FAMILY ENGAGEMENT IN PAEDIATRIC COCHLEAR IMPLANT HABILITATION:

the clinicians' perspective

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A thesis submitted in partial fulfilment of the requirements for the degree of
Master of Audiology, University of Auckland, 2022.

Abstract

Background: Strong family engagement is known to be an important predictor of outcomes for children who receive cochlear implants. However, the barriers and facilitators of family engagement in the paediatric cochlear implant habilitation process have seldom been explored in the literature. It is important to develop an understanding of these barriers and facilitators so that they can inform family-centred clinical practice, and improve the outcomes of children with cochlear implants.

Methods: The present study aimed to explore clinicians' views on family engagement, and uncover what clinicians perceive to be the barriers and facilitators of family engagement. A mixed methods approach was used, consisting of a survey and interviews. The survey contained both closed- and open-ended questions about the research topic. The interviews were used to gain more in-depth insight about the strategies that clinicians used to facilitate engagement. Interviews were analysed with reflexive thematic analysis.

Main results: There were 41 survey participants and 7 interview participants. Clinicians identified cultural, emotional, educational, socioeconomic, and access-based barriers to family engagement. Several strategies were also identified to help overcome these barriers including improving cultural safety, improving accessibility to services, and increasing families' connectedness to the habilitation centre and wider community.

Conclusions: Clinicians believe that family engagement is crucial for success of the cochlear implant habilitation process. The clinician-identified strategies can significantly improve family engagement, and may be useful for future clinical practice. While several strategies for family engagement were identified, many clinicians feel that further progress is required to truly break down the barriers to family engagement and make the habilitation process equitable for all families.

Acknowledgments

First and foremost, I would like to thank my supervisor Holly Teagle for letting me take on this project. Your ongoing support and guidance has made this whole process feel so much smoother! Thank you for always being understanding and reassuring me when I need it, I am very truly grateful. I also want to thank everyone in the Audiology department, especially Sharon, Min, and the HATC team – I have learnt so much from all you.

To everyone who took part in this study, thank you for taking the time to contribute to my project. A special thanks to my seven wonderful interview participants – each of you had such valuable perspectives and brought depth and richness to the research. I also want to thank everyone who advised me on the development and analysis process, your feedback and advice was greatly appreciated.

To the Wildly Academic People, Sophie T and Maral, thanks for always being there to convince me I deserve another iced latte. To Mahima and Dinithi, thank you for all the support throughout these *unprecedented times* and for listening to my stress rants. And to my fellow Holly's Angels, Abbey and Ji-Hee, I've loved having you guys by my side through this journey. I also want to acknowledge the remaining members of my MAud cohort, I am grateful to have met all of you and will cherish our time spent together (even the Zoom meetings)! To everyone else I've met along the way, thanks for taking me on board and making my time at Auckland uni so much fun!

Brett, I can't thank you enough for sticking by me and always believing in me. Your unwavering support and calming energy never fails to lift my spirits. I can't wait to see what the 'stings has in store for us. Last but of course not least, my family: Chris, Maree, Moth, Michael, and Suzie. Your support means the world to me and I can't wait to see you guys more often this year.

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1. Chapter 1: Introduction

Technological advances of the late 20th century led to the development of implantable hearing devices, like cochlear implants. Cochlear implants can facilitate excellent auditory access to children with significant hearing losses; this access to sound can be the gateway to higher level communication skills, enriched cognitive development, academic achievement, and psychosocial maturation. As we have become more familiar with implantable technology, the age that implantation can occur has drastically reduced, with some children now receiving implants by six months old.

The absence of hearing, which is the foundation of spoken communication development, has far-reaching impacts on childhood development. Whilst cochlear implants can provide unparalleled auditory access for deaf children, the habilitation process requires vigilant perseverance and commitment from the families involved. Post-implantation outcomes are dictated by far more than the surgical placement of the device. They are the result of daily commitment to consistent device use, exposure to an enriched sound environment, and persistent engagement with the child and their therapeutic interventions. Without strong family engagement to ensure these things, paediatric cochlear implant users will not achieve their potential to master speech and language. Alongside this are clinical decisions that must accommodate each family's values and philosophies on child rearing, identity, community and culture.

