

‘It’s all on me’: Exploring Experiences of Parents with Hearing-Impaired Children in the  
NDIS and Impact on Family Wellbeing

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**DECLARATION**

This report contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this report contains no materials previously published except where due reference is made.

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**Angela Asimakopoulos**

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### Abstract

Parents of hearing-impaired children face unique experiences and challenges, including emotional responses to diagnosis, adapting to their child's needs, and overall changed life circumstances. They face complex decisions surrounding hearing devices, communication, and education. Additionally, such parents in Australia have been confronted with another prominent challenge, navigating the National Disability Insurance Scheme (NDIS). The scheme is in its infancy, with numerous issues reported. Therefore, ongoing research into NDIS experiences is warranted. No research to date has explored the impact of the NDIS on the wellbeing of families with hearing-impaired children, a noteworthy endeavour for future research.



## **1. Background: Parents of Deaf/Hearing-Impaired Children**

### **1.1 Unique Experiences and Challenges**

Like parents of children with disabilities, parents of deaf or hearing-impaired children often enter new territory and embark on a journey characterised by unique experiences and challenges. This is particularly true for hearing parents. These challenges have been extensively documented across the literature and will be discussed throughout this thesis. Research exploring experiences of those raising hearing-impaired children has substantial value in identifying areas where families require further support (Jackson, Traub, & Turnbull, 2008). Nonetheless, it is only in the last few decades that professionals have begun to recognise the complex experiences of this population (Feher-Prout, 1996). Consistent with the deaf literature, (e.g., Herman & Morgan, 2011), this literature review will utilise the terms “deaf” and “hearing-impaired” interchangeably.

### **1.2. Diagnosis and Subsequent Experiences**

Over 90 percent of hearing-impaired infants are born to hearing families (Moores, 2001). Often hearing parents have little to no experience, or prior contact, with hearing-impaired persons and consequently, lack understanding of the implications encompassing deafness (Feher-Prout, 1996). Resultantly, and widely demonstrated across the literature (e.g., Calderon & Greenberg, 1999; Ebrahimi, Mohammadi, Pirzadeh, Shamshiri, & Mohammadi, 2017; Jackson et al., 2008; Young & Tattersall, 2007), hearing parents can experience significant stress in response to learning that their child is deaf, in adapting to their child’s unique needs, and changed life circumstances. Hearing parents can also be overcome by intense or mixed emotions like denial, grief, guilt, and anxiety (Feher-Prout, 1996; Kurtzer-White & Luterman, 2003). Therefore, the diagnosis is a critical incident (Ebrahimi et al., 2017), eliciting strong reactions. However, in addition to the initial reactions, and adjustments accompanying this event, to inform decision-making, parents encounter large volumes of new knowledge and issues related to hearing loss (Feher-Prout, 1996).

### **1.3. Decision-Making Responsibilities**

Upon diagnosis, parents are faced with making a myriad of complex and pivotal decisions on behalf of their deaf child which can ultimately influence their future (Porter, Creed, Hood, & Ching, 2018). This comprises decisions about technological hearing devices, communication modality, and education (Jackson et al., 2008; Porter et al., 2018). Over the last few decades, the choices available have expanded, making decision-making more challenging and overwhelming for parents (Feher-Prout, 1996). To help facilitate rational and informed decision-making to address their child's needs, parents must also face the challenge of accessing support services and liaising with professionals familiar with deafness, including audiologists, speech pathologists, sign-language interpreters, Ear, Nose and Throat (ENT) specialists, and Teachers of the Deaf (Jackson & Turnbull, 2004; Simpson, Stewart, & Douglas, 2016).

#### **1.3.1. Devices**

Parents receive information regarding hearing devices to assist their child (Kecman, 2019). There are two routes parents can undertake, dependent on the severity of deafness or preference: digital hearing aid amplification and cochlear implantation (Kurtzer-White & Luterman, 2003). Hearing aids are digitally programmable devices that amplify residual hearing (Kurtzer-White & Luterman, 2003) and the latter, a surgically implanted device that provides a sensation of hearing through direct auditory nerve stimulation (Feher-Prout, 1996). However, choosing between the two can be a source of parental stress (Jackson & Turnbull, 2004) and is rarely an easy decision (Kurtzer-White & Luterman, 2003). Although cochlear implantation is suited to those who do not benefit from auditory amplification, the invasive nature of the surgery has sparked contentious debate (Jackson et al., 2008; Kurtzer-White & Luterman, 2003). Other reasons rendering device selection difficult for parents include that cochlear implantation destroys remaining traces of residual hearing in the implanted ear

(Jackson et al., 2008) and controversies around implantation in the Deaf Community (Kurtzer-White & Luterman, 2003).

### **1.3.2. Communication**

During early childhood intervention, parents are confronted with decision-making around the child's communication modality (Kurtzer-White & Luterman, 2003). Parents can choose from oralism and sign-language (Jackson & Turnbull, 2004). Some parents prefer their child to develop speech and to employ this method to communicate (Jackson et al., 2008). Alternatively, parents choose to have their child sign, with some parents undertaking the challenge of learning sign-language (Jackson et al., 2008). Others choose a mixture of both modalities; bilingualism (Porter et al., 2018). Nevertheless, the choice regarding which communication modality to prioritise can be stressful, emotional and challenging for parents due to firmly held attitudes, biases and varied professional opinions on how to optimise language acquisition (Kurtzer-White & Luterman, 2003).

### **1.3.3. Education**

After early childhood intervention, parents make choices about their deaf child's education (Feher-Prout, 1996). Parents are encouraged to choose a path that maximises their child's potential to lead a fulfilling life (Luckner, 2010). However, this decision is seldom uncomplicated due to debates surrounding deaf education, generating uncertainty and stress (Jackson & Turnbull, 2004). Some parents enrol their child in a mainstream school with in-classroom adjustments explicitly tailored for their child's needs like seating arrangements, noise reduction, in-classroom interpreters, note-takers, microphone FM technology and visiting Teachers of the Deaf (Lloyd, 2013; Luckner, 2010; Watson & Parsons, 1998). Some mainstream schools may have specialist hearing-impairment units that offer deaf students additional academic supports (Lloyd, 2013). Others may enrol their child in a specialist deaf school (Power & Hyde, 2002).

Furthermore, while parents are supported by professionals in their decision-making, the decisions they make on behalf of their deaf children are unquestionably a source of stress and are fundamentally challenging.

#### **1.4. Additional Experiences/Challenges/Stressors**

In addition to the experiences above, hearing parents may experience other stressors and potential obstacles related to their child's disability. A common obstacle constitutes communication barriers. Following diagnosis, parents may stress because they lack direction regarding how to efficiently communicate with their child without barriers (Feher-Prout, 1996). In fact, Quittner et al. (2010) uncovered communication difficulties as a highly ranked stressor for parents of deaf children. Some studies capture other potential stressors. In Jackson et al. (2008), parents reported that elevated stress levels were associated with accumulating information; concerns about the child's safety and health; financial and time demands; and worries regarding their futures. Some parents also expressed worry that their children would not be presented with equal opportunities in life. The theme of parental concerns and worries about the future is consistent across studies (e.g., Ebrahimi et al., 2017; Jackson et al., 2008). Research has identified that another challenge for parents may include the experience of stigmatisation, isolation, rejection and social exclusion from peers (e.g., Ebrahimi et al., 2015; Foroughan, Movallali, Salimi, & Asad-Malayeri, 2007; Gregory, Bishop, & Shelton, 1995). Moreover, the literature has demonstrated that a deaf child has the potential to impact many domains of family life, including supports for the child, parenting, family resources and interactions (e.g., Jackson et al., 2008; Jackson & Turnbull, 2004). Therefore, it is evident that the impact of a child's deafness has far-reaching effects on hearing parents and families.

#### **1.5. Heterogeneity and Complexity**

While deafness in the family is an emotionally-charged experience for hearing parents, it is important to note that not all experiences are negative and distressing; some are positive and inherently diverse. The literature has highlighted that the implications of a deaf child in a hearing family are not as detrimental as once thought (Feher-Prout, 1996), where the diagnosis was likened to a death experience (Luterman, 1999). For instance, personal reports have suggested that the adjustment to deafness can facilitate parental personal growth (Feher-Prout, 1996). It is also suggested that the child's unique needs and increased demands can augment family relationships through improving quality time and bonding (Jackson et al., 2008). Diagnosis can provide parents relief and reassurance, shorten grieving and motivate them to seek out information and solutions (Kurtzer-White & Luterman, 2003; Young & Tattersall, 2007).

Another important consideration is that the experiences and perspectives of deaf parents of deaf children can differ from those of hearing parents. While hearing parents are more likely to appraise their child's diagnosis as a highly stressful event, hearing-impaired parents typically welcome it (Moore, 2001), or express indifference (Jackson et al., 2008). Decision-making may be less strenuous for deaf parents since they have experience living with hearing-impairment and therefore, have access to resources unknown to hearing parents (Feher-Prout, 1996). Deaf parents may also react more negatively to cochlear implants, especially if they identify with Deaf Culture (Feher-Prout, 1996). Therefore, research suggests that the implications of a deaf child can vary according to the experience and hearing-status of the parent. However, many studies tend to only capture the views and experiences of parents with typical hearing themselves (e.g., Jackson et al., 2008; Simpson et al., 2016). Thus, qualitative research in this area exploring the voices of deaf parents is lacking and should also be considered.

Overall, while there are shared challenges unique to these parents and their children, one must not generalise and must acknowledge that all experiences are inherently complex and heterogeneous.

### **1.6. Importance of Research into this Population**

Research has extensively documented the complex experiences and challenges pertaining to this population of hearing parents and their deaf children. As demonstrated by the literature, it is undeniable that these parents require additional support, particularly those new to deafness in the family. Plentiful evidence suggests they undergo an exhaustive journey to address their child's needs. Generally, the literature has illustrated issues parents may go through and highlighted extra stressors related to their child's disability. However, in addition to these pre-existing experiences and challenges, in recent years, Australian parents of hearing-impaired children have been confronted with another prominent challenge; navigating the newly introduced National Disability Insurance Scheme (NDIS).

## **2. The NDIS**

### **2.1. What is the NDIS?**

The NDIS was launched in Australia in 2013 and represented a tremendous transformation in Australian disability history (Reddihough, Meehan, Stott, & Delacy, 2016). The national roll-out of the NDIS is managed by the National Disability Insurance Agency (NDIA; Lakhani, McDonald, & Zeeman, 2018). The NDIS constitutes a shift from a disability service-centred approach to an individualised approach. Previously, disability services received funding to administer specialised supports to individuals (Productivity Commission, 2011). The NDIS replaces this system, by instead offering personalised funding packages to consumers (Simpson & Baldwin, 2017), and ensures a lifetime's support and care for individuals with a congenital or acquired disability up until the age of 65 years (Collings, Dew, & Dowse, 2016; Tracey, Johnston, Papps, & Mahmic, 2018; Walsh &

Johnson, 2013). This includes personalised funding packages for families/caregivers of children with disabilities (Simpson & Douglas, 2016).

