

ORIGINAL ARTICLE OPEN ACCESS

Meeting the Needs of Aboriginal and Torres Strait Islander People With Hearing Loss in the Context of the National Disability Insurance Scheme

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Received: 27 May 2024 | **Revised:** 1 December 2024 | **Accepted:** 24 February 2025

Funding: This work was supported by the National Disability Research Partnership.

Keywords: Aboriginal and Torres Strait Islander | disability policy | health equity | hearing loss | National Disability Insurance Scheme

ABSTRACT

Hearing loss is a poignant issue in many Aboriginal and Torres Strait Islander communities and, without sufficient support, it can also contribute to disabling life experiences. The National Disability Insurance Scheme (NDIS) is intended to provide support to eligible people experiencing disability, however, to effectively serve this population, it requires a nuanced understanding of their lived experiences, support needs and how these needs can be met within the context of the NDIS. This article presents findings from a qualitative analysis of yarnings with 15 Aboriginal and Torres Strait Islander NDIS participants who are *deaf* or *hard of hearing*. The findings demonstrate the support needs of this group are diverse, encompassing socio-cultural, communication, health and disability specific support domains. The capacity of the NDIS to address these needs varied, from positive to sub-optimal outcomes. The study highlights the need for significant reform within the NDIS to better meet the needs of this population.

1 | Introduction

Aboriginal and Torres Strait Islander people experience disability at twice the rate of the general population (Australian Bureau of Statistics [ABS] 2019; Puszka et al. 2022). The high prevalence of ear disease and associated hearing loss is a significant contributor, with estimates of hearing loss ranging from ~43% to 50% among Aboriginal and Torres Strait Islander Australians aged 15 years and older (ABS 2019; Pender et al. 2022). Other estimates include 18%–40% in urban environments and 30%–90% within remote communities (ABS 2019; Avery 2018; Barney 2010). The high prevalence of ear disease and hearing loss results from complex, inter-related factors associated with socio-economic inequities, environmental conditions (e.g., crowded housing, air pollution and poor water quality) and biomedical risks (e.g., age, gender, low birth weight and malnutrition) (Burns and

Thomson 2013; Howard 2012). Inadequate access to health services, under-diagnosis and ineffective treatment have further contributed to higher rates of severe infections and more permanent hearing damage in this population (Howard 2012).

Research investigating the experiences of Aboriginal and Torres Strait Islander people with disabilities has comprehensively highlighted the key challenges and barriers faced by this population in relation to accessing and engaging with disability services. The research has built a strong narrative regarding the impacts of colonisation on service design and delivery, as well as the consequences of poor cultural competency (Puszka et al. 2022; Ferdinand et al. 2021; Phuong 2017; Gilroy et al. 2013; Avery 2018; Cooms et al. 2022). The enduring impact of colonisation, manifested in pervasive intergenerational trauma, remains deeply embedded in many social structures in Australia, including disability services,

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and continues to undermine the well-being of Aboriginal and Torres Strait Islander people (Avery 2018; Gilroy et al. 2013; Cooms et al. 2022). Research shows that Australian disability services are primarily based on western medical and social models of care, which often neglect the cultural and holistic needs of Aboriginal and Torres Strait Islander people and poorly align with their conceptualisations of well-being and disability (Phuong 2017; Puszka et al. 2022; Gilroy et al. 2013). This westernised model of care, combined with a lack of cultural awareness and competency in disability services, can lead to a plethora of harmful effects, including the use of culturally insensitive diagnostic processes, inadequate or inappropriate care plans, displacement from Country and community to access services and direct and indirect experiences of racism from service providers (Phuong 2017; Cooms 2022). These challenges contribute significantly to poorer care experiences and worse health outcomes for Aboriginal and Torres Strait Islander people (Ferdinand et al. 2021; Phuong 2017; Avery 2018; Puszka et al. 2022; Cooms et al. 2022). Moreover, this failure to acknowledge and respect cultural frameworks in service provision not only undermines quality of care and overall well-being outcomes, but also contributes to reinforcing colonial power structures, perpetuating the ongoing disadvantage and marginalisation of this population (Cooms 2022; Cooms et al. 2022).

Aboriginal and Torres Strait Islander people who are *deaf* or *hard of hearing* can face more complex and challenging life circumstances compared to non-Indigenous people with hearing loss (Avery 2018; Barney 2010; Howard 2012). This group is subject to a unique form of intersectional discrimination, attributed to their overlapping Aboriginal and Torres Strait Islander identity and disability status, which exposes them to both racism and ableism (Cooms et al. 2022; Avery 2018). The intersectionality framework highlights how these intersecting minority identities can intensify marginalisation and contribute to greater barriers in achieving equity (Crenshaw 1991; Avery 2018; Cooms et al. 2022).