The potential impacts of committing to cochlear implant habilitation are far from fleeting for both the child and their family. The mastery of language affords deaf children a life-long access to literacy, higher-level thinking and reasoning, and psychosocial fulfilment. In light of the far-reaching benefits that cochlear implants can have, it follows that clinicians involved in the habilitation process are motivated to enable each child and family to reach their full potential. One large facet of this is developing an understanding of the various barriers and facilitators to family engagement, so that clinicians can empower families and uplift those who require additional support.

1.1. Personal statement

When I started this research project, the words "family engagement" did not hold significant meaning to me. Now as I near the end of my MAud journey, I consider family engagement to be a passion, and something I hope to carry with me throughout my career in paediatric audiology. Over the last two years, I have also learned a lot about Deaf culture and its surrounding history. I credit the insightful works of Mauldin (2016; 2019) for painting an astute picture of the copious challenges faced by children with cochlear implants and their families. Mauldin’s work, alongside my own personal experiences, informed many of the values and beliefs that guided my reflexive thematic analysis in the present study.

Throughout this thesis, I aimed to ensure that my writing was respectful towards and inclusive of Deaf culture. I also hoped to shed light on the systemic barriers that are currently limiting family engagement, and illustrate how they unfairly impact the outcomes of many children who are Deaf or hard-of-hearing.

2. Chapter 2: Literature review

2.1.The human auditory system

The human auditory system enables people to detect sound waves from their surroundings and interpret them into meaningful information, such as speech or environmental sounds. It consists of many intricate components, and can be divided into the peripheral and central auditory systems. The peripheral auditory system is primarily located in the temporal bones of the skull and includes the outer ear, middle ear, inner ear, and auditory nerve (Musiek and Baran, 2020). While the central auditory system includes a series of auditory nuclei in the brainstem, midbrain, and cortex (Musiek and Baran, 2020).

2.1.1. The peripheral auditory system

The peripheral auditory system consists of the outer, middle, and inner ear. Together, these structures function to transform sound waves from the environment into electrical signals encoding information about the frequency, timing, and spatial origin of sounds (Musiek and Baran, 2020). The pinnae of the outer ears are the first points of contact between external sounds and the auditory system. At the innermost aspect of the ear canal is the tympanic membrane, or eardrum, which is the boundary between the ear canal and the middle ear (Musiek and Baran, 2020). The tympanic membrane is vibrated by sound waves, and these vibrations exert force towards the middle ear. The middle ear is home to the malleus, incus, and stapes bones – known collectively as the ossicular chain (Pickles, 2012). The malleus is attached to the tympanic membrane, allowing it to transmit auditory information down the ossicular chain towards the inner ear.

The middle and inner ear are connected via the stapes footplate, which attaches to the oval window of the cochlea, which is a fluid-filled labyrinth with a snail shell-like shape. The cochlea contains the organ of Corti, which holds approximately 30,000 inner and outer hair cells that are used for sound detection (Musiek and Baran, 2020). The cochlea is also tonotopically organised, with the highest frequencies detected at the basal end and lowest frequencies towards the apex (Pickles, 2015). Inner hair cells in the cochlea are innervated by auditory nerve fibres (Pickles, 2015). These individual nerve fibres continue beyond the cochlea and converge to form the auditory nerve, which extends to the brainstem (Pickles, 2015). Nerve fibre bundles are specific to certain regions of the organ of Corti, which correspond to different frequencies. As they ascend the auditory pathway, these fibres preserve their spatial information, thus maintaining the tonotopic arrangement of the auditory system.

2.1.2. The central auditory system

The central auditory system is comprised of several brain structures, all of which preserving some degree of tonotopicity (Pickles, 2015). Closest to the peripheral auditory system is the cochlear nucleus, which acts to preserve the firing patterns produced by the auditory nerve in response to sound (Musiek and Baran, 2020). Fibres from the cochlear nucleus project bilaterally to the superior olivary complexes, thus marking the first crossover of auditory information (Musiek and Baran, 2020; Pickles, 2015). The lateral lemniscus is the next major nucleus in the pathway, followed by the inferior colliculus – an important relay station between the forebrain and brainstem (Pickles, 2015). The penultimate structure of the auditory pathway is the medial geniculate body, which plays a part in coding the intensity of sounds (Musiek and Baran, 2020). Lastly, information is sent to the auditory cortex in the temporal lobe where higher-level processing occurs. This allows us to assign meaning to different sounds and understand speech signals (Pickles, 2015).

