslan, Key Word Sign, home sign, Yolgnu Matha, Warlpiri, Pitjantjatjara, Eastern Arrente, Galpu, Murrinh-Patha, Eastside Kriol, Modern Tiwi, Western

Arrarnta, Warumungu and Gurindji. Each yarning began with an Acknowledgment of Country, followed by socialising and sharing of recent news and experiences. The yarnings then shifted between social topics and more specific conversations around individuals' experiences within the context of the NDIS. Each yarning participant was reimbursed equally for their time through their preferred mechanism (e.g., fuel vouchers, food hampers, gift card).

JB recorded each session, translated, transcribed and then summarised transcripts 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 presented in this paper include 1) *Interwoven socio-cultural, health and disability-related needs and aspirations*; 2) *Navigating the NDIS and health system interface*; and 3) *Proper-way engagement within and across interfacing systems in support of better outcomes.*

Quantitative Methods

Alongside the yarnings, a tailored dataset containing de-identified individual-level information of NDIS participants on 31 August 2022 was obtained for analysis of information on participant plan budgets and spending on services and supports. Descriptive statistics are used to present the socio-demographic profile of active NDIS participants in Australia and the sub-set of participants in the Northern Territory. 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.

Findings

Overall, our findings highlight Aboriginal and Torres Strait Islander NDIS participants who are Deaf or Hard of Hearing living in the Northern Territory are more likely to be living in socio-economic disadvantaged areas when compared to the wider NDIS population.

Proportionally, they also received smaller NDIS plan budgets and spent less of it. Yarning narratives help provide an understanding of factors that may be contributing to these trends alongside challenges in having their interwoven socio-cultural, health, and disability needs and aspirations met within the context of the NDIS and its interface with the health system.

Quantitative Results

As of 31 August 2022, 40,178 or 7.3% of the 548,487 active NDIS participants across Australia and 50.3% of the 5,112 participants within the Northern Territory identified as Aboriginal and Torres Strait Islander people. Of the 2,571 Aboriginal and Torres Strait Islander NDIS participants residing in the Northern Territory, approximately 210 had ‘hearing impairment’ (NB this is the terminology used by the NDIS) recorded as their primary or secondary disability, and a further 290 had spent some of their funding on hearing or speech-related services. This latter group was included in our analysis 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 Aboriginal and Torres Strait Islander communities, we also note that these numbers are likely to be an underestimate of the number of Aboriginal and Torres Strait Islander NDIS participants who experience hearing loss, or who may be eligible for the NDIS, but are not currently accessing it.

Nationally, a higher proportion of Aboriginal and Torres Strait Islander NDIS participants were living in socio-economically disadvantaged areas (44.4% versus 28.8%). This gap between Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander NDIS participants was even more evident within the Northern Territory (41.6% versus 8.6%) and even greater among Northern Territory Aboriginal and Torres Strait Islander NDIS participants who were Deaf or Hard of Hearing (58%) (Table 1).

Table 1

Socio-Demographic and Disability-Related Profiles of Active Participants in Australia on 31 August 2022

National (N=548,487)