## **2.2. Why a NDIS?**

The NDIS' implementation was based on evidence that Australian disability services were underfunded, fragmented, inequitable and primarily centred around the needs of service providers and not individuals (Productivity Commission, 2011; Reddihough et al., 2016). Before the NDIS, most Australians with disabilities did not receive individualised funding and were given little choice. Resultantly, the purpose of the NDIS is to permit individuals with disabilities, carers and their families more choice and control over services and supports (Reddihough et al., 2016; Warr et al., 2017). The NDIS aims to increase independent lifestyles and promote inclusion within the community (Commonwealth of Australia, 2013; Reddihough et al., 2016). Most notably, the NDIS intends to improve the wellbeing and quality of life (QoL) for individuals with disabilities, their carers and family members (Mavromaras, Moskos, Mahuteau, & Isherwood, 2018; Reddihough et al., 2016). Therefore, the NDIS is an ambitious initiative that strives to better the lives of those affected by disability.

## **2.3. NDIS Processes**

NDIS funding packages are available to those who fulfil eligibility criteria including evidence of a permanent and significant disability, and entitlement to disability-related care/support (Simpson et al., 2016; Warr et al., 2017). Once approved, individuals, carers, or family members are required to meet with a NDIS planning officer to formulate an individualised support plan shaped by their goals (Reddihough et al., 2016; Simpson et al., 2016). This also means that where the person is a child, the individualised plan can include the family's needs (Tracey et al., 2018). After assessment, individuals can choose from various flexible options such as selecting from a wide range of service providers or self-

managing funds. Irrespective of the option chosen, the need for funded support is subject to reassessment, particularly as circumstances change (Reddihough et al., 2016).

#### **2.4. Self-Directed Funding**

The NDIS is Australia's first self-directed funding (SDF) scheme or model (synonymously individualised funding) for disability (Lakhani et al., 2018; Simpson et al., 2016). SDF models allocate funds to people with disabilities or their carers so that they can purchase personalised disability supports (Ottmann, Laragy, & Haddon, 2009). These have been successfully adopted and comprehensively researched internationally (Reddihough et al., 2016). Studies on international SDF models have highlighted positive outcomes, particularly higher autonomy amongst adult consumers (e.g., Glendinning et al., 2009). This enhanced autonomy has been linked to significant positive impacts like better family relationships (Poll & Duffy, 2008); lower reliance on others (Adams & Godwin, 2008); improved QoL (Head & Conroy, 2005); increased positivity, confidence and motivation (Arksey & Kemp, 2008); and improved service satisfaction (Glendinning et al., 2008). Similarly, the literature has indicated that individualised funding processes facilitate self-determination, choice and control (Reddihough et al., 2016; Simpson et al., 2016). Overall, evaluations of these models have demonstrated more positive outcomes for both individuals with disabilities and their families in contrast to traditional service-based models (Productivity Commission, 2011).

However, SDF outcomes of children with disabilities and their families are under-researched, with most studies conducted on adults with disabilities (Simpson & Douglas, 2016). Additionally, the few studies reporting outcomes of children with disabilities generally do not focus on one disability, rather, they include multiple disabilities (e.g., Dew et al., 2013; Ottmann et al., 2009; Simpson & Douglas, 2016). Therefore, more focused research is warranted on the outcomes of SDF models for specific disability populations of children and



their families, such as the hearing-impaired, so that their support needs can be better identified and potentially addressed more effectively (Simpson et al., 2016).

## **2.5. Research into NDIS Experiences**

The NDIS is still in its infancy, where similar international schemes have been developed over more extended periods (Warr et al., 2017). Hence, much more work is needed to ensure the NDIS' effectiveness for specific disability groups. Research is only starting to explore the experiences, perspectives and impacts of the scheme on its participants and those involved in their care. The current NDIS literature maps reoccurring consumer experiences and challenges. Findings from NDIS research to date have been mixed, presenting both positive and negative accounts.

### **2.5.1. Positive Accounts**

Positive accounts include that self-managing has brought an influx of opportunities (Simpson et al., 2016); high NDIA satisfaction (Reddihough et al., 2016); positive planner experiences (Collings, Dew, & Dowse, 2019; Purcal, Hill, Meltzer, Boden, & Fisher, 2018); and perception of supports as adequate (Foster et al., 2016). In a study by Ranasinghe, Deepa, White and Russo (2017), parents of children with developmental disabilities reported that the NDIS registration process, accessing funds, and correspondence with the NDIA was not difficult. Most of these parents also reported satisfaction with both the NDIS and NDIA. Similarly, Warr et al.'s (2017) qualitative study exploring the experiences of people with disabilities in the NDIS and family members/carers, revealed positive experiences. This included diminished service waiting times, and increased funding to access required resources and services (Warr et al., 2017). Parents/carers of young children with disabilities, who chose to self-manage, reported appreciating the opportunity to customise packages, along with the increased ability to select workers and services. Additionally, several participants reported increased choice regarding the access or provision of services, and some

reported high satisfaction with NDIS processes. For instance, some participants outlined that the NDIS provided a clearer and less stressful means of combining services compared to what they had formerly experienced. Moreover, experiences of increased choice or control over supports has also been reported in other literature (e.g., Collings et al., 2019; Mavromaras et al., 2018).

### **2.5.2. Negative Accounts/Criticisms**

Conversely, the NDIS has been frequently delineated as a “complex system” (Warr et al., 2017, p. 5) fraught with numerous issues. Staffing issues are commonly reported, including a lack of continuity (Mavromaras et al., 2018; Simpson et al., 2016; Warr et al., 2017); planner staff being untrained, unqualified, inexperienced, or lacking knowledge of the disability sector (Warr et al., 2017); and high staff turnover (Mavromaras et al., 2018; Warr et al., 2017). Often participants report failure to be notified of their planner changing (e.g., Collings et al., 2019; Simpson et al., 2016). These issues have been shown to adversely impact individuals. For instance, people with disabilities or carers have experienced frustration over engaging with new planners (Warr et al., 2017) which often required them to repeat their circumstances (Simpson et al., 2016). Staffing issues have also disrupted application processes (Simpson et al., 2016), prevented consumers from establishing effective relationships with staff and slowed progress towards desired outcomes (Mavromaras et al., 2018).

Challenges surrounding advocacy also arise. People with disabilities often need to self-advocate, or family members/carers advocate on their behalf regarding support needs, so that appropriate funding is allocated (Mavromaras et al., 2018; Warr et al., 2017). People have expressed the importance of effectively articulating needs, bringing in supporting evidence, and being prepared to confidently build a strong case (Simpson & Baldwin, 2017; Simpson et al., 2016). Some have had to explain the impact of the disability to underinformed

planners (Simpson et al., 2016; Warr et al., 2017). Consequently, advocacy has been described as stressful (Simpson et al., 2016; Warr et al., 2017).

Lack of equity regarding access to funding, services, support, and outcomes, has been identified as another issue (e.g., Mavromaras et al., 2018; Purcal et al., 2018). This includes inconsistencies in funding allocation, where some families have been declined funding for services other families have had funded (Simpson et al., 2016). Additionally, approval waiting times vary, with some individuals reporting lengthy waitlists for essential services or inexpensive products (Warr et al., 2017). Hence, some individuals experience substantial delays. Communication processes and messages have been described as inconsistent and, in some circumstances, there have been high service demands with limited supply (Warr et al., 2017). Therefore, some people are unable to have timely access to necessary services. In fact, findings from Warr et al. (2017) suggested the NDIS does not pay enough attention in promoting equity.

People have also encountered the challenge of information overload. NDIS participants and family members/carers have described being confronted with overabundant information, causing them to feel overwhelmed (Simpson & Baldwin, 2017; Simpson et al., 2016; Warr et al., 2017). In Warr et al. (2017), many people recounted feeling overwhelmed by the large volumes of information and available choices. Thus, the NDIS is an information-dense scheme, where participants and families/carers often struggle to navigate, process, prioritise and apply information (Warr et al., 2017).

The literature has highlighted that current and prospective participants and families/carers report insufficient knowledge, limited understanding, or challenges in understanding the system (e.g., Howard, Blakemore, Johnston, Taylor, & Dibley, 2015; Hui, Cortese, Nikidehaghani, Chapple, & McCombie, 2018). For instance, Lakhani et al. (2018) found that although prospective participants attended NDIS information seminars, they

reported a lack of understanding and disclosed confusion. Over half exhibited uncertainties around how the NDIS would impact them and service provision. Participants in Warr et al. (2017) raised concerns that an inability to understand the system, its requirements and costs, disadvantaged people with disabilities. For instance, they may not be able to articulate requests appropriately and therefore, not have their needs sufficiently addressed. Such issues have been attributed to the scheme's complexity, poor communication networks, contradictory information, difficulties yielding accurate and reliable information (Warr et al., 2017), and information presented in indigestible formats (Simpson et al., 2016). Lack of understanding has also led to under-utilisation of plans (Hui et al., 2018), thereby placing individuals at risk of missing out on necessary supports and experiencing unimproved outcomes (Lakhani et al., 2018).

Other issues reported in the NDIS experience include: carers feeling unsupported or unheard; communication-related issues; self-management hardships; onerous paperwork; dissatisfaction with approval and planning processes; concerns that views are overlooked; complaints about the online portal system; time-consuming administrative requirements; and no perceived increases in opportunities and choice (e.g., Mavromaras et al., 2018; Purcal et al., 2018; Simpson et al., 2016; Warr et al., 2017). For instance, in Warr et al. (2017), administrative problems overrode positive changes in many participants' experiences. This, in turn, detrimentally impacted individuals', families' and carers' physical and emotional wellbeing.

Overall, the literature's mixed findings highlight that the NDIS has issues and is still evolving. It also suggests that the NDIS is failing to address some consumers' needs, which can affect their QoL, health and wellbeing (Warr et al., 2017). Consequently, there is an emphasised need for ongoing research into NDIS experiences and outcomes "across and

within disability groups and over time” to gain invaluable insights into how the scheme is proceeding (Simpson et al., 2016, p. 157; Warr et al., 2017).