The impacts of intersectional inequality further compound the challenges associated with hearing loss, manifesting in complex and significant social, economic and health challenges. Communication barriers, compounded by racial discrimination, can result in increased experiences of bullying, isolation, neglect and exploitation (Avery 2018; Barney 2010). Economic disadvantage is more pervasive in this cohort, marked by lower levels of educational attainment, employment and financial stability compared to non-Indigenous and non-disabled individuals (Avery 2018; Trounson et al. 2022; Ziadat and Al Rahmneh 2020). Mental health outcomes are also poorer, with higher rates of emotional distress, anxiety, trauma, depression and substance misuse (Barney 2010; Olusanya et al. 2019; Tripathi and Saranya 2022). Additionally, higher rates and risks of co-occurring physical health conditions for Aboriginal and Torres Strait Islander people can contribute to more disabling circumstances (Australian Institute of Health and Welfare [AIHW] 2022c). These complexities are further exacerbated by poorer access to disability, health and social services due to geographic, socio-economic and bi-cultural barriers (Avery 2018; Trounson et al. 2022). These systemic inequities and challenging experiences also increase the risk of interaction with the criminal justice system (Vanderpoll and Howard 2012). This complexity in life circumstances can influence how Aboriginal and Torres Strait Islander people with hearing loss may engage with or benefit from social policies and

programmes such as Australia's National Disability Insurance Scheme (Barney et al. 2022).

The National Disability Insurance Scheme (NDIS) was established in 2013 by the Federal Government of Australia and is administered by the National Disability Insurance Agency (NDIA) (Ferdinand et al. 2021). The NDIS allocates individualised funding to eligible participants to enable them to purchase the support they require to live an ordinary life, participate in their community and achieve their self-determined goals (Australian Government 2013; Townsend et al. 2018). To be eligible for the NDIS, an individual must have an impairment that is or is likely to be permanent; substantially reduces their functional capacity and capacity for social or economic participation and requires lifetime support (National Disability Insurance Agency [NDIA] 2022).

As of June 2020, approximately 1700 Aboriginal and Torres Strait Islander NDIS participants reported having a 'hearing impairment' (5.3% of the 32,400 Aboriginal and Torres Strait Islander NDIS participants), of which 1000 reported this as their primary disability (AIHW 2022a). Despite the high prevalence of hearing loss in this population, the NDIA's Aboriginal and Torres Strait Islander Engagement Strategy and the more recent progress update do not include reference to this participant cohort (NDIA 2017, 2022).

The lived experiences of Aboriginal and Torres Strait Islander people who are deaf or hard of hearing are not well represented in disability or social research or NDIS policy and strategies (Phuong 2017). To date, existing literature has focused on investigating the broader experiences of Aboriginal and Torres Strait Islander NDIS participants or the experiences of non-Indigenous NDIS participants who are deaf or hard of hearing. A study by Treloar (2021) explored the NDIS experiences of non-indigenous adults who are deaf or hard of hearing, highlighting that participants experienced significant difficulties in having their disability specific needs recognised by the NDIS, undermining access to relevant supports related to personal care, community participation and workplace support. Furthermore, poor understanding of hearing loss and the needs of participants by NDIS staff resulted in ineffective plans that did not meet participant needs or self-determined goals. Treloar (2021) suggested that the NDIS needs to improve its engagement with deaf communities to better understand their support needs and preferences.

Given the high prevalence of hearing loss among Aboriginal and Torres Strait Islander communities and the lack of research on their specific experiences within the NDIS, this article aims to address this gap by exploring the support needs of this population and examining their outcomes in the context of the NDIS.

2 | Method

2.1 | Research Design

This article presents findings from a secondary analysis of qualitative data collected through a project examining the NDIS plan utilisation experiences of Aboriginal and Torres Strait Islander NDIS participants who are deaf or hard of hearing in the Northern Territory (Barney et al. 2022). The study found that

participants encountered significant challenges in navigating the NDIS to address their needs. However, the primary analysis did not specifically examine the types of support participants needed or to what extent these needs were being fulfilled.

This secondary analysis aimed to investigate the support needs and outcomes of this participant cohort in the context of the NDIS. The research questions addressed by this article are:

1. What are the support needs of Aboriginal and Torres Strait Islander NDIS participants who are deaf or hard of hearing?
2. To what extent are these needs being met by the NDIS?