	Non-Aboriginal and Torres Strait Islander Australians	Aboriginal and Torres Strait Islander people	Aboriginal and Torres Strait Islander Deaf or Hard of Hearing participants [#]	Aboriginal and Torres Strait Islander participants with hearing or speech spending [+]
Number of participants	N=508,309	N=40,178	N=1,913	N=5,634
Age at data extraction N (%)				
0 to 6	79,223 (15.6)	7,915 (19.7)	274 (14.3)	1,015 (18.0)
07 to 14	130,964 (25.8)	11,346 (28.2)	447 (23.4)	2,857 (50.7)
15 to 18	41,591 (8.2)	3,711 (9.2)	190 (9.9)	559 (9.9)
19 to 24	41,245 (8.1)	3,808 (9.5)	199 (10.4)	312 (5.5)
25 to 34	44,406 (8.7)	3,772 (9.4)	216 (11.3)	267 (4.7)
35 to 44	40,671 (8.0)	3,181 (7.9)	141 (7.4)	179 (3.2)
45 to 54	48,774 (9.6)	3,243 (8.1)	187 (9.8)	206 (3.7)
55 to 64	59,151 (11.6)	2,589 (6.4)	195 (10.2)	195 (3.5)
65+	22,284 (4.4)	613 (1.5)	64 (3.3)	44 (0.8)
Women, N (%)	190,507 (37.5)	14,156 (35.2)	941 (49.2)	1,834 (32.6)
Living in socio-economically disadvantaged areas * N (%)	146,224 (28.8)	17,845 (44.4)	861 (45.0)	2314 (41.1)
Number of participants in Northern Territory	N=2,541	N=2,571	N<210	N<290
Northern Territory participants living in socio-economically disadvantaged areas *, N (%)	218 (8.6)	1,069 (41.6)	121 (58.2)	76 (26.5)

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.

An overview of the distributions of total plan size, spending, and utilisation in Australia and across the Northern Territory (Table 2). Aboriginal and Torres Strait Islander NDIS participants in the Northern Territory had larger plans in general relative to the national figure, but utilisations were lower. Within this, those who are Deaf or Hard of Hearing had comparatively lower plan budgets again. Utilisation was particularly low for participants with primary or secondary hearing loss identified in their plans (medians are 29% in the Northern Territory and 32% nationally).

Table 2

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	26.7k (16.9k, 60.2k)	14.9k (7.7k, 36.1k)	61.0 (38.0, 81.9)

service spending			
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.

Qualitative Findings

Overwhelmingly, yarnings highlighted the complex life trajectories experienced by participants, influenced by insufficient access to services and supports to navigate through the functional challenges that hearing loss can present, and within the context of persistent structural disadvantage. Capabilities to have their interwoven socio-cultural, health, and disability-related needs and aspirations met, were similarly hampered by the limited supply of culturally safe and communication-responsive information, supports and services within the context of the NDIS and its interfacing systems, as further described below. Within the findings, we have preferenced the voice of participants through sharing summaries of their yarning stories, noting the use of pseudonyms and changes to locations and other potentially identifying factors to protect confidentiality.

Interwoven Socio-Cultural, Health and Disability-Related Needs and Aspirations

Repeated early childhood ear infections compounded by limited access to health services were common among participants. Subsequent hearing loss was compounded by insufficient access to hearing (e.g., hearing aids, amplification devices) and communication supports (e.g., development of ways of communicating and language) which undermined participation across key life domains including education, employment and social participation. Coupled with factors such as removal from family and Country, these challenges often contributed to more complex life trajectories and interaction with other systems such as child protection and the Criminal Justice System.

Most participants experienced co-occurring physical health conditions (e.g., kidney disease, diabetes, hepatitis, musculoskeletal conditions, acquired brain injury), compromised social and emotional well-being, and drug and alcohol misuse (often associated with a history of complex trauma) and resulting in compounding functional disabilities. Yet access to coordinated, culturally safe and communication-responsive services and supports required across multiple systems were limited. Multifaceted barriers encompassed limited availability of interpreters, transport issues, discrimination, and fear of services due to previous negative experiences. Poor health literacy and confusing NDIS processes further contributed to participants' unmet health and disability-related needs, amplifying their experience of disability. The further away from services participants resided, the more this cycle of unmet needs was experienced.

Many participants were hopeful that the NDIS could improve their access to relevant services (e.g., counselling, allied health) and supports (e.g., cultural and communication supports to access relevant services, daily living support) to improve health and well-being outcomes. This proved effective for some: e.g., Sophie was able to "*attend sessions run by mental health services"* and "*working with the psychologist was able to address the issues of drug and alcohol consumption".* However, without sufficient coordination between systems and support to utilise NDIS plans in this way, sustaining access to required supports and positive health outcomes was challenging for many.