## **2.6. Gaps in the Literature**

While there is evidence of a growing body of research into NDIS experiences, perspectives and issues, it is still small in scale, containing little published empirical studies. These studies have identifiable gaps. They tend to explore a variety of disability groups together, rather than focus on one disability type (e.g., Foster et al., 2016; Howard et al., 2015; Lakhani et al., 2018; Tracey et al., 2018; Warr et al., 2017), sometimes highly skewed towards one group. For instance, while Lakhani et al.’s (2018) study, covered a range of disabilities, the findings primarily (98.5%) captured the perspectives of those with intellectual disability (or carers). This research also tends to collectively consider the experiences or perspectives of consumers with a disability and their family members/carers (e.g., Foster et al., 2016; Lakhani et al., 2018; Warr et al., 2017). That is, it integrates multiple perspectives and does not focus on one cohort’s experiences. For example, Warr et al. (2017) conducted interviews with people with disabilities, family members, and carers. Like SDF studies, some NDIS-related studies have not accounted for the experiences of children with disabilities and their families/parents (e.g., Collings et al., 2019; Foster et al., 2016). Additionally, these studies have often excluded disabilities like hearing-impairment (e.g., Foster et al., 2016; Ranasinghe et al., 2017; Warr et al., 2017) or have not explicitly focused on a hearing-impaired population (e.g., Howard et al., 2015; Lakhani et al., 2018; Mavromaras et al., 2018; Tracey et al., 2018). For instance, while Warr et al. (2017) included various disability types, they did not incorporate the experiences of hearing-impaired individuals or their family members.

Overall, scholarly research into the NDIS and the hearing-impaired is lacking. Not much is known about the experiences of this group in the context of the NDIS aside from

small published evidence indicating that the NDIS has increased the demand of Auslan sign-language interpreters and induced an interpreter shortage (Jackson, 2015; Massa, Withers, Leggett, Dirago, & Yoon, 2015); a high service demand with limited supply (Warr et al., 2017). Therefore, this particular disability group has received little attention in research thus far on the NDIS, despite anecdotal evidence that the scheme is failing to meet the needs of such individuals and their families. As previously discussed, there is also an absence of focused research into NDIS experiences. This includes the experiences of parents with hearing-impaired children in the NDIS.

To the best of our knowledge, there are only two published studies: one quantitative (Simpson & Baldwin, 2017) and one qualitative (Simpson et al., 2016), explicitly focusing on parents (or synonymously, caregivers) of deaf children and the NDIS.

In Simpson and Baldwin (2017), the quality of online information concerning the NDIS for caregivers of hearing-impaired children was analysed and evaluated. They found that only 8 percent of websites about hearing loss directed caregivers to information about the scheme. Although the quality of NDIS information was found to be good, caregivers' accessibility was limited. This was raised as worrisome as caregivers seeking supports online, would need to possess pre-existing knowledge of the NDIS or rely on referrals to be guided to NDIS information so they can obtain its benefits. However, due to the recency of the scheme, and since the NDIS is still evolving, the findings of this study may be outdated; it is therefore likely that caregivers' accessibility to this information has since advanced. Moreover, this study did not account for these caregivers' lived experiences of the scheme.

Simpson et al. (2016) utilised the NDIS as a case study to explore the experiences of families with young hearing-impaired children partaking in a SDF scheme. Specifically, they explored how parents/caregivers navigated the initial NDIS planning appointment by interviewing 11 parents recruited from specialist education services. The analysis uncovered

central themes in caregivers' lived experiences: lack of support; advocacy; managing information; and reliance on external experts. Like current NDIS research into consumer experiences, they identified both positive and negative accounts. Most parents professed that their primary source of support was the child's intervention service, whom they respected and had developed a close relationship. They expressed little connection with the NDIS itself; they felt a lack of interest and found correspondence difficult. As demonstrated in NDIS literature, participants reported: interacting with planners lacking a background in disability; lack of continuity; and feeling unsupported/unheard. Parents also experienced frustration over regurgitating their child's circumstances with each new appointment or planner. This was regarded as an extra source of burden in addition to other stressors. Parents also felt inclined to be exceptional advocates for their child to increase their chances of receiving vital resources and avoiding rejection. Many were faced with the unexpected task of leading sessions and explaining the impact of hearing-impairment. Advocacy was outlined as daunting, anxiety-inducing, and identified as an additional source of burden in their lives. Parents reported feeling overwhelmed by the plethora of information provided by the NDIS at various stages. They also found it difficult to relate this information to their family's circumstances or hearing loss. Before initial NDIS contact, most parents reported relying heavily on advice and guidance from hearing loss experts, pre-existing professionals in their child's life, and the child's intervention service. Parents reported that these external supports mitigated stress and aided focus on other priorities. A small fraction of parents reported positive NDIS experiences like developing good relationships with NDIS staff/planners and appreciation for financial support.

However, Simpson et al. (2016) only considered the experiences of families already joined in with specialist education/early intervention services, of whom they had established strong relationships, received pre-existing supports, and obtained assistance regarding NDIS

processes. They did not account for the experiences of caregivers unaffiliated with such services; those left to their own devices to seek out information and support. The findings were also constrained to experiences of parents with typical hearing with deaf children who only communicated orally. Thus, future research should also represent the views of hearing-impaired parents and children who communicate via sign-language or a mixed modality. Data was also collected in 2015 in two trial sites, and the NDIS has progressed since. Therefore, with the ever-evolving NDIS, parents' experiences are subject to transformation, so ongoing research into this area is valuable.

### **3. Wellbeing and the NDIS**

As mentioned earlier, one of the NDIS' aims is to improve the wellbeing and QoL for individuals with disabilities, their carers and family members (Mavromaras et al., 2018; Reddihough et al., 2016). A component of the NDIS evaluation report (Mavromaras et al., 2018) examined the trial sites' wellbeing and QoL outcomes. More specifically, it aimed to understand the extent to which the inception of the NDIS has improved wellbeing.

Quantitative surveys and qualitative interview data uncovered that overall, the NDIS led to modest wellbeing improvements in individuals with a disability. However, the findings vary. For instance, no evidence of the NDIS increasing the wellbeing of families/carers of individuals with disabilities was found. Rather, parents of children with disabilities reported a negative impact on wellbeing. The research also found that the NDIS did not have an impact on child participants' wellbeing. Therefore, the results suggest that not everyone has experienced increased wellbeing resulting from NDIS participation; the benefits of the scheme are unevenly distributed and not shared by all.

Varied wellbeing was found to be related to factors like age, disability type, time in the NDIS, whether service demands were addressed, and education levels. Despite improvements induced by the NDIS, the evaluation found that the reported wellbeing of



participants and families/carers remained considerably below the national average. However, the report is broad in scope and multi-faceted. For instance, it has not explored the specific outcomes for the hearing-impaired, parents of children with hearing-impairments or their families. Indeed, no research to date has explored the impact of the NDIS on the wellbeing of families with hearing-impaired children. Although one study (Simpson et al., 2016) examined the experiences of parents with hearing-impaired children, an empirical study that integrates an exploration of wellbeing is yet to be seen. Given the implications discussed earlier and throughout this literature review, this is a noteworthy endeavour for future research.

Moreover, qualitative research in this area would allow parents of hearing-impaired children an opportunity to share their experiences of the NDIS, its impact on their family's wellbeing, and ultimately have their voices "heard". This is important because persons involved in the NDIS are rarely presented with this opportunity (Warr et al., 2017). Furthermore, such research holds additional value as it may offer implications for NDIS service providers and the NDIA like highlighting gaps in service provision or delivery; offering insights into improving NDIA services; and suggesting potential new areas of inquiry.

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‘It’s all on me’: Parents of Hearing-Impaired Children’s NDIS Experiences and Wellbeing

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#### Author Note

This article is intended for potential submission to the American Annals of the Deaf. However, the journal guidelines do not specify a minimum or maximum word count. Therefore, the current manuscript length adheres to the Master of Psychology thesis’ research report component length requirement of between 5,000 and 8,000 words (including in-text references, figures and tables).

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### Abstract

Previous literature has shown that parents of hearing-impaired children are confronted with unique experiences, challenges and additional stressors related to their child's disability. With the inception of the National Disability Insurance Scheme (NDIS), such parents in Australia have been faced with another prominent challenge; navigating the scheme. Little research has explored the experiences of parents of hearing-impaired children in the NDIS, and no research has explored the NDIS' impact on the wellbeing of these families. The present study aimed to explore this utilising a qualitative research design. Semi-structured interviews were conducted with nine South Australian parents of hearing-impaired children participating in the NDIS. Seven themes were identified via thematic analysis. Themes pertaining to parental experiences included: parent as advocate, communication issues, inconsistencies in NDIS, navigational difficulty of the NDIS, and seeking resources and guidance beyond the NDIS. Themes related to wellbeing included: the stress paradox for the parent, and access to funded services beneficial for the child and family. The results strengthened previous findings in the NDIS literature and revealed that such parents continue to face many challenges. While overall child and family wellbeing were enhanced, the wellbeing of parents involved in navigating the scheme suffered. Together the findings show that the NDIS is a work in progress, fraught with numerous problems, and needs to undergo improvements to make navigation easier and reduce the strain on parents. Suggestions for future research and practical implications were also identified.

*Keywords:* hearing-impairment, children, parents, National Disability Insurance Scheme, family, wellbeing

### **Parents of Hearing-Impaired Children**

Research has highlighted that parents of hearing-impaired children are confronted with many unique experiences, challenges and additional stressors related to their child's disability. This has included: strong emotional responses following diagnosis, adapting to their child's extra needs, and transformed life circumstances (Calderon & Greenberg, 1999; Jackson, Traub, & Turnbull, 2008; Young & Tattersall, 2007). Parents additionally face complex decision-making responsibilities surrounding their child's hearing devices, communication modality, and educational options (Jackson & Turnbull, 2004; Kurtzer-White & Luterman, 2003; Porter, Creed, Hood, & Ching, 2018). Research has shown that these decisions are seldom straightforward, can be a source of stress and pose fundamental challenges (e.g., Jackson & Turnbull, 2004). Such outcomes are particularly prevalent for hearing parents, whereas, for hearing-impaired parents, it can differ due to personal lived experience (Feher-Prout, 1996). Nevertheless, the literature has suggested that these parents embark on an exhaustive journey to ensure that their hearing-impaired child's needs are met. In conjunction with these pre-existing experiences and challenges, with the inception of the National Disability Insurance Scheme (NDIS), such parents in Australia have been faced with another prominent challenge; navigating the new scheme.

### **NDIS and Self-Directed Funding**

Introduced in 2013, the NDIS is Australia's first self-directed funding (SDF) scheme for disability and signifies a vast transformation in Australian disability history (Reddihough, Meehan, Stott, & Delacy, 2016). It constitutes a shift in disability service provision by offering personalised funding packages to individuals with disabilities, whereas previously, disability services obtained funding to administer specialised supports (Productivity Commission, 2011; Simpson & Baldwin, 2017). Therefore, the NDIS grants people with permanent disabilities, their carers or families more choice and control over disability-related

services and supports (Reddihough, et al., 2016; Warr et al., 2017). It also presents the opportunity to choose a funding package or self-manage funds for more flexibility (Reddihough et al., 2016). Where the NDIS consumer is a child, these responsibilities reside with carers/parents and individualised plans may include the family's needs (Tracey, Johnston, Papps, & Mahmic, 2018). Overall, the NDIS aims to better the lives of those with a disability and their families by promoting community inclusion and increasing independent lifestyles (Commonwealth of Australia, 2013; Reddihough et al., 2016).