2.2 | Research Theory

This study employs an integrated methodological framework combining standpoint theory, an interpretivist paradigm and a phenomenological approach to examine the experiences of Aboriginal and Torres Strait Islander people who are deaf or hard of hearing.

Standpoint theory highlights the unique knowledge of marginalised groups, emphasising their lived experiences as critical insights into social structures and power dynamics (Harding 1991). By centring the voices and experiences of participants, this study aims to challenge dominant narratives and amplify perspectives that have historically been excluded or overlooked (Harding 1991). An interpretivist paradigm complements this approach by focusing on the subjective realities of participants as shaped by their socio-cultural and historical contexts and recognising that meaning is co-constructed through their interactions with the world (Pervin and Mokhtar 2022). Phenomenology deepens this understanding by exploring how participants then attribute meaning to their experiences as Aboriginal and Torres Strait Islander people who are deaf or hard of hearing, paying close attention to the complex interplay of personal, cultural and social dimensions that shape their realities.

This approach requires reflexivity on the part of the researcher to critically reflect on their positionality and how this influences their interpretations, ensuring that the study remains centred on the perspectives and lived experiences of the participants.

2.3 | Sample

Fifteen yarning sessions were conducted as part of the parent study. Several languages, often in combination, were used during the yarnings. These included Signed English, Basic Auslan, Key Word Sign, home sign, Yolŋu Matha, Warlpiri, Pitjantjatjara, Eastern Arrernte, Galpu, Murrinh-Patha, Eastside Kriol, Modern Tiwi, Western Arrarnta, Warumungu and Gurindji. The yarnings were translated and summarised by co-lead researcher Jody Barney for qualitative data analysis. The data set for this secondary analysis included the yarning transcripts of all participants ($n = 15$) involved in the parent study. Participant transcripts are identified using pseudonymous codes (e.g., P1, P2) to maintain confidentiality.

All study participants were located in the Northern Territory, aged 18 years and older, identified as Aboriginal and Torres Strait Islander and deaf or hard of hearing and held an NDIS plan. Participants were recruited through purposeful and snowball sampling methods, using the existing networks of Jody Barney. The demographics of participants are outlined in Table 1. Participant locations included Mparntwe (Alice Springs), Jawoyn/Dagoman/Wardaman Country (Katherine), Larrakia (Darwin), Waramungu Patta Country (Tennant Creek, Barkly) and Jabiru (Kakadu). The Rural, Remote and Metropolitan Area (RRMA) classification was applied to determine the location category.

2.4 | Data Analysis

This secondary data analysis provided a more in-depth investigation into aspects of the data set which were not addressed or only partially addressed in the parent study.

This study followed a reflexive thematic approach to qualitative analysis, using Braun and Clarke (2019) as a guide. This approach aligns with the paradigmatic assumptions of the study and ensures qualitative data are analysed in a way that acknowledge the subjectivity of participants' experiences, while also recognising the reflexive influence of the researcher's interpretations.

Multiple readings of the transcripts were undertaken and major themes were identified deductively by drawing on the research questions and broader literature. An inductive process was then used to identify additional emerging themes. A thematic coding framework was developed following these deductive and inductive processes and discussion with co-authors, shown in Table 2. The framework was utilised to analyse the full data set. Transcripts of the summaries of the yarning sessions were transferred into NVivo 12 for assistance with data management for analysis.

The thematic analysis process involved drawing meaning from participants' lived experiences that could add to the knowledge and understanding of the phenomena being investigated. During

TABLE 1 | Participant demographics.

Variable	Number or average	
Disability	Deaf	$n = 9$
	Hard of hearing	$n = 6$
Age	Mean = 39 years	
Gender	Female	$n = 7$
	Male	$n = 7$
	Sister-girl	$n = 1$
Location	Remote	$n = 7$
	Rural	$n = 5$
	Metropolitan	$n = 2$
	Incarcerated	$n = 1$

the analysis, the major themes identified revolved around key support domains and participant outcomes within the context of the NDIS.

2.5 | Ethical Considerations

This research was conducted in alignment with the National Health and Medical Research Council guidelines and the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research, emphasising integrity, respect and community collaboration (National Health and Medical Research Council (NHMRC) et al. 2018; AIATSIS 2020).

The parent project received ethics approval (reference number 13317-31505) from the University of Melbourne Human Research Ethics Committee, and approval was amended to extend to this secondary analysis. The informed consent of participants was obtained in the parent study and was extended to this supplementary study.