Elma's Story - Let Down by Just Another White Fella System.

Complex childhood experiences, compounded by alcohol misuse and homelessness contributed to Elma spending two years in custody. During this time, she was not provided with an interpreter and found it difficult to communicate with staff and other inmates. Upon release, Elma's access to the NDIS was requested by a public guardian. With interpreter support, Elma requested accommodation, technology to keep her safe, and help to find a job. She also requested support to visit family on

Country. But Elma struggled to stay engaged with NDIS supports. Her risk behaviours escalated and she was hospitalised. Her plan remained underutilised, and she was again in custody Without appropriate communication support and access to NDIS-funded supports, Elma was facing 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."

NDIS support to maintain or enhance connections to Country, family, community and culture were seen as vital to the health and well-being of participants and their families. While at times precarious, such connections were also central to participants fulfilling their cultural obligations to care for and be cared for by family. Over time, improved access to cultural and communication supports through the NDIS helped some participants advocate for more localised and individualised supports that enabled them to remain on Country and fulfil cultural obligations. Nonetheless, participants still remained fearful that plans would be changed in a way that undermined their aspirations.

Daniel's Story - Inconsistent Control Over How the NDIS Meets Needs and Aspirations.

With the support of an advocate, Daniel re-gained access to his lost NDIS supports after a hospitalisation in 2020. Daniel was subsequently moved off Country into disability accommodation. This was extremely distressing for Daniel and he soon moved back home. What he most wanted from the NDIS was support to fulfil his obligations to help care for family requiring ongoing support. With the aid of cultural and language interpreters, Daniel communicated these aspirations and received the training required to provide this care, in turn providing more stability for himself and his family. Daniel then wanted to start using his plan to try other things. But changes made to his recent plan, like employment 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."*

For several participants, the limited availability of culturally safe and communication-responsive health and disability services and supports on Country meant they had to move off Country to access services. Commonly, this had a detrimental impact on holistic physical, mental, emotional and spiritual well-being outcomes, particularly when these services were experienced as culturally unsafe and unaccommodating of complex communication needs, such as those experienced by Jana.

Jana's Story - Systemic Dislocation from Country.

Jana's public guardian applied for the NDIS on her behalf. She was moved into a disability accommodation setting with another woman that she had a poison relationship with. Not only was this distressing, but it also meant family stopped visiting. There was a constant stream of new staff, but Jana was glad when some staff move on: "They not nice me then. They bad me and this [photo of worker] *she hit me lots." Jana was moved to different accommodation, but with insufficient funding for cultural and communication supports. Jana is confused why she doesn't see the interpreter anymore as she thought they were friends and is increasingly distressed: "No, I go my home to* [name of Country]. *I no live here* [disability accommodation setting]. *This not my home. I want to go see my family and go to my school, see my friends."*

Navigating the NDIS and Health System Interface

Significant challenges in navigating the NDIS and interfacing systems often meant that most participants had experienced disruptions and barriers to accessing socio-cultural, health and disability-related supports. Navigating the NDIS and health system interface was particularly challenging for participants requiring higher levels or fluctuating support through tertiary health services. Key issues centred around disrupted access to disability-related supports and confusion over who was responsible for the provision of cultural and communication supports (e.g., sign language interpreters) and allied health services when accessing hospital care.

Participants were also frustrated and confused at the limitations placed on their NDIS plan and the disruption to existing reciprocal cultural obligations and arrangements around caring. Caring and receiving care were deeply entwined within kinship and cultural obligations and were highlighted by participants as an important component of their sense of self and belonging. Individuals rarely considered their care and caregiving needs in isolation from the needs of family and community and their own obligations to care for and support others. ‘Payment for care’ for external disability service provision, was also seen as undervaluing and/or disrupting with culturally endorsed care provided by family.