Moreover, SDF models have been successfully implemented internationally and extensively researched (Reddihough et al., 2016). Evaluations of these models (e.g., Head & Conroy, 2005) have demonstrated many positive outcomes for consumers like improved autonomy and quality of life (QoL). It is recognised that such schemes are more advantageous to families with higher socioeconomic status and educational levels as they generally fare better with navigating such a system (Dew et al., 2013). However, outcomes of SDF models concerning children with disabilities and their families or parents are under-researched, with most studies based on adults (Simpson & Douglas, 2016). The few studies reporting child outcomes generally combine disability types without focusing on one disability (e.g., Dew et al., 2013; Ottmann, Laragy, & Haddon, 2009). Therefore, more focused research is warranted to explore the outcomes of these models on children with specific disabilities and their families, such as the hearing-impaired to help potentially identify areas that may require further support.

### **Research into NDIS Experiences**

Research has only started to explore the NDIS experiences and perspectives of participants and people involved in their care. The scheme is still in its early days, whereas internationally, similar schemes have been established over longer periods (Warr et al., 2017). Therefore, substantial work is required to ensure the effectiveness of the NDIS

regarding specific disability populations. Current NDIS literature has identified experiences and challenges faced by consumers and those involved in their care. To date, findings from NDIS research into experiences have revealed both positive and negative accounts.

Positive accounts have included: carers/parents appreciating customisation associated with self-managing (Warr et al., 2017); increased opportunity (Simpson, Stewart, & Douglas, 2016); good planner experiences (Collings, Dew, & Dowse, 2019); and satisfaction with NDIS processes (Ranasinghe, Deepa, White, & Russo, 2017). Notably, in Warr et al. (2017) participants and family members/carers outlined that the NDIS provided a clearer and less stressful means of combining services compared to what they experienced prior.

In contrast, the NDIS has often been described as a “complex system” (Warr et al., 2017, p. 5), containing countless issues which are widespread across the literature. Common issues in the NDIS experience have entailed: staffing issues like high turnover and inexperience; challenges and pressures surrounding advocacy; lack of equity regarding access to funds and supports; information overload; difficulties in understanding system processes; lack of support; and issues regarding communication channels (e.g., Collings et al., 2019; Howard, Blakemore, Johnston, Taylor, & Dibley, 2015; Lakhani, McDonald, & Zeeman, 2018; Mavromaras, Moskos, Mahuteau, & Isherwood, 2018). Such issues have shown to adversely impact individuals, carers, and families. For instance, they have been disruptive, slowed progress, and caused stress or frustration (e.g., Simpson et al., 2016; Warr et al., 2017).

The mixed findings across the literature emphasise that the NDIS is not without flaws and is still evolving. They also indicate that the NDIS is failing to meet the needs of some consumers and their families, which can impact their health, QoL and wellbeing (Warr et al., 2017). Resultantly, ongoing research into NDIS experiences and outcomes over time is

imperative for gaining insights into how the scheme is progressing (Simpson et al., 2016; Warr et al., 2017).

### **Gaps in NDIS Literature**

Though research regarding NDIS experiences, perspectives and issues continues to grow, there exist few published empirical studies, and many have identifiable gaps. Such studies tend to: integrate disability groups, sometimes skewed towards a group (e.g., Lakhani et al., 2018); collectively consider the experiences or perspectives of the consumer, carers and family members (e.g., Warr et al., 2017); and be similar to SDF studies in that they rarely account for the experiences of children and their parents/families (e.g., Foster et al., 2016). Additionally, they have either excluded the hearing-impaired or not explicitly focused on such a demographic (e.g., Ranasinghe et al., 2017). Overall, scholarly research pertaining to the NDIS and the hearing-impaired has received little attention, although anecdotal evidence suggests that the needs of such individuals and their families are not sufficiently addressed. As previously outlined, focused research exploring NDIS experiences is absent, and this includes the experiences of parents of hearing-impaired children participating in the scheme.

To the best of our knowledge, only two published studies have explicitly focused on parents or caregivers of hearing-impaired children within the NDIS. Simpson & Baldwin (2017) focused on analysing and evaluating online information concerning the NDIS and hearing loss and did not explore caregivers' lived experiences of the scheme. While the quality of this information was good, there was low accessibility. However, due to the recency of the scheme at the time of the study, caregivers' accessibility to this information has likely improved. The second (Simpson et al., 2016) employed the NDIS as a case study to explore the experiences of caregivers of hearing-impaired children with membership in a SDF scheme, mainly focusing on how they navigated the initial planning meeting. Their analysis uncovered shared core experiences, including: lack of support from the NDIS, where

correspondence was difficult, and their child's intervention service was their primary source of support; the anxiety-inducing and daunting task of advocacy; being overwhelmed by the information provided by NDIS; and, relying on external professionals in the field of their child's disability for NDIS-related advice or guidance. However, the study was constrained to the experiences of parents with children who participated in specialist education/early intervention services (wherein parents received assistance with NDIS processes) and to parents with typical hearing with hearing-impaired children who communicated orally and primarily wore bilateral hearing aids. Moreover, data was collected in 2015 during the NDIS trial period, and the scheme has progressed since. Given the ever-evolving nature of the NDIS, experiences are likely to have changed and therefore, further research is warranted.

### **NDIS and Wellbeing**

Furthermore, one of the NDIS' objectives is to enhance the wellbeing and QoL for people with disabilities, their carers, and families (Mavromaras et al., 2018; Reddihough et al., 2016). Aside from the NDIS evaluation report (Mavromaras et al., 2018), little research has explored the impact of the NDIS on wellbeing. The report showed that not everyone experienced increased wellbeing during the NDIS trial. While the NDIS overall led to improvements in the wellbeing of adults with disabilities, there was no evidence of an increase in the wellbeing of carers/families. Rather, parents of child participants reported a negative impact on personal wellbeing and that the NDIS did not contribute to the wellbeing of their children. Varied wellbeing was linked to factors like disability type, age, duration of NDIS participation, education levels, and whether support needs were met. Wellbeing increases were related to higher inclusion, independence and decreased financial burden. Often decreases in wellbeing were related to stress and unmet needs. Notably, the wellbeing of both participants and carers/families remained remarkably below the national Australian average. Although the findings highlighted the importance of ongoing wellbeing evaluation,

the research is broad and multifaceted; more focused research continues to be needed.

Moreover, the few empirical studies investigating wellbeing in the context of the NDIS have shown that parents/carers report low levels of subjective wellbeing (Snow & Donnelly, 2018) and that addressing their mental wellbeing proves challenging (Gilson et al., 2018). Despite endeavours to explore wellbeing, no research to date has explored the impact of the NDIS on the wellbeing of families with hearing-impaired children.

### **Aims and Research Questions**

While Simpson et al. (2016) explored the experiences of such parents, an empirical study expanding on this by integrating an exploration of wellbeing is yet to be seen. Given the pre-existing experiences and challenges faced by parents with hearing-impaired children, this research holds additional value. The present study serves to contribute a sorely needed and growing body of NDIS research, address some gaps identified in previous research, offer insights into improving the NDIS, and suggest areas for future research efforts. This study aims to answer the following research questions: 1) What are parents of hearing-impaired children's experiences with the scheme? 2) What impact has the NDIS had on their family's wellbeing?

### **Method**

A qualitative research design employing individual semi-structured interviews was utilised. This design allowed for the generation of rich data and gave participants a voice regarding their experiences with the NDIS and its impact on their family's wellbeing (Braun & Clarke, 2013).

### **Participants**

Nine participants from South Australia were interviewed. They comprised of parents over the age of 18 years with at least one hearing-impaired child under the age of 18 years participating in the NDIS. Children were required to have a confirmed diagnosis of congenital hearing loss in the absence of other significant disabilities. This requirement was



to ensure that the child had hearing loss from birth as the research was orientated towards hearing-impaired NDIS participants (i.e., children participating in the NDIS due to another disability were excluded). Parents were required to be fluent in both written and oral English. This criterion was put in place so that if a hearing-impaired parent expressed interest in the study, they were aware that they would be required to communicate verbally during the interview since, due to limited resources, sign-language interpreters were not able to be offered.

Overall, eight females and one male volunteered to participate (age range: 31-50 years,  $M = 40.1$ ,  $SD = 6.9$ ). Often the child's primary caregiver agreed to partake; in no instances did both parents participate. The majority of participants had attained university-level education. One parent was hearing-impaired, whereas all others had normal hearing levels. All parents had only one child in the family with hearing loss (age range: 1-13 years,  $M = 5.8$ ,  $SD = 4.0$ ). Children varied in their degree of hearing loss and the hearing amplification device used. The communication mode used by eight of the children was oral/spoken English, and one child endorsed a mixed modality (both sign-language and oral/spoken English). Children were either enrolled in an early childhood intervention service or a mainstream school. Length of participation in the NDIS varied, ranging from eight months to four years. Children had needs related to their disability and accessed supports funded by the NDIS. The types of supports accessed included auditory verbal therapy, occupational therapy, physiotherapy, Teacher of the Deaf, speech therapy, swimming lessons, assistive technology and programs from early childhood intervention services. Table 1 and Table 2 outline parent and child demographic characteristics.

[Insert Table 1 here- see Appendix A]

[Insert Table 2 here- see Appendix B]

## Materials

**Demographic information form.** Before the interview, demographic information about the participant and their child was obtained.

**Semi-structured interview schedule.** A semi-structured interview schedule guided the researcher for all interviews. The schedule included a series of open-ended questions relating to the two research questions. The open-ended questions allowed for a rich, in-depth exploration of parents' experiences. When necessary, the researcher used probes and asked unplanned questions in response to participants' emerging accounts. Schedule questions were also balanced to allow for the exploration of both positive and negative experiences so as not to influence participants' responses in a particular direction. Example questions included: "How is the NDIS meeting your needs?", "What are some of the challenges, obstacles, or problems you have faced?" and "How do you feel the NDIS has played a role in shaping your wellbeing?" Parents of children who had received supports before the inception of the NDIS, were asked additional questions like, "Before the NDIS was introduced, what access to services and resources did you have?" As interviews progressed, the researcher made slight adjustments to the schedule; questions were added or modified. No further adjustments were made after the fourth interview.

## Procedure

This study was approved by the School of Psychology Human Research Ethics Subcommittee at the University of Adelaide. Parents were recruited through various means including hard-copy and electronic flyers advertising the study; promotion of the research by programs, services or agencies serving the hearing-impaired; and passive snowballing. Potential participants were invited to contact the researcher to express their interest at which time they were provided with a participation information sheet (see Appendix C). Those who remained interested were sent a consent form (see Appendix D). After consent was granted, depending on participant preference, a face-to-face or telephone interview was arranged.