2.2. Hearing loss and deafness in children

Every year, around 200 children are born with hearing loss in New Zealand (Digby et al., 2021). Hearing loss can be defined as a lack of access to usable sound frequencies (Digby et al., 2021). Between individuals, hearing loss can vary significantly in the frequencies or intensities that are inaccessible. Potential causes of hearing loss are also extremely diverse, and differing sites of lesion can create different types of hearing loss.

There are three main types of hearing loss: conductive, sensorineural, and mixed. In children, conductive hearing loss is fairly common. This refers to a lesion in the outer or middle ear that inhibits sound transmission to the cochlea. Conductive hearing loss is most often caused by a temporary ear infection, which rarely causes lasting damage or requires long-term intervention (Barr et al., 1973). Conversely, sensorineural hearing loss is almost always permanent. As the name suggests, sensorineural hearing loss refers to a lesion in the sensory (*i.e.* cochlea) and/or neural (*i.e.* auditory nerve) aspect of the auditory system. Loss of cochlear hair cells is the most common cause of sensorineural hearing loss – these cells cannot repair or regenerate once they are damaged, hence why sensorineural loss is permanent (Kwan et al., 2009). Dysfunctional hair cells can be congenital, or acquired through viral infections, trauma, or ototoxic medications (Cunningham and Tucci, 2017). If conductive and sensorineural lesions co-occur, this is referred to as a mixed hearing loss.

Table 1. Classifications of degrees of hearing loss severity

Degree of hearing loss	**Hearing threshold in dB HL**
Slight	16-25
Mild	26-40
Moderate	41-55
Moderately-severe	56-70
Severe	71-90
Profound	≥91

There are also varying classifications of hearing loss severity, ranging from “slight” to “profound” (Table 1). These classifications of severity are meaningful, as they can often inform which habilitation path is best for the child (Hornsby et al., 2011). Typically, children with mild to moderately-severe hearing loss will benefit from hearing aids. For severe to profound losses, most hearing aids cannot provide ample amplification for speech comprehension, and cochlear implants or sign language should be considered. The term “deaf” can be used to describe a range of hearing losses. Often, it refers to those with severe to profound hearing loss (Blanchfield et al., 2001; Robinshaw; 1995) – and this is how “deaf” will be used in the present study.

2.2.1. Cultural Deafness

Millions of people worldwide live with a hearing impairment. A subset of these people identify as culturally Deaf – *n.b.* the capital “D” is used to distinguish between being culturally Deaf or physiologically deaf. Deaf culture can be thought of as the shared beliefs and values of the Deaf community. Like any culture, the beliefs of the Deaf community are nuanced and multifaceted, but at its core, Deaf culture is about rejecting the notion that spoken language and hearing culture are the apotheoses of our society (Chapman and Dammeyer, 2017).

Historically, deafness has been medicalised and treated as an ailment that needs “fixing” – despite the fact that deafness alone rarely *needs* medical intervention (Blume, 1997; O’Brien and Placier, 2015). This focus on fixing or curing disabilities is informed by the medical model of disability. A key component of modern Deaf culture is stepping away from this outdated view of deafness and embracing social definitions of disabilities (Newton, 2020). The social model of disability argues that many disabilities are exacerbated by poor acceptance and accommodation from society – meaning that affected individuals are disabled by their *environment*, not their condition (Kattari et al., 2017; Keyes et al., 2015). An example of a disability that is now accepted and accommodated by society would be myopia, or short-sightedness. As glasses have become both accessible and socially acceptable, the public perception of myopia has shifted from it being a disability to being a simple variation of human nature. The perception of deafness could follow a similar path if the use of sign language and hearing devices became more widely accepted. Progress has been made towards Deaf acceptance in recent times. In 2022, *CODA* (a film depicting the lives of a Deaf family) won the coveted Oscar for Best Picture at the 94th Academy Awards ceremony – making it the first film with a predominantly Deaf cast to do achieve this feat (Lee, 2022).