The parent project was co-designed and led by Jody Barney, a proud Birri-Gubba and Urangan woman who is deaf and has over 35 years of experience working with culturally and linguistically diverse Aboriginal and Torres Strait Islander communities. Her deep cultural connections were essential for obtaining community permissions, facilitating ethical engagement and ensuring the project reflected community values and cultural integrity. Her ability to communicate using multiple local sign languages enabled participants to share their experiences in their preferred languages, honouring their ways of knowing (Gilroy et al. 2013). The lead investigator guided all stages of the project, including the design, implementation, analysis and dissemination of findings back to communities. This ensured the research followed a co-production model reflective of cultural values and ethical rigour. While the research team also included non-Indigenous members, including the primary author of this supplementary study, all members were deeply committed to conducting research that aligned with the priorities and aspirations of

Aboriginal and Torres Strait Islander peoples (AIATSIS 2020; NHMRC et al. 2018).

The outcomes of this research have directly contributed to the development of online resources designed to promote culturally safe and communication responsive service delivery for Aboriginal and Torres Strait Islander NDIS participants, ensuring tangible benefits for the communities at the heart of this study.

3 | Results

The results of this study explore the support needs of Aboriginal and Torres Strait Islander people who are deaf or hard of hearing in the Northern Territory and their outcomes in the context of the NDIS. The findings demonstrate that the support needs of participants were diverse and varied based on their unique capabilities, goals and priorities as well as the complexity of their broader life circumstances.

Participants in this study reported a wide range of complex and challenging life experiences. Participant stories highlighted past and present experiences of domestic violence, sexual assault, co-occurring disabilities, mental and physical health conditions, housing insecurity, financial hardship, interactions with the justice system, removal from family and displacement from Country. These contextual factors, along with variability in participant demographics (see Table 1) related to disability status, geographical location and gender, are likely to influence their support needs and outcomes within the NDIS. While this study does not focus on exploring how these factors shape participants' experiences, their significance should not be overlooked when considering the findings. Understanding these dynamics is crucial for interpreting the diversity of needs and outcomes among participants and for informing future research and practice.

Identified support needs were categorised into five key domains: (1) communication support; (2) social and cultural support; (3) health and well-being related support; (4) disability specific and daily living support and (5) capacity building enabling economic participation. Outcomes of focus included if and what support participants received through the NDIS and whether participants' self-determined needs and goals were met. The findings reveal that the ability of the NDIS to meet participant support needs varied significantly and outcomes fluctuated between individuals and across different support domains.

3.1 | Communication Support

Communication support was a fundamental need for all participants. This included support to communicate with others as well as to improve personal communication skills. For example, participants wanted 'interpreters to help [them] around the community' and 'to engage with service providers' as well as 'technology to assist in communication' (P11). For participants wanting to improve their personal communication skills, they expressed a desire to 'learn more English' (P6),

TABLE 2 | Coding framework.

Nodes	Sub-nodes
Support needs	<ul style="list-style-type: none"> • Social and cultural needs • Communication needs • Economic participation needs • Health and wellbeing related needs • Disability specific and daily living needs
Outcomes in the context of the NDIS	<ul style="list-style-type: none"> • Support received • Support not received <ul style="list-style-type: none"> • Needs met • Need not met • Positive outcomes • Negative outcomes

increase ‘cultural signing for context and comprehension’ (P1) and increase capacity for ‘verbal utterances, signs and written text’ (P1).

Participants’ communication support needs were met to varying degrees through their NDIS plans. Positive outcomes were more likely to be achieved when participants were provided with interpreters and assistive communication devices or technology. Participants explained that ‘access to communication helped develop better relationships’ (P2) and enabled them to ‘express more regarding [their] life’ (P2). Participants with goals to improve their personal communication skills often received sufficient support to enable this. For example, P8 ‘attended TAFE 1 day a week to learn Auslan’ and P9 ‘was able to engage services that taught at home and tutored herself and her children to develop their Auslan skills’. However, several participants lacked sufficient support and expressed that they experienced ‘huge unmet needs around [their] participation and communication access’ (P7). P9 explained that ‘the hours of interpreting were used up in the first 3 months’ and ‘when requesting interpreters for hospitals and justice services she was denied’. Furthermore, when communication support was available, it was not always effective or accessible to all participants. For example, P2 explained that the ‘use of interpreters on screen was problematic’ and other participants identified difficulties related to poor access to technology and a limited understanding of how to use digital communication tools and platforms.

3.2 | Social and Cultural Support

Participants highlighted the importance of social inclusion and the need for support to engage with others and participate in their communities. Participants wanted NDIS support to improve their ‘capacity to engage with other people’ (P12), to ‘increase communication and socialisation’ (P12) and to ‘participate in community activities’ (P12). Some participants also wanted support with building relationships, including opportunities ‘to make friends’ (P13) and have ‘lasting friendships with family’ (P9).