Prior to each interview, the researcher clarified the purpose of the research and provided participants with the opportunity to ask questions. The researcher then reviewed the completed consent forms and obtained demographic information before commencing the interview.

All interviews were audio-recorded to enable transcription and data analysis. Six interviews were undertaken face-to-face, and three were conducted via telephone. Interview lengths ranged from 21 to 45 minutes, with an average length of 33 minutes. After their interview, participants were offered a \$20 gift voucher as reimbursement for their time and effort. Data collection ceased after the ninth interview as data saturation had been achieved (Guest, Bunce, & Johnson, 2006).

Interviews were transcribed verbatim using the orthographic transcription notation system outlined by Braun and Clarke (2013). Participants (and their children) were allocated a pseudonym to maintain confidentiality and anonymity. All potentially identifying information, including the names of agencies who disseminated study information, was removed from transcripts.

In accordance with Tracy's (2010) "Big Tent" criteria for excellence in qualitative research, the researcher kept an audit trail to document their decision making and activities to achieve transparency and to help monitor the rigour and trustworthiness of the research findings. To allow for 'member reflections' (Tracy, 2010), participants who requested a copy of their interview transcript and/or a draft of the findings were provided with the relevant document(s). Four participants responded, reporting satisfaction with the content.

When conducting qualitative research, it is essential to engage in self-reflexivity to identify and minimise researcher bias (Braun & Clarke, 2013; Tracy, 2010). The researcher was hearing-impaired. While they were not an NDIS participant, they had lifelong lived experience of hearing-impairment. Considering the researcher's insider status, a reflection

journal was kept so that they could engage in reflexive practice. The researcher's hearing-impairment may have influenced interactions with parents. Some parents may have felt more comfortable disclosing certain information, or there may have been an assumption that their experiences were inherently understood by the researcher and therefore, did not require any further elaboration.

### **Data Analysis**

Data analysis was undertaken using Braun and Clarke's (2006) six-step approach to thematic analysis, conducted within a realist/essentialist framework. That is, it focused on reporting the experiences, meanings and reality of participants (Braun & Clarke, 2006). An inductive approach was adopted; the initial coding and subsequent theme development were drawn from the content of the data.

All data analysis was conducted manually to enable the researcher deeper, active engagement with the data. After thorough immersion with transcript content and noting of initial ideas, the researcher organised the data into meaningful units. This was achieved through systematic coding of the entire dataset, allocating equal attention to each transcript. All content potentially relevant to the research questions were coded. While the researcher focused on identifying semantic codes, some partially latent codes were also allowed to ensure coding was not just restricted to the obvious and explicit meanings, but also considered more implicit meanings. However, codes were predominantly semantic to adhere with the realist theoretical framework and mirror participants' experiences. Codes and all relevant data extracts were collated together. Following this, codes were combined or discarded to form candidate themes which were then reviewed against the collated extracts and the whole dataset to determine whether the themes captured the meaning of the dataset pertaining to the research questions. Themes were then refined and named accordingly. Deviant cases; material counter to the main patterns were also considered. Finally, to improve

the trustworthiness of the selected themes, the analysis was reviewed by the research supervisors, and minor refinements were made.

## Results

Seven themes were identified with five themes pertaining to the first research question and two themes pertaining to the second research question. The themes related to “What are parents of hearing-impaired children’s experiences with the scheme?” included: 1) Parent as advocate, 2) Communication issues, 3) Inconsistencies in NDIS, 4) Navigational difficulty of the NDIS, and 5) Seeking resources and guidance beyond the NDIS. The themes regarding “What impact has the NDIS had on their family’s wellbeing?” included: 6) The stress paradox for the parent, and 7) Access to funded services beneficial for the child and family. In some instances, deviant cases are acknowledged. The themes are presented below.

### **Theme 1: Parent as Advocate**

All parents expressed that in their experience with the NDIS, they played an important role in advocating for their hearing-impaired child. Many parents described having to persevere and relentlessly fight for and voice their child’s needs. This notion is captured in the following extracts. Erica highlighted the importance of the role of advocate:

“You’ve got to optimise their development and independence so they can flourish as adults [...] you’ve got to be their advocate always and just fight for what they need”  
(Erica).

It was often emphasised that in being an advocate, it was necessary to be ‘pushy’. Alexis noted:

...when it comes to the NDIS, be pushy and if your child needs that support and they need those therapies or you know, auditory verbal therapy, speech therapy, occupational therapy, any type of therapy that they need, don't be scared to speak your

voice, be an advocate for your child because if you're not, then your child's going to be lost in the system. (Alexis)

All parents engaged in advocacy-related tasks, including researching and informing themselves about the NDIS; learning how to prioritise funds and be strategic; and collecting evidence of their child's disability in the form of records, reports, and letters. Such tasks were viewed as imperative in ensuring that their child's needs were met:

When you are putting your application for NDIS, any little detail that you can visually see or you know, that you've had testing done-you've got to give all that information-if you don't, they just look at you as another number. (Alexis)

As advocates for their child, there was a shared understanding that families were better off if they knew how to "play the system" (Andrea). For instance, many parents highlighted the importance of strongly and cautiously presenting their child's case as this was perceived as influencing fund allocation. Monique eloquently expressed this:

...you need to present your information as strongly as possible [...] your child might be having a great day today, but most of the other days they're having many meltdowns [...] or things are really hard, so you need to be talking to them like it is not a good day and you need to not be overly positive. You need to really be very clear that this is an ongoing thing [...] if you are mentioning too much additional help [...] they're likely to cut your funding, so [don't] mention anything which will be detrimental to your funding. (Monique)

However, for many parents, advocating for their child was not without challenges. Despite being strong advocates and doing what was in their child's best interests, some parents felt that they were not listened to, were forced into "rules and regulations" (Andrea) that did not apply to their circumstances. Several parents mentioned that due to a lack of NDIS staff

understanding and training in the disability sector, they had to explain the impact of the child's hearing-impairment:

...when I was on the phone with one person in the NDIS contact centre, I was explaining Brett's problem-what it was and he said, 'well um that doesn't necessarily mean that he can't hear'. I said 'his ear is closed' and he could not understand [...] some of the people that work there have no idea in regards to different types of conditions that can be considered a disability and I said 'I'll send you a photo then you'll understand' and he sort of got it ((laughs)) yep, there's a lot of frustration.  
(Chloe)

Interestingly, one parent, a hearing-impaired father, mentioned how his hearing-impairment placed him at an advantage in advocating for his child. Michael noted:

...having hearing loss myself has helped in the sense that I was able to help express, advocate for what Aaron needed through the NDIS [...] I was once a child with hearing-loss too. I know what's as NDIS always says 'reasonable and necessary' for my son. (Michael)

## **Theme 2: Communication Issues**

In their experience with the NDIS, the majority<sup>1</sup> of parents reported encountering various issues related to communication with the NDIS across multiple facets. Communication issues included how difficult NDIS was to contact, miscommunication, problems with the online portal, and lack of staff continuity. Most parents found this very frustrating, disruptive and inconvenient. Communication with the NDIS proved to be very challenging for most parents. In fact, one parent repeatedly described communication with

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<sup>1</sup>Statements like "the majority of/most/many parents" typically refer to six or more parents.

the NDIS as a “total nightmare” (Sue). Many of these issues are captured in the following extracts. Monique described the inconvenience and difficulty related to contacting the NDIS:

...it can be difficult to contact people [...] if you call the line, you never get through, so you have to email and then hope that someone will kind of respond to you, but it's not easy to necessarily access the person that is working with you and providing or finding if any circumstance changes or if you need to clarify anything, so that is also a little bit challenging. (Monique)

Similarly, the experience of miscommunication was prevalent and can be seen in the extract from Lauren:

...dealing with NDIS over the phone can be quite painful having been given incorrect information. So for example, when I needed to update bank details, just trying to get details upload-updated online, I couldn't do it and then when I spoke to them on the phone, it took several phone calls to actually update my details ((laughs)) which I think is pretty ridiculous. (Lauren)

Parents commented that the lack of staff continuity compounded communication issues. They consequently found themselves having to recap information to new staff members; having to repeat themselves “ten million times” (Sue). As a result, several parents expressed a desire to be assigned to specific caseworkers so that they did not have to deal with different people and the subsequent communication breakdown associated with it. Many parents echoed Alexis' sentiments:

You should have the same person every year [...] you should have the same team- someone in the same team that knows what's going on, not a new every Tom Dick and Harry coming in every week, every month, every year [...] reading through your notes and having to go through everything again. (Alexis)



In particular, parents noted a general lack of communication on the part of NDIS; that there was not much “collaboration” (Erica) and a failure to check-in with parents. A common occurrence of this was evident in parents’ requests to review plans before they were actioned:

“I got told that I would be able to see the plan before they put it through-they just keep putting it through [...] you need more visibility around the actual plan before it's approved.” (Sue)

However, not all parents experienced communication issues; one mother, who had not opted to self-manage, outlined that communication with the NDIS was “pretty good” (Harriet). In contrast, of the few parents who experienced services in a “pre-NDIS world”, all reported that communication was less gruelling when disability services were in control:

...always someone to call. If there was a problem, someone would help me and be on the line [...] that was before [...] the good experience is that I could always call someone and have a chat just informally. Also, if there was a need, someone would come out and meet with us... (Andrea)

### **Theme 3: Inconsistencies in NDIS**

All parents were confronted with an array of inconsistencies regarding NDIS processes. These were widespread, including instability around funding, plans and waiting periods. Parents attributed these inconsistencies to the ever-changing nature of the scheme. Parents often explicated how frequently things in the NDIS changed: “it’s just new and forever changing” (Sue). Although many parents indicated they received funding at a level that suited their child’s needs, they reported that funding levels also frequently changed: “They always cut your funds. They’re not quite the same each year” (Erica). Similarly, many parents reported a lack of consistency with plans: “Your plan, it changes every year, so you kind of start from the beginning every year” (Sue).