Raynor’s Story - Juggling Health and Disability Needs Across Interfacing Systems.

Raynor wanted her NDIS plan to help find safe housing, employment, and communication supports so she could better engage with the health system and family. Raynor’s health was deteriorating, yet her access to health services was complicated by confusion over which system was responsible for funding interpreters for appointments, and a high turnover of NDIS support workers to help her meet her health and disability-related needs when out of hospital. Raynor’s next plan focused on finding more suitable housing so that her Aunty and sister could care for her in a more culturally appropriate way. NDIS support to help Raynor visit Country also enhanced her sense of wellbeing.

Without sufficient advocacy and cultural supports to navigate the NDIS and health interface, reciprocal approaches to caring were often difficult to have recognised within the planning and coordination processes. This was felt most deeply by people closer to the end stage of life, where coordination between the NDIS and health systems to make this time as culturally safe as possible is critical.

Raynor’s next plan was reduced as she was seen to need more medical support rather than disability supports. Raynor 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." Upon review, the NDIS increased supports, enabling Raynor to engage fulltime nursing support in the home, but moving into care seems inevitable as her health deteriorates. She is also 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.*

'Proper Way' Engagement Within and Across Interfacing Systems in Support of Better Outcomes

More effective navigation to attain improved health and well-being outcomes was made possible when participants and their families had access to sufficient cultural and communication supports within their NDIS engagement and service utilisation. Sufficient supports enabled participants to have their needs and aspirations more clearly understood and articulated within NDIS planning, which ideally then enables individuals, their families and NDIS services to engage with the relevant interfacing systems.

Central to this was 'Proper way' engagement (i.e. meaningful engagement that respects and values the importance of kinship, culture and communication systems in engaging with and developing approaches to planning and delivery of supports), whereby participants, families, cultural guardians and advocates were respectfully involved in helping services develop a shared understanding of interwoven needs and aspirations and how these could best be met through the NDIS and/or other systems. For example, in Raynor's case, the provision of both appropriate language interpreters and cultural supports was paramount to the effective relaying and advocating of how the NDIS could best support Raynor as her health and end-of-life care needs increased. Appropriate interpreters and cultural supports were those who were proficient in the participant's preferred language and were able to communicate with them at a level they understood. There was also benefit in engaging interpreters that the participant knew and trusted, particularly those with whom they had a long-term relationship.

> *Daniel attended 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.*

Communication and cultural supports were also essential for individuals and families to work with services to better enable appropriately supportive service provision that nurtured connections to family, Country and culture. ‘Proper way’ engagement was particularly vital when supports on Country were no longer available and re-location was the only available option, i.e., when informal supports genuinely felt that due to age or other circumstances, they are no longer able to provide sufficient support to family members with complex disability.

Abi’s Story - Painting Again Through 'Proper Way’ Engagement.

> *Abi was brought up by her Aunties. She communicates using a local signing system. She is a very skilled artist, selling her work to support her families. Her Aunties worried they were no longer able to sufficiently support Abi and were hopeful the NDIS would help share in Abi’s care. During their first meeting, Abi and her Aunties were not asked about what might work best for them, leaving them very distressed and confused. Guardianship was appointed and Abi was moved into care. The Aunties were not sufficiently engaged in the process and could not visit the accommodation due to COVID restrictions. Abi was also not supported to participate in Sorry business when one of the Aunties passed away. Abi stopped painting because she felt her spirit was broken. A cultural advocate who had known Abi for a long time, facilitated Abi’s remaining Aunty to engage with the service provider. Abi communicated that she didn’t want to live in care. Her Aunty explained that supports were not available on Country, but that she would visit every few days and help teach the workers how to cook her way so Abi can eat right way.* It was through this ‘Proper

> *way' engagement that the cultural protocols to support Abi have been enabled. Her Aunty is now co-guardian and visits regularly and Abi is starting to visit and re-engage with her community. Abi started to paint again.*

Limitations

This was a small study funded through the National Disability Research Partnership pilot research scheme. With 15 yarnings completed and only in the Northern Territory, it cannot be seen as representative of the experiences of all Aboriginal and Torres Strait Islander NDIS participants who are Deaf or Hard of Hearing. We also note that we spoke to more individuals who are Deaf as opposed to Hard of Hearing. Given the sample size, it was not possible to further tease out the differing experiences between these two groups. We also focused the process on individuals and did not engage with service providers or policy makers. With more resources, garnering these perspectives within future research will help triangulate our findings.