The ability for the NDIS to support social engagement and participation varied. Some participants achieved positive social outcomes through engagement with support workers, behavioural practitioners, cultural consultants and interpreters. With this support, participants were able to more actively and effectively engage in ‘activities in community’ (P6), such as attending ‘day programmes’ (P1), which provided them with opportunities to ‘make friends and see family’ (P2). However, some participants felt the NDIS did little to support their social engagement and community participation, explaining they received ‘limited and restrictive supports in seeing family’ (P14) and have become ‘increasingly isolated’ (P14) despite receiving an NDIS plan that was intended to enable social participation.

Support to meet cultural needs and obligations was similarly important, with the majority of participants expressing a desire to build and maintain their connection to culture, community and Country. Participants emphasised the importance of having support to enable them to meet their cultural goals and obligations within their family and broader community. Key examples

were NDIS support to ‘attend ceremonies and cultural events’ (P2), to ‘visit family and go on Country’ (P3), to ‘complete Sorry Business’ (P8) and ‘to support [their] family in a strong cultural way’ (P11).

The capacity for the NDIS to support participants in their connection with culture, family, community and Country was largely inconsistent. For several participants, the NDIS fell short in its ability to support cultural needs. Participants explained that they experienced ‘little opportunity to be involved in ceremony’ (P12) and were not supported to engage in cultural ‘protocols’ (P10), such as ‘Sorry Business’. The lack of support to meet cultural needs was particularly relevant for participants living in supported independent living (SIL) accommodation, which was often located off Country, further contributing to a disconnect from culture and community. The inability of the NDIS to meet participants’ cultural needs, and in some cases, displacing participants from Country and community, contributed to poorer levels of engagement and poorer overall outcomes. However, a small number of participants were able to use their NDIS plans to achieve positive outcomes in this domain. Some participants engaged with cultural consultants, interpreters and support workers who were able to more effectively understand and support their specific cultural needs and obligations and were able to support their participation in activities that enhanced their cultural connectedness. This included support for ‘cultural visits home’ (P1), ‘being on Country with family’ (P1), spending time ‘with elders doing cultural activities’ (P6) and support to ‘attend ceremony and participate in Sorry Business’ (P2).

3.3 | Health and Well-Being Related Support

Support to manage health and well-being related needs was a key theme, encompassing improving access to services, improving health literacy and lifestyle behaviours and support to engage with interfacing services outside of the NDIS. Physical health needs varied considerably between participants, with some wanting support to manage complex conditions including ‘kidney disease, liver disease, diabetes, atrophy and hepatitis’ (P3) and others wanting support to ‘maintain a healthy lifestyle’ (P2) and achieve simple fitness goals. Support requests included ‘access to good medical support and allied health services’ (P8), support ‘to go to the gym’ (P2), ‘in-home hospital care’ (P11) and improved access to ‘OT and speech therapy’ (P11).

The capacity of participants to use their NDIS plans to address their physical health needs varied. Some participants experienced positive outcomes, including improved access to services like ‘home hospital care’ (P11) and ‘allied health services such as physio and podiatrist’ (P11) as well as NDIS support to access resources to help them adopt a ‘healthy lifestyle’ (P2). The NDIS was also able to provide support to participants to improve their engagement with mainstream providers through the provision of ‘Aboriginal supports and interpreters’ (P5) to attend appointments. However, a small number of participants were left without sufficient support due to the poor coordination of care at the interface between the NDIS and the health system. For example, P3 is living with several complex co-morbidities; however, ‘follow-up medical interventions were not sustained, and no support was provided’ by the NDIS or the health system.

Similarly, mental health support was desired by participants in their effort to 'improve mental health well-being' (P11), cope with 'emotional distress' (P9) and address complex issues related to 'drugs and alcohol' (P8) and 'trauma, abuse and neglect' (P9). Participants wanted support to access psychologists and 'counselling services' (P8) as well as 'specialist supports' (P9) to address these challenges.

Participants' mental health needs were able to be met to varying degrees within the context of the NDIS. Services and practitioners engaged to provide support included counselling services, psychologists and mental health support workers. Other services and providers included forensic psychologists, recovery coaches, family violence services and alcohol and other drug services. Many participants experienced positive outcomes engaging with these providers. For example, P8 was able to 'attend sessions run by mental health services' and through 'working with the psychologist was able to address the issues of drug and alcohol consumption'. However, some participants did not receive sufficient mental health support, particularly in times of grieving or following traumatic events. For example, P3 expressed that following a traumatic house fire 'she wasn't provided counselling, she wasn't provided with support'. There were often gaps where the NDIS did not facilitate connecting participants with the support they needed to address mental health challenges.