Additionally, parents mentioned variable waiting periods regarding their initial application/funding approval, as well as for reviews and responses, with some parents experiencing substantial delays. Sometimes changes in the system such as criteria changing were accountable. An example of this is highlighted in Chloe's description of her child's significantly delayed application:

We had confirmation that he would need assistance, so that was probably about two and a half years ago. It got knocked back because they said he had unilateral hearing loss, so that wasn't covered [...] So it took two years from when he was born to get the funding because they changed the requirements [...] One minute unilateral was covered next minute it's not. So yeah, that took us a long time to get that. (Chloe)

Notably, a lot of parents spoke of inequities "across the board" (Harriet), emphasising a disparity in NDIS funding and service provision. For example, Erica stated:

...what's stupid is I've seen some people get rejected requests for things that other people have had approved and their kids pretty much have very, very similar needs. It doesn't make much sense, like I said it hasn't been consistent. (Erica)

Moreover, such inconsistencies led several parents to experience uncertainty and doubts regarding their future with the NDIS, particularly around whether the NDIS would continue to provide funding for services to sufficiently address their child's needs:

...I feel that there is a lot of uncertainty around the future of our funds. For instance, our funding has gone down from what we initially had when started off. We did not expect this. However, we still feel it's enough for what we need, but if they cut it down more next year, we're not sure if Aaron is going to get the funds he needs [...] I suppose there is a lot of uncertainty around the NDIS. There is not much consistency at all. (Michael)

#### **Theme 4: Navigational Difficulty of the NDIS**

Across the sample, most parents recounted that the NDIS was not easy to navigate; that it was “hard work” (Andrea) and the reasons they attributed to this were often shared. This included the lack of clarity and confusion around NDIS processes; the time-consuming nature of processes; and information overload. Generally, many parents described the NDIS as too complex or multifaceted, which only made navigation arduous. Most parents called for the simplification of the system. Erica provided a detailed description:

I wasn't expecting it to be so complicated. I expected it to be more straightforward. Instead it's like that picture you see where it's like here's point A and there's point B and you see it's not a straight line, it's a bit of a scribbly mess actually ((laughs)) [...] it's too complex, more complex-complicated than it should be. It should be simpler yeah [...] like I said it's like a massive web with a lot happening from different angles [...] just make things easier for everyone to understand, you know ((sighs)) break it down more and simplify it [...] NDIS definitely needs to undergo some major um-well improvements as there isn't much clarity around things, it's confusing, they've let down people... (Erica)

In turn, many parents mentioned that poor NDIS staff or planner experiences inhibited progress as well as a lack of support on NDIS' behalf, that further contributed to the navigational difficulty experienced by parents:

...if you get a bad person that doesn't know what the hell they're doing, has no empathy than there for a job to do whatever they need to do [...] you're not going to get anywhere [...] so positively if you get a good person you get, you know, what you're asking for done. (Alexis)

It is also noteworthy that despite being highly educated, parents still experienced difficulties navigating the NDIS. No matter how educated parents were, it did not act as a buffer or work in their favour. Several parents expressed this sentiment, for example:

...I'm an educated person who has studied a lot and if I am finding the system really difficult to navigate, I can just only imagine how um someone who is from a different socio-economic background to me, would struggle [...] I should be able to articulate his needs. (Monique)

Well it's hard to navigate for everyone and I've got [post-graduate qualifications] and I find it very hard the language ((pause)) also not knowing who to talk to you know, it's a very impersonal system. If you have a question or if you need help, there's no one you can actually go to. (Andrea)

However, not all parents experienced navigational difficulties. One parent who professed little involvement with NDIS processes (and who was not self-managing), described the NDIS as “proactive” and articulated that everything had been relatively “straightforward” (Harriet).

### **Theme 5: Seeking Resources and Guidance Beyond the NDIS**

Many parents turned to a host of sources for support to ease the burdens associated with navigating the NDIS. Parents utilised a variety of sources for advice, resources or guidance. Notably, these were not from the NDIS directly; rather, they were from external sources like their child’s early intervention service, health professionals in their child’s life, other parents, or via online support groups on social media. These platforms were perceived by parents to be helpful and supportive. Indeed, many parents reported a lack of affiliation or connection with the NDIS directly. Parents with children enrolled in early childhood intervention services primarily relied on staff members for assistance with NDIS processes and reported that these services helped set their child up with the NDIS:

...I had really good support from the [early childhood intervention service] helping me ask for the correct things because, you know, it's all new to me so that was

positive [...] [staff member] helps me, but no one from NDIS has helped me with anything. (Chloe)

Several parents also described turning to other professionals in their child's life who understood the implications of hearing-impairment, such as speech pathologists, Ear Nose and Throat surgeons and audiologists:

...the only person that's assisted me with [the NDIS] is actually the speech therapist seeing Daniel every fortnight [...] she helped me in preparing for what supports they would be asking for in the initial stages [...] what supports I should be looking for ongoing and what services are available that are going to further Daniel's learning.

(Lauren)

Numerous parents mentioned that they sought advice and recommendations from other parents of hearing-impaired children who were also utilising the NDIS. Where parents were not the recipients of advice, they were providers or shared their experiences with other parents. For example:

If I have met a parent whose child is on the NDIS and who seems to have managed to work out how to get some decent funding, like if their child seems to be able to go to quite a few sessions or things like that, I just asked for any advice that they might have. I've done that a few times with different parents. (Monique)

Additionally, some parents recounted utilising online social media support groups to ask questions or seek information that they could apply to their circumstances. Chloe demonstrates an instance of this:

...I'm on a Facebook group [...] I read through those posts and just see what they're speaking about with NDIS [...] 'what did you apply for?', 'what did you get?', 'how much did you apply for?' so I'll read through those and if I see something I think 'oh I didn't even think that I could have applied for that' [...] so I'll probably get more

information from the group and people that have been successful in their application.

(Chloe)

Finally, most parents attested to the importance of making good connections, accessing useful resources such as information pamphlets or sessions offered by service providers, and staying informed to make NDIS navigation easier.

### **Theme 6: The Stress Paradox for the Parent**

When parents spoke of the NDIS' impact on family wellbeing, most orientated their talk towards their personal wellbeing which was often talked about in terms of "stress" or "pressure". As such, parents described the NDIS as simultaneously causing and removing stress; a paradox or "double-edged sword". The NDIS thus, both heightened and alleviated stress for parents. Interestingly, this paradox affected the primary caregiver of the child, since parents' accounts showed that navigating the NDIS was predominantly the primary caregivers' responsibility, and this consisted of all the mothers in the study. Although some had support from a partner or spouse, they often emphasised that the responsibility of the NDIS was inherently theirs, for instance: "I'm the one that does everything [...] that's on me" (Sue), "so primarily I've done it all" (Monique), "this NDIS stuff has mostly been up to me to sort out, it's been my responsibility" (Erica), "it falls on me" (Chloe), "it's just me" (Harriet), "it's been my responsibility" (Lauren), and "it's all on me" (Andrea).

Sources of stress for parents were wide-ranging, including the application process, delays, planning, worries about funding, and lack of support. In particular, the work and responsibility that came with the NDIS were identified as an additional burden in the lives of parents. One which placed pressure or strain on many parents, and in turn, detrimentally impacted their wellbeing. Notably, the majority of parents opted for self-managing, which they described as stressful, whereas the few with funding packages reported being less stressed in comparison. While self-managing was deemed a source of stress, many parents

preferred to self-manage and professed its benefits like its flexibility and how it enabled greater control:

...[self-managing] can pose some additional challenges [...] it can be difficult [...] it's my responsibility to arrange everything [...] it can be quite stressful at times because it's more work [...] but it's nice having that control to customise [...] and be more creative rather than slotted right into something... (Erica)

Concurrently, parents reported that the NDIS had reduced their stress. When parents spoke of their wellbeing, all reported that the NDIS had alleviated financial stress and consequently expressed gratitude for the funds they received. Additionally, several parents highlighted that the NDIS took away the stress of worrying that their child was not having their needs met and took the pressure off them having to do extra work with their child. This stress paradox is captured in the following extracts. Alexis described the NDIS as simultaneously removing and adding pressure:

...it's [NDIS] taken the pressure off me having to stress about her receiving the type of services that she needs to get her to move forward, but at the same time it's put stress on me because when you have like I said, lack of communication, people not responding, waiting periods, it then puts you down and down [...] basically, you know, it's taking the pressure off of me having to do certain things with my daughter, but it's also put the pressure on me because if you don't [...] chase after things, no one is there helping and it puts the stress back on you. (Alexis)

While Michael spoke of the lessening of financial burden, he still experienced stress, which detrimentally impacted on his wellbeing:

...these things, they aren't cheap if you pay out of pocket, so NDIS-it's made things easier from a financial perspective [...] financially it has lessened the burden, but

emotionally it's been very challenging at times and ((long pause)) demanding. That stress clearly isn't good for my wellbeing. (Michael)

Additionally, Sue outlined experiencing stress, but at the same time, described experiencing less pressure:

...stressful for me because I'm the one that does everything [...] it's taking the pressure off me personally, because it means I can access, because I'm not a teacher, I'm not a speech therapist, so Veronica needs a lot of that support and so it means I've got support. Otherwise, I would be trying to do it all myself for her... (Sue)

However, not all parents experienced this effect with regards to their wellbeing. One parent with an infant child, who had been with the scheme for a short time, articulated that the NDIS had not impacted their wellbeing. Additionally, the small portion of parents who experienced pre-NDIS disability service provision reported experiencing fewer pressures previously as there was little involvement on their behalf; the responsibility ultimately lay with the service providers catering for their children:

...it's [NDIS] become another task in my life and my life is full of to-do lists, whereas before I just had a provider ringing me up regularly. I could have a chat, we could on the spot make a decision and services will just roll on, which took lots of work off my shoulders. Whereas, now it's all on me and yeah, it's become another burden in everyday life. (Andrea)

### **Theme 7: Access to Funded Services Beneficial for the Child and Family**

Most parents' experiences highlighted that access to NDIS funded services had noteworthy positive impacts on wellbeing. However, parents predominantly spoke of this impact across two levels: the child and the family as a whole. Parents expressed that access to the NDIS made mostly positive contributions towards their child's wellbeing, as well as the wellbeing of their family. Most parents reported that their child was having their needs met



by the NDIS and that they were benefiting enormously from the funded services and supports; they “made a world of difference” (Alexis) and “broadened [their] horizons” (Chloe). This included progression with speech, communication, improved listening skills, and social skills. Importantly, parents described this access as having a positive impact on their child’s wellbeing in that it improved facets of their child’s life such as their development, personal growth, inclusion and independence, and presented them with more opportunities. For example:

His [child’s] wellbeing is much better off [...] he hasn’t really been affected in regards to the negative side of it, but the positive side is that yes, it’s definitely helping him with his life and development. His speech is coming along really well [...] he’s able to interact, you know, with children his own age and have little conversations and obviously that way he feels included in life with other kids that haven’t got any hearing problems. So for his wellbeing I think that’s been very important... (Chloe)

Similarly, several parents reported that access to NDIS funded services had positive connotations for the wellbeing of their family as a whole and contributed to an overall increase in family wellbeing. The common reasons parents attributed to this included that it enabled more family time, improved family relationships, and created more family cohesion.

Michael highlighted this:

...we do get more time together as a family, you know because we don’t have to focus on providing interventions for Aaron ourselves. We’re both busy people ((pause)) instead that responsibility lays-goes to an external provider or service whatever, that way we can go do some activities as a family [...] go to the movies, go for drives, we can spend our time equally between the two boys [...] I think overall for my whole family there has been an improvement in wellbeing... (Michael)

When parents discussed family wellbeing, they rarely spoke of the impact of the NDIS on their other children. However, in the instances where parents mentioned their other children, they explicitly stated that the NDIS had not impacted their wellbeing. This was generally attributable to their other children's obliviousness to their sibling's NDIS participation and their overall absence in NDIS processes: "...her sibling didn't even realise she was part of the NDIS" (Sue).