Discussion

The challenging life circumstances experienced by many Aboriginal and Torres Strait Islander people who are Deaf or Hard of Hearing are entwined with the legacy of colonisation in deep structural disadvantage and social inequities. These contribute to the greater burden of ear disease, compounded by insufficient access to health services and hearing supports to overcome subsequent communication and social inclusion barriers, impacting their participation across all life domains (Avery, 2018; Phuong, 2017; Puszka et al., 2022; Trounson et al., 2022). Greater investment in addressing the underlying causes of poor ear health; enhancing community and services' awareness of hearing loss; improving access to diagnosis and treatment of ear disease; enhancing access to communication and social supports for people impacted by hearing loss are recognised; and improved data linkage to understand both the prevalence and impact of hearing loss are all urgently needed (Australian Government, 2020; Harkus et al., 2023; Pender et al., 2022). Nonetheless, more must be done to better support existing Deaf or Hard of Hearing NDIS participants who continue to experience substantial challenges in having their interwoven socio-cultural, health and disability-related needs and aspirations met. This requires immediate action by the NDIS and interfacing systems.

Enhancing Understanding of Hearing Loss and its Impact Within the NDIS

Our quantitative analysis highlighted that Aboriginal and Torres Strait Islander NDIS participants in the Northern Territory usually receive higher plan budgets compared to the general NDIS population. Yet comparatively, Aboriginal and Torres Strait Islander participants who were Deaf or Hard of Hearing received smaller and utilised less of their NDIS budgets than participants who were not Deaf or Hard of Hearing and Deaf non-Aboriginal and Torres Strait Islander NDIS participants. Our yarnings gleaned several interrelated reasons why this may be the case. Insufficient communication and cultural supports to help these participants learn about the NDIS and engage with NDIS staff and processes, often interacted with inadequate NDIS understanding of the complex and disabling life circumstances they experience. Within this, the issue of undiagnosed, unmanaged, or unrecognised hearing loss means it may not be considered by the NDIS when determining eligibility or support needs. Understanding hearing loss and its potential impact on interwoven socio-cultural, health, and disability-related needs and aspirations is essential within any system Aboriginal and Torres Strait Islander people are interacting with (Hearing Australia, 2022).

It is therefore paramount that governments and the NDIS invest in improving the knowledge and skills of the NDIS and interfacing systems workforce in relation to this understanding of hearing loss within Aboriginal and Torres Strait Islander communities. Improved knowledge and understanding would enable earlier recognition and diagnosis of hearing loss. Ideally, this would support health practitioners assisting eligible Aboriginal and Torres Strait Islander people to accurately and holistically, document their health and disability-related needs in determining NDIS eligibility, facilitating navigation of the NDIS and interfacing systems to connect with required services and supports. In turn, this would ideally ensure individuals with hearing loss had access to improved support across all life domains and systems (Harkus et al., 2023).