3.4 | Disability Specific and Daily Living Support

Disability specific and daily living support needs were identified by most participants. This included support with daily living activities, functional capacity-building, access to specialist disability accommodation and engagement with hearing support services. Participants seeking 'support for daily activities' (P13) required assistance with tasks such as cooking, cleaning, shopping, gardening, transport and driving. Other participants preferred a capacity-building approach with a focus on 'learning to be independent' (P6). Some participants wanted assistance 'finding a place to live' (P6). Several participants also emphasised the need for better access to allied health and hearing support services to assist them with their disability specific needs, including 'speech therapy to learn how to use hearing aids' (P1).

In most instances, the NDIS enabled participants to receive support to meet their disability specific and daily living support needs. Providers engaged to deliver support for daily living needs included SIL services, support workers, allied health professionals and home maintenance services. Positive outcomes included the provision of '2:1 support' (P11) and 'home help' (P11) to enable participants to 'stay at home safely' (P11). Some participants were able to develop new skills and build their capacity to live more independently, including learning how to 'clean and cook' (P14) and 'go shopping' (P14). Undesirable outcomes in this domain were primarily related to housing support and SIL services. This included some participants having 'no access in applying for housing' (P11), experiencing frequent 'shifts in SIL provision' (P7) and experiencing harmful and 'restrictive practices' (P7) from SIL staff. In cases where participants received accommodation support, this often came at the expense

of having to move off Country and away from community. The impact of disrupting these connections was often detrimental to their well-being.

3.5 | Capacity Building Enabling Economic Participation

Capacity building enabling economic participation was a key support need identified by participants. This included support to improve financial literacy, pursue or maintain education or vocational training and to engage in employment. Support to improve financial literacy included learning how to manage money, navigate cultural humbugging practices (i.e., making unreasonable or excessive demands for money or material possessions from one's family or other connections) and working towards simple savings goals. Educational pursuits included improving 'literacy and numeracy skills' (P8) and attending 'TAFE classes' (P8). Additionally, several participants wanted NDIS support to 'find meaningful employment' (P9).

Many participants who sought to develop their capacity for economic participation were able to do so with the support they received through their NDIS plans. Participants were supported to engage with disability employment agencies and education providers, and with the aid of support workers and interpreters, they were able to achieve their goals in this area. Positive outcomes included participants being supported to attend vocational institutes and participate in 'literacy and numeracy training' (P8) as well as support to find paid work, which enabled participants to meet their 'obligations for employment and generate savings' (P9).

4 | Discussion

This study investigated the experiences of Aboriginal and Torres Strait Islander NDIS participants who are deaf or hard of hearing in the Northern Territory, with a focus on understanding their support needs and examining their outcomes in the context of the NDIS. The findings revealed that the support needs of this cohort are diverse and complex. The ability of the NDIS to address these needs varied considerably, resulting in both positive and sub-optimal outcomes for participants across different support domains.

The findings of this study provide valuable insight into the varied support needs of Aboriginal and Torres Strait Islander people who are deaf or hard of hearing. These include support for social and cultural participation, communication, economic engagement, physical and mental health and daily living and disability specific support. These findings reflect the far-reaching implications associated with hearing loss and highlight the need for comprehensive support that considers the holistic impact of hearing loss throughout a person's life (Howard 2012; Burns and Thomson 2013). As expected, the identified support needs also aim to address the various intersecting and complex life challenges experienced by this population, as previously described in the literature, such as those related to their Aboriginal and Torres Strait Islander identity as well as their

disability status. Participants expressed a strong desire to overcome challenges related to social and cultural participation and reduced opportunities for economic engagement and achievement (Avery 2018; Trounson et al. 2022; Barney 2010; Ziadat and Al Rahmneh 2020). These challenges were often related to bi-cultural needs and communication barriers, which presented another key support area identified by participants (Avery 2018). Participants also highlighted the importance of managing co-occurring physical and mental health conditions, which have been extensively highlighted by prior research (AIHW 2022c; Olusanya et al. 2019; Tripathi and Saranya 2022). Finally, the findings demonstrate that participants wanted support to overcome previously identified accessibility barriers related to health, disability and social support services (Avery 2018; Trounson et al. 2022).