However, not all parents described access to NDIS funded services as having a beneficial impact on the wellbeing of their child or family. A mother (Andrea) who experienced services before the inception of the NDIS, reported "little impact" on her child's wellbeing and described the "previous system" as more impactful, which she attributed to the "really good supports" experienced prior. Additionally, two parents with young children explicated that access to the NDIS had not impacted their family's wellbeing, for instance: "it's [family wellbeing] been similar over the years" (Harriet).

In contrast, in the few instances where it was outlined by parents, restricted access to NDIS funded services (e.g., a reduction in services/supports due to funding cuts) had the opposite effect on wellbeing. Parents described a more deleterious impact:

...when we had more access to things, it felt like the wellbeing was probably better because we were, you know, making these great connections with people and we weren't so isolated [...] having to access things in small doses and not adequate time needs definitely is not great for wellbeing. (Monique)

### **Discussion**

This study, using thematic analysis of qualitative interviews, explored the experiences of parents of hearing-impaired children participating in the NDIS and the impact of the scheme on their family's wellbeing. The themes will be discussed relative to previous literature and conclusions drawn from the overall results, summarised.

The themes relating to the first research question highlighted some of these parents' prominent NDIS experiences and shed light on shared challenges. They reinforce several findings of previous NDIS research describing consumer experiences and challenges.

The NDIS experience encouraged parents to be relentless advocates for their hearing-impaired children. They were strategic in presenting their child's case and emphasised their child's needs to maximise their funding for supports. This is similar to findings from previous research indicating that parents/carers adopted the role as advocates for NDIS participants in their care and often had to explain the implications of the disability to underinformed NDIS staff/planners (e.g., Simpson et al., 2016; Warr et al., 2017).

Parents' experience of encountering various communication-related issues within the NDIS is consistent with past literature. For instance, numerous issues related to communication like miscommunication, lack of communication on behalf of NDIS and high staff turnover, were also found in Warr et al. (2017) and similarly posed challenges.

Parents described experiencing many inconsistencies due to the ever-changing nature of the NDIS. While previous research revealed that participants, carers and families experienced similar inconsistencies (e.g., funds/plans frequently changing), they also noted inequities regarding funding allocation and services mentioned by the parents in the present study (e.g., Simpson et al., 2016; Warr et al., 2017). Parents' uncertainties and insecurities about their child's future with NDIS, also resembled the anxieties of carers and families concerning the sustainability of the NDIS identified in Mavromaras et al. (2018).

The navigational difficulty experienced by parents and the scheme's complexity are widely reflected in the current NDIS literature (e.g., Simpson & Baldwin, 2017; Warr et al., 2017). However, the finding that highly educated parents from good socioeconomic backgrounds struggled to navigate the system stands in contrast to previous literature indicating that people with these attributes fare better navigating such schemes (e.g., Dew et

al., 2013). The reasons for this are unclear, but highlight that even highly able parents find the NDIS challenging to navigate.

Parents described resorting to guidance and support from external sources unaffiliated with the NDIS to ease the burdens of NDIS navigation. These sources (e.g., child's early intervention service and online social media groups) were recognised as helpful and supportive. Such findings echo previous research, where parents of children with disabilities consulted a range of sources including the internet, professionals in their child's life, and other parents of children with disabilities (Tracey et al., 2018). Similarly, the child's early intervention service was a highly valued source of assistance regarding funding schemes. These findings are reflective of Simpson et al. (2016), and as in their study, many parents reported little direct connection or relationship with the NDIS.

Moreover, the themes relating to the second research question highlighted how the NDIS contributed to the wellbeing of such families. The finding that the NDIS caused parents stress and pressures maps onto previous NDIS literature where carers and families experienced stress (e.g., Warr et al., 2017). This finding is also congruent with Schwartz (2004), where it was highlighted that SDF schemes can cause parental stress as their decision-making responsibilities increase. While self-managing was perceived as a source of stress, like past research, its heightened flexibility, choice and control was valued (e.g., Warr et al., 2017). The finding that the NDIS also led to decreases in stress/pressures was also found in previous literature, for example, reduced financial burden (e.g., Mavromaras et al., 2018). However, these findings suggest that in conjunction with the pre-existing challenges and stressors related to their child's disability (e.g., Jackson & Turnbull, 2004), the NDIS is another source of stress encountered by these parents, which detrimentally impacts their wellbeing.

The findings revealed that access to funded NDIS services predominantly had positive connotations for the wellbeing of children and the family as a whole. In the current study, parents often described NDIS access as having a positive impact on their child's wellbeing in that it improved aspects of their child's life like independence and inclusion. This finding is contrary to previous findings indicating that child NDIS participants experienced no impacts on wellbeing (Mavromaras et al., 2018). This may be attributable to the fact that many of the children in the study were having their needs (e.g., speech, listening and social skills) met by the NDIS. While previous NDIS explorations of family wellbeing revealed mixed findings with minimal evidence of family wellbeing increases (Mavromaras et al., 2018), many parents in the study reported enhanced wellbeing for their overall family as it granted more family time and improved family relationships. This outcome could have resulted from the length of NDIS participation, with most children participating in the NDIS for several years, perhaps resulting in more observable differences in wellbeing compared to those within the trial period research.

Together, these findings emphasise that the NDIS is a lot of work for parents and is not without challenges, especially for those self-managing. Most notably, findings regarding some of the experiences found in this study, are similar to that of Simpson et al. (2016) and suggest that parents of hearing-impaired children's NDIS experiences have not changed dramatically in the last few years and that they continue to face similar challenges. Also, the wellbeing findings uncovered that the hearing-impaired child and overall family are generally reaping positive impacts concerning their wellbeing. On the other hand, parents faced with the responsibility of navigating the scheme (i.e., the primary caregivers in the present study), experienced more adverse impacts on their wellbeing.

### **Strengths of the Study**

Overall, the study provided a much-needed contribution to a growing body of NDIS literature. It provided insight into the experiences of a cross-section of parents currently navigating the scheme. The methodology allowed parents an opportunity to share their experiences openly and ultimately have their voices “heard”; something that persons involved in the NDIS are rarely presented with (Warr et al., 2017).

The study addressed several gaps identified in previous literature. It provided more focused NDIS research into experiences and more research into SDF models regarding children with specific disabilities and their parents/families. Importantly, it focused on the experiences of parents with hearing-impaired children; an area that has received little attention thus far in the context of the NDIS. It provided a more diverse sample compared to the study which it expanded on (i.e., Simpson et al., 2016). That is, it captured some experiences of parents with children who were not joined in with specialist education services, included more children with cochlear implants, and accounted for unilateral hearing loss. Importantly, the study captured the experience of a hearing-impaired parent and a child who did not just endorse oral communication, which revealed some unique findings (e.g., parent’s hearing-impairment advantageous in advocating for the child).

Furthermore, it was the first study to explore the impact of the NDIS on the wellbeing of families with hearing-impaired children. Thus, the study also provides a foundation for future research to build on.

### **Limitations and Future Research Implications**

A significant limitation included the lack of father involvement in the study. Although the term “parent/s” was utilised throughout the study, views were predominantly constrained to mothers. Therefore, fathers’ experiences are not adequately reflected in the findings and further research recruiting more fathers is required to address this disparity. Additionally, the attendance of one parent in each interview appeared to hinder in-depth discussions of family

wellbeing, as parents generally orientated their talk towards their wellbeing. More research with both parents would provide more comprehensive insights into family wellbeing.

Many participants were highly educated, Caucasian, and from good socioeconomic backgrounds; the study represented the “usual suspects” (Braun & Clarke, 2013). As such, the findings do not represent more disadvantaged families, who may face additional challenges and are likely to have different experiences to those in the current study. Henceforth, future research incorporating a sample with more socioeconomic, educational, and cultural diversity, is valuable.

The study’s limited resources (i.e., inability to offer sign-language interpreters for interviews) may have inadvertently restricted the ability to recruit hearing-impaired parents. This limitation has been acknowledged, and future research should endeavour to offer sign-language interpreters so that more hearing-impaired parents, particularly those who only communicate through sign-language, can voice their experiences navigating the NDIS on behalf of their hearing-impaired children. This is important since qualitative research exploring the voices of this demographic is lacking (e.g., Jackson et al., 2008; Simpson et al., 2016) and such research has the potential to reveal novel and meaningful findings. In fact, the hearing-impaired parent in the study raised several interesting issues unrelated to the core themes. For instance, they mentioned an Auslan interpreter shortage induced by the NDIS, and how NDIS was often failing to meet the needs of a signing hearing-impaired demographic. This issue has been briefly referred to in previous literature (e.g., Massa, Withers, Leggett, Dirago, & Yoon, 2015) and suggests that more research with signing hearing-impaired NDIS participants would be of interest.

The study may have attracted parents who sought a platform to vent their frustrations or problems with the NDIS. Therefore, these findings may not be reflective of all parents

within this cohort. For instance, it may have underrepresented those with more positive NDIS experiences.

The wellbeing reported in the current study was subjective. However, wellbeing is a complex, fluid, ambiguous construct and conceptualisations vary across individuals (Mavromaras et al., 2018). Therefore, when participants spoke of the NDIS' impact on wellbeing, it was based on their interpretation of wellbeing. Moreover, future research efforts employing quantitative methods would be beneficial to build on the current findings. Incorporating an objective measure of wellbeing could help identify specific factors contributing to reduced wellbeing for parents and families. This has potential to provide useful information on how to best optimise their wellbeing whilst they navigate the scheme.

Finally, the study was conducted in one Australian state with its own service settings and policies. Since the NDIS is a national reform, these findings may not be transferrable at the national level.

### **Practical Implications**

The findings of this study have practical implications. Parents' experiences highlighted that overall, the NDIS is still a work in progress and needs to undergo more improvements to make navigation easier and reduce the strain on parents. Some improvements include more staff training regarding specific disabilities to ease the burdens associated with advocacy and improving communication channels within the NDIS. Additionally, more attention to consistency and equity is required to reduce parental vigilance and anxieties about their child's future with the NDIS. NDIS processes also need to be simplified so that it is less burdensome for parents to navigate.

The study suggests that the needs of parents/caregivers navigating the NDIS warrant more acknowledgement. That is, the need to support the parent, not only the child and to be sensitive to parents' personal needs as they navigate the scheme. The arduous work,



challenges and responsibilities that came with the NDIS, caused parents in the study to experience stress and pressures, which often came at the expense of their wellbeing. This demonstrates a call for more supports and resources for caregivers to help alleviate the demands, stress and pressures the NDIS has imposed on them. This includes the provision of emotional support, self-help resources, and information for parents on supporting their wellbeing. This could be in the form of peer support programs focusing on wellbeing, complimentary seminars from service providers, and online information provided by the NDIS. Resources that parents can refer to (e.g., emotional supports/counselling) while they await access/approval may also be of use.