Addressing Interfacing System Complexities

Our research reflects that several yarning participants struggled to navigate the interface between the NDIS and health systems. Federal, state and territory governments have developed and agreed to apply principles to determine the responsibilities of the NDIS versus other interfacing mainstream systems (Department of Social Services, 2015). Ongoing intersectoral collaboration to further clarify roles and responsibilities specifically at the point of interface and particularly in relation to the funding of supports, is essential to achieving positive outcomes for individuals and the effectiveness of both the NDIS and health systems (Commonwealth of Australia & Department of the Prime Minister and Cabinet, 2023; Foster, Borg et al., 2022; Foster, Bowley et al., 2022; Houston et al., 2020; McAllister et al., 2022). Responding to some of these issues, the NDIA is progressively rolling out Health Liaison Officers (HLOs) to work with hospital staff to support NDIS eligible in-patients to navigate the NDIS and facilitate discharge to required services and supports (National Disability Insurance Agency, 2023). As this initiative is relatively recent and the number of HLOs in place is limited, the effectiveness of the role in improving the NDIS and tertiary health system interface is not yet understood. Further, it is unclear at this stage to what extent this role will be extended into regional and remote area tertiary health services. Nonetheless, ensuring HLOs are provided with sufficient training and resources to appropriately engage with Aboriginal and Torres Strait Islander Deaf or Hard of Hearing participants to understand their individual support needs, is essential for their capacity to appropriately liaise with tertiary health and disability service providers. Given the HLO role does not address issues within the primary health system, it is essential that the program learn from and engage with Aboriginal Disability/NDIS Liaison Officers that provide NDIS navigation support from within some Aboriginal Community Controlled Health Services.

Investing in Community-led Solutions

Even with an adequately trained NDIS, health and disability workforce, improving how Deaf and Hard of Hearing participants engage with and benefit from the NDIS and interfacing systems will remain difficult unless solutions can be found to address the dearth of trained interpreters and cultural supports who can help facilitate ‘proper way’ engagement. Building the capacity of existing interpreters to better support Aboriginal and Torres Strait Islander people with diverse linguistic and communication needs is part of the solution. Additionally, working with communities to build the capacity of existing individuals with knowledge and skills in communicating through local sign languages to take on paid roles within the NDIS and health sector should be explored.

Indeed, enhancing support for the design and delivery of Aboriginal and Torres Strait Islander-led solutions to provide localised health and disability support where people most need it is critical. The current limited supply of such localised solutions for Aboriginal and Torres Strait Islander people who are Deaf or Hard of Hearing contributes to individuals and families having to move off Country to access services. For many, this undermines their health and social and emotional well-being, particularly when services and supports accessed are not able to meet their cultural and communication needs and aspirations. Working with individuals and communities to identify strategies to encourage and enable community members to gain qualifications to provide paid NDIS supports within community should therefore be further pursued by the NDIA in partnership with community organisations. Exploring ways to enable more participants and their families to provide culturally endorsed Aboriginal and Torres Strait Islander ways of caring and receiving care within the context of the NDIS and its interface with health systems is similarly warranted. Indeed, one of our yarning participants was supported to utilise their NDIS plan to develop skills to provide care for family members in line with cultural obligations and reciprocal ways of caring. Learning from existing Aboriginal and Torres Strait Islander approaches and models to provide disability-related services and supports - such as has been achieved through the Machado-Joseph Disease foundation and Synapse - within communities is an essential next step (Charlesworth & Fien, 2022; Massey et al., 2018).

Conclusion

‘Proper way’ engagement with Deaf or Hard of Hearing Aboriginal and Torres Strait Islander people is essential to ensuring they gain equitable access to the NDIS. Within this, appropriate communication and cultural supports to navigate and benefit from the NDIS are required. However, the issue of undiagnosed, unmanaged, or unrecognised hearing loss means it may not be considered by the NDIS when determining eligibility or support needs. Identification, understanding and an effective response to the often complex and disabling life circumstances experienced by Aboriginal and Torres Strait Islander people who are Deaf or Hard of Hearing requires action by the NDIS and all interfacing systems. Ongoing intersectoral collaboration affirmed with governments' funding, needs to empower Deaf or Hard of Hearing Aboriginal and Torres Strait Islander people to establish locally led solutions that address their interwoven socio-cultural, health and disability related needs and aspirations.

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