The results of this study provide insight into the goals and priorities of Aboriginal and Torres Strait Islander people with hearing loss. This is an area that has had little coverage in the existing body of literature. In particular, the results highlight the importance of maintaining a sense of culture, connection, belonging and identity. These constructs have been identified by prior research as important protective factors within Aboriginal and Torres Strait Islander cultures that build strength and resilience and promote well-being (Avery 2018; Hunter et al. 2021). Achieving these goals is supported through the ability for participants to connect with community, Country and family; perform their cultural responsibilities and obligations; achieve greater capacity for socio-economic participation and function successfully in daily life (Barney 2010; Avery 2018). Furthermore, the support needs and goals identified by participants in this study reflect the holistic and multifaceted conceptualisation of health and well-being that is held by many Aboriginal and Torres Strait Islander people more broadly and is often overlooked or disregarded by westernised systems (AIHW 2022c). This view recognises that health and well-being are not focused on the elimination or negation of disability, illness or injury, but that it is a holistic consideration of a person's entire physical, mental, social, emotional, cultural and spiritual well-being and the inter-connectedness of these dimensions (Avery 2018; AIHW 2022b).

The NDIS model continues to predominantly reflect western medical and social models of disability services (Puszka et al. 2022; Avery 2018). Such models can be seen to perpetuate a deficit-based narrative of disability, defining disability in terms of deficit relative to an idealised human condition and aiming to minimise its perceived negative impacts (Avery 2018; Cooms 2022). The medical model frames disability as a bio-medical issue to be 'cured' or mitigated, while the social model attributes the deficit to environmental barriers and aims to remove these (Avery 2018). However, neither model aligns with Aboriginal and Torres Strait Islander peoples' understandings of disability or recognises the potential of a strengths-based or affirmative approach to disability support (Avery 2018; Puszka et al. 2022; Phuong 2017). Alternative frameworks, such as those proposed by Avery (2018) and Gilroy et al. (2020), advocate for strengths-based approaches grounded in cultural inclusion. These models seek to improve the human experience through positive affirmation, leveraging social practices and structures

that focus on individual and collective strengths (Avery 2018; Gilroy et al. 2020).

The variability in the capacity of the NDIS to meet the support needs of Aboriginal and Torres Strait Islander people who are deaf or hard of hearing was evidenced by the fluctuating outcomes experienced by participants across various life domains. While some participants were able to achieve positive outcomes in relation to having some of their needs met to varying degrees, others were left without sufficient or culturally appropriate support that at times resulted in detrimental outcomes. Inadequate support across one or more domains resulted in experiences of reduced opportunities for social, cultural and economic participation, exacerbated mental and physical health conditions, increased engagement in harmful behaviours, sometimes leading to interactions with the justice system and continuing accessibility barriers to systems and services. Furthermore, significant constraints within how the NDIS and support services currently engage with Aboriginal and Torres Strait Islander participants who are deaf or hard of hearing meant that even when support was provided, it often came at the cost of disruptions to critical connections with family, community, Country and culture. As such, there is still a considerable discrepancy between what participants expect from the NDIS and the outcomes experienced in actuality by this cohort.

The inability of the NDIS to provide participants with adequate support for their diverse and unique needs reflects systemic failures that mirror the historical marginalisation of Aboriginal and Torres Strait Islander people with disabilities. The inability of participants to access bi-culturally appropriate services within the NDIS highlights the ongoing struggle of navigating a system that has long been inadequate in addressing the complex, intersectional needs of this cohort. These systemic gaps not only reflect the enduring legacy of colonisation, characterised by the dislocation from Country, culture and self-determination, but also demonstrate how the NDIS may further perpetuate these colonial impacts. While the NDIS is designed to empower individuals through choice and control, its reliance on neoliberal principles that emphasise market-driven solutions and individual responsibility may overlook the broader cultural, social and historical needs of Aboriginal and Torres Strait Islander people with disabilities (Phuong 2017; Edwards 2024). This neoliberal approach can exacerbate existing inequalities by failing to provide the necessary support to marginalised communities (Edwards 2024). For this cohort, the NDIS does not yet function as a tool for empowerment, but rather reinforces historical patterns of exclusion and discrimination. The frustration voiced by participants when their needs were unmet or when cultural disconnects were exacerbated supports their deep mistrust in a system that continues to marginalise them (Puszka et al. 2022; Avery 2018; Phuong 2017; Gilroy et al. 2016). Despite facing significant challenges, participants in this study demonstrated remarkable resilience and strength in navigating a complex and often unresponsive system. Their ability to adapt and persist, despite systemic barriers, highlights their profound strength, resilience and hope (Avery 2018).