### **Conclusions**

Despite its limitations, this qualitative study contributes to a growing body of knowledge concerning NDIS experiences and adds to the limited NDIS literature regarding the experiences of parents of hearing-impaired children within the NDIS. Importantly, it provides a new contribution to the literature - no previous studies have explored the impact of the NDIS on the wellbeing of families with hearing-impaired children. The findings strengthen previous findings in the NDIS literature, particularly common challenges and issues faced by those navigating the scheme. Furthermore, this research suggests that in the context of the NDIS, such parents are indeed experiencing additional pressures, challenges and stressors related to the scheme. It also showed that while access to NDIS funded services had positive impacts for the wellbeing of the child and family, the parents' responsibility of navigating the NDIS often came at the expense of their wellbeing. As such, it highlights that the NDIS is a work in progress, fraught with numerous issues, and needs to undergo further improvements to make navigation easier and reduce strain on parents, more specifically mothers who are more likely to be the primary caregivers.

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## Appendix A

Table 1

*Parent Demographic Characteristics*

N	Pseudonym	Gender	Age	Hearing Status	Highest Level of Education	Children in Family	Children with Hearing Loss
1	Monique	Female	31	Hearing	Postgraduate degree	3	1
2	Andrea	Female	48	Hearing	Postgraduate degree	2	1
3	Sue	Female	46	Hearing	Postgraduate degree	2	1
4	Harriet	Female	35	Hearing	Undergraduate degree	2	1
5	Chloe	Female	43	Hearing	Year 12	2	1
6	Alexis	Female	36	Hearing	Undergraduate degree	3	1
7	Michael	Male	33	Hearing-loss	TAFE diploma	2	1
8	Erica	Female	50	Hearing	Undergraduate degree	2	1
9	Lauren	Female	39	Hearing	Year 12	1	1

## Appendix B

Table 2

*Child Demographic Characteristics*

N	Gender	Age (years)	Degree of Hearing Loss	Age Hearing Loss Identified	Type of Hearing Amplification Device	Mode of Communication	Education	Time with NDIS
1	Male	4	Profound	Birth	Unilateral CI	Oral	Early intervention	4 years
2	Female	13	Moderate	5 years	Bilateral HA	Oral	Mainstream school	3 years
3	Female	10	Profound	7 weeks	Bilateral CI	Oral	Mainstream school	4 years
4	Male	3	Moderate	5 months	Bilateral HA	Oral	Early intervention	3 years
5	Male	2	Profound	Birth	Unilateral HA	Oral	Early intervention	8 months
6	Female	5	Profound	Birth	Bilateral CI	Oral	Mainstream school	4 years
7	Male	6	Severe	Birth	Bilateral HA	Mixed	Mainstream school	2 years
8	Female	9	Severe	Birth	Bilateral HA	Oral	Mainstream school	3 years
9	Male	1	Moderate	4 weeks	Bilateral HA	Oral	Early intervention	10 months

*Note.* Number assigned to child corresponds with parent participant in Table 1. Unilateral = one ear; Bilateral = both ears; CI = cochlear implant; HA = hearing aid; Oral = communicates with spoken English; Mixed = communicates with both spoken English and/or sign-language



## Appendix C

## Copy of Participant Information Sheet

**PARTICIPANT INFORMATION SHEET**

**PROJECT TITLE:** *Parents of hearing-impaired children's experiences with the NDIS and its impact on family wellbeing.*

**HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER:** H-2019-1908

**PRINCIPAL INVESTIGATOR:** Professor Martha Augoustinos

**STUDENT RESEARCHER:** Angela Asimakopoulos

**STUDENT'S DEGREE:** Master of Psychology (Health)

You are invited to participate in the research project described below.

**What is the project about?**

This research project is about exploring the experiences of parents of hearing-impaired children participating in the National Disability Insurance Scheme (NDIS) and the impact that the scheme has had on their family's wellbeing.

**Who is undertaking the project?**

This project is being conducted by Ms Angela Asimakopoulos. This research will form the basis for the degree of Master of Psychology (Health) at the University of Adelaide under the supervision of Professor Martha Augoustinos and Dr Melissa Oxlad.

**Who can participate?**

You can participate if you (the parent):

- ✓ Are over the age of 18 years.
- ✓ Are fluent in English (that is, you can understand both written and oral English).

**And have a child:**

- ✓ With a confirmed diagnosis of permanent congenital hearing loss (i.e. hearing loss from birth) in the absence of other significant disabilities.
- ✓ Who is a NDIS participant (pending, current, or past).

**What does the study involve?**

If you agree to participate, you will participate in an interview about your experiences of the NDIS and its impact on your family's wellbeing. Prior to this, we will ask for some basic demographic information. Interviews can take place at the University of Adelaide (North Terrace Campus), over the telephone, or in another public location at a time that is convenient to you. The interview will be audio-recorded so that an anonymous transcript can be made of the interview. You will have the option to receive a copy of the transcript and you may choose to receive a copy of the draft findings.

**How much time will my involvement in the project take?**

Interviews will take approximately one hour of your time. You will be reimbursed for your time. At the conclusion of your interview, you will receive a \$20 Coles voucher.

**Are there any risks associated with participating in this project?**

As you are being asked to discuss your child's health and your involvement with the NDIS, you may encounter some emotional distress during the interview. However, every effort will be made to minimise this possibility, and you will be provided with a list of supports that you may wish to access after the interview. These include contact details for support and telephone helplines. You can view these supports at the end of this information sheet. You can also choose not to answer particular questions, or to end the interview at any time.

**What are the potential benefits of the research project?**

This study allows parents of hearing-impaired children an opportunity to share their experiences of the scheme and ultimately have their voices "heard". This study also serves to add to a newly growing body of research into NDIS consumers' experiences of the scheme. The research may result in highlighting gaps in service provision or delivery, offer insights into improving the services of the National Disability Insurance Agency (NDIA), and offer suggestions for future research efforts in the area. However, there are no immediate benefits to participants for their involvement in the project. The information provided by you is solely for research purposes and the researchers will not be able to provide you any personal assistance or advice regarding the NDIS.

**Can I withdraw from the project?**

Yes, participation in this project is completely voluntary. If you agree to participate, you can choose not to answer specific questions or can withdraw from the study at any time until the start of the data analysis phase.

**What will happen to my information?**

Your name and any identifying information will remain confidential and will be removed from any publications or reports that arise from the data. Confidential interview transcripts will be made from the audio-recordings, however only the named researchers will have access to the interview transcripts, for the purpose of analysis. All materials and data will be securely stored. Information gained in the project will be written as a thesis and may be potentially published in a journal article. Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

**Who do I contact if I have questions about the project?**

If you would like more information or have questions about the study, you can contact the student researcher, Ms Angela Asimakopoulos.

**What if I have a complaint or any concerns?**

The study has been approved by the University of Adelaide's School of Psychology Human Research Ethics Subcommittee (approval number H-2019-1908). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research 2007 (Updated 2018). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult one of the Research Supervisors. However, if you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: [hrec@adelaide.edu.au](mailto:hrec@adelaide.edu.au)

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

**If I want to participate, what do I do?**

Please email Ms Angela Asimakopoulos on [REDACTED] for further details. You will then receive a consent form and can arrange a time for an interview.

**Researchers' Contact Details:**

**Ms Angela Asimakopoulos**

[REDACTED]

**Dr Melissa Oxlad**

[REDACTED]

**Professor Martha Augoustinos**

[REDACTED]

**Support Resources:**

**Lifeline Australia**

Phone: 13 11 14

*Line available 24 hours a day/7 days a week*

**Beyond Blue**

Phone: 1300 22 4636

*Line available 24 hours a day/7 days a week*

## Appendix D

## Copy of Consent Form

**CONSENT FORM**

1. I have read the attached Information Sheet and agree to take part in the following research project:

<b>Title:</b>	<i>Parents of hearing-impaired children's experiences with the NDIS and its impact on family wellbeing.</i>
<b>Ethics Approval Number:</b>	<b>H-2019-1908</b>

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.
3. Although I understand the purpose of the research project, it has also been explained that my involvement may not be of any benefit to me.
4. I agree to participate in the activities outlined in the Participant Information Sheet.
5. I consent to be:  
Audio recorded  Yes  No
6. I would like to receive a copy of:  
My interview transcript  Yes  No  
The draft findings  Yes  No
7. I understand that I am free to withdraw from the project at any time up until data analysis.
8. I have been informed that the information gained in the project will be written as a thesis and may be potentially published in a journal article.
9. I have been informed that in the published materials I will not be identified and my personal results will not be divulged.
10. I understand that my data- that is, the audio interview and subsequent written transcript, will not be used for any other purposes other than for this specific research project and will not be made available to any other researchers. However, I understand that the findings reported in the thesis or any other publications, may be used by other researchers.

11. I understand my information will only be disclosed according to the consent provided, except where disclosure is required by law.

12. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

**Participant to complete:**

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Researcher to complete** (after going through this consent form with participant prior to interview):

I have described the nature of the research to \_\_\_\_\_  
and in my opinion, they understood the explanation.

Signature: \_\_\_\_\_ Position: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix E

Copy of Instructions to Authors/Contributors for Chosen Scientific Journal

# AMERICAN ANNALS OF THE DEAF

## **How do I submit an article to the *Annals*?**

Articles and essays are welcomed from all countries. All submissions must be in English and be submitted as a Word document (no PDFs). Contributors should submit papers electronically to Dr. Peter V. Paul ([paul.3@osu.edu](mailto:paul.3@osu.edu)).

There is no minimum or maximum length (within reason). The font size is 12, and we recommend Times New Roman or Times. Please call out tables and figures in the manuscript where they should be placed (e.g., <insert table 1 near here>) and include these items at the end of the text after the reference list (or appendix, if you include this item) in ONE document.

(If your paper is accepted for the journal, we will ask for any figures to be sent in their original formats as separate files.)

It is critical to adhere to the style of the sixth edition of the *Publication Manual of the American Psychological Association* (APA). APA provides guidelines regarding headings and the type of information to be included in each heading for primary (empirical) and secondary (analysis) research manuscripts. APA also provide guidelines for footnotes, tables, figures, and abstracts. Sample papers can be found in the APA (pp. 41–59).

We also ask that you provide keywords (at the end of the abstract) and identify the main author for correspondences.

Except for the title page, the text should be double-spaced.

**Permissions.** Contributors are responsible for obtaining permission to reprint tables, figures, illustrations, and large extracts. Copies of the permission letters must accompany the manuscript.

**Proofs.** One set of proofs will be sent to the lead author. Contributors are responsible for proofreading and returning the proofs by the given deadline.

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