At present, the NDIA has not formally recognised Aboriginal and Torres Strait Islander people who are deaf or hard of hearing as a priority group in its Aboriginal and Torres Strait Islander

Engagement Strategy (NDIS 2017). Furthermore, the results suggest the NDIS is not adequately resourced to accommodate the great diversity of these communities, including the complexity of their needs and preferences. This reinforces barriers to acknowledging the support needs of this group, accurately reflecting these in NDIS plans, having appropriate and effective support services available that can meet their needs and having the capacity to engage in a way that is culturally appropriate. The NDIS Act states that the NDIA is tasked to 'develop and enhance the disability sector' (s 118(1) (c), NDIS Act), but the results of this study, and those preceding it, suggest that it currently lacks the ability relating to bi-cultural competency and service and support accessibility (Phuong 2017).

This study demonstrates that significant reconfiguration of the NDIS's approach, design and service provision is essential to give Aboriginal and Torres Strait Islander people with disability, their families and communities the best chances of achieving service equity (Phuong 2017). The NDIS must prioritise the development of policies, strategies and services tailored to the specific needs of this population and help to address the complex interplay of social, economic, environmental, cultural and political factors that shape their experiences of disability and access to support (Phuong 2017). Decolonising disability services is essential to this transformation, requiring the incorporation of Aboriginal and Torres Strait Islander people's values and practices while also acknowledging the historical context and ongoing effects of racism in service design and delivery (Puszka et al. 2022; Phuong 2017; Cooms et al. 2022). This process necessitates Aboriginal and Torres Strait Islander governance and reform leadership while also relinquishing ineffective westernised models and mainstream solutions (Puszka et al. 2022). Collaborative partnerships with Aboriginal and Torres Strait Islander disability communities are critical, positioning them as knowledge holders and leaders in the design and delivery of solutions that are accessible, effective and culturally responsive (Puszka et al. 2022). These steps are crucial to ensuring that the NDIS adopts a holistic, culturally inclusive and strengths-based approach, meeting the needs of this group in a culturally respectful, responsive and empowering way.

4.1 | Strengths and Limitations

This secondary analysis is of data derived from a small sample of Aboriginal and Torres Strait Islander NDIS participants who are deaf or hard of hearing living across multiple areas in Australia's Northern Territory. While small, the sample size was sufficient to examine the phenomenon of interest and address the research questions posed. Additionally, the diversity in participant age, ability, gender, socio-economic circumstance and location strengthens the external validity of the findings. It is important to acknowledge that the sample included more individuals who identify as deaf than those who identify as hard of hearing. This imbalance could impact the generalisability of the findings given that the experiences of these two groups can differ. A strength of this study lay in the prioritisation of the voices of Aboriginal and Torres Strait Islander people who are deaf or hard of hearing and in the richness of the data analysed, which provides a comprehensive understanding of the diverse experiences of this population.

5 | Conclusion

This study provides insight into the multifaceted and diverse support needs of Aboriginal and Torres Strait Islander people who are deaf or hard of hearing and their outcomes in the context of the NDIS. The findings emphasised the complex intersectionality for this population, in relation to both race and disability and how this is reflected in their support needs and experiences engaging with the NDIS. The study revealed the support needs of this participant cohort are varied and complex and the ability of the NDIS to address these varied considerably. The findings of this study and the existing body of research suggest that significant reform is required by the NDIS to better meet the needs of this population. The NDIS should seek to collaborate with Aboriginal and Torres Strait Islander people with hearing loss and their communities to facilitate the design and delivery of policies and strategies that are culturally responsive and effective.

Author Contributions

Hannah Lack: conceptualization, formal analysis, writing – original draft. **Jody Barney:** conceptualization, funding acquisition, investigation, methodology, writing – review and editing. **Alexandra Devine:** conceptualization, investigation, funding acquisition, writing – review and editing, methodology. **Marie Huska:** conceptualization, investigation, funding acquisition, writing – review and editing, methodology. **Damien Howard:** writing – review and editing, conceptualization, investigation, methodology, funding acquisition.

Acknowledgements

We acknowledge the traditional owners of the lands and nations on which this project was implemented and pay our respects to the elders past and present. We acknowledge all Aboriginal and Torres Strait Islander people whose experiences were drawn upon in this project and pay respect to their families, kin and Country across Australia. The data collection for this project was funded by the National Disability Research Partnership. The contents presented, however, do not necessarily reflect the views of the funder. Open access publishing facilitated by The University of Melbourne, as part of the Wiley - The University of Melbourne agreement via the Council of Australian University Librarians.

Conflicts of Interest

The authors declare no conflicts of interest.

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