Many disabled communities feel that the stigma surrounding disabilities must be broken down so that disabled individuals can feel safe integrating into society. The Deaf community are not alone in their fight against ableism, with the autistic and blind communities voicing similar opinions (Botha et al., 2021; Kattari et al., 2017; Woods, 2017). These communities are also calling for a change in language to reflect new attitudes towards disability. This includes intentionally opting for *identity*-first language (*e.g.* disabled people) over *person*-first language (*e.g.* people with disabilities) (Dunn and Andrews, 2015). Person-first language was popularised in the late 20th century as disabled people fought to be seen as more than just their disability (Gernsbacher, 2017). Over time, however, disabled people have come to accept and reclaim their disabled identity. Many disabled communities now agree that person-first language perpetuates the idea that disabilities are inherently negative, because it attempts to separate the person from their disability – whereas disabled people feel that their personhood is unequivocally intertwined with their disability (Botha et al., 2019; Dunn and Andrews, 2015). It is also worth highlighting that person-first language is seldom used in reference to non-disabled children – the identity-first terms "typically developing children" or "normally hearing children" are considered neither controversial nor offensive (Gernsbacher, 2017). This is because being non-disabled carries no negative connotations. It follows that adopting identity-first language for disabled people can be a small step towards acceptance and equity for disabled communities. For this reason, identity-first language is primarily used throughout this thesis.

In the context of family engagement for paediatric cochlear implantation and the extended habilitative journey needed for optimal outcomes, it is important to consider cultural Deafness as a valid option for deaf children. The value of Deaf culture can often be overlooked, even in settings where one may expect it to be readily embraced. For example, it is estimated that only one in five teachers in schools for the deaf are proficient in sign language (Maluleke et al., 2021). Medical and social approaches to habilitation can be undertaken simultaneously, however, many families opt for a solely medical-based approach due to a lack of awareness surrounding the richness and benefits of Deaf culture. It is vital that families are sufficiently educated on all available options for their child, so that they can make informed decisions that align with their own unique values. This notion of empowering families to be actively engaged in the habilitation process is at the core of the present research questions.

2.2.2. Impacts of deafness: Speech and language

Hearing loss can have a myriad of flow-on effects for a child. Most notably are the potential impacts on speech and language development. Note that although "speech" and "language" are colloquially considered interchangeable, the terms are in fact distinct. The former refers specifically to *spoken* language. Whilst "language" encapsulates any written, spoken, or signed form of communication that follows its own phonological, morphological, syntactic, semantic, and pragmatic rules (Murray et al., 2019). Language competencies can also be divided into receptive skills (*i.e.* understanding communication) and expressive skills (*i.e.* using language/behaviour to communicate) (Cupples et al., 2018; Kennedy et al., 2006).

As normally-hearing children are developing, they rely on auditory input to build their understanding of speech and language. Particularly during the first years of life, a child's speech and language skills grow exponentially. A significant proportion of this lexical and spoken language development comes from "incidental learning" (Banai et al., 2020; Christ and Chiu, 2018; Swanborn and de Glopper, 1999) – which refers to the process of learning language skills from overheard speech. Resultantly, children with hearing loss are significantly disadvantaged in their ability to acquire spoken language. Children who have milder hearing loss or receive timely intervention will often have sufficient access to speech to support first-language mastery at a developmentally-appropriate rate (Hall et al., 2019). However, as the degree of hearing loss increases, a child's access to spoken language input generally decreases, which leads to more significant delays in their auditory-verbal development (Nicholas and Geers, 2007). If a child has extremely limited access to spoken language (without a hearing device), this can lead to language deprivation (Glickman and Hall, 2018; Hall et al., 2019).

Due to the pronounced benefits of incidental learning, language deprivation is exceptionally rare in normally-hearing children and is seldom observed beyond extreme cases of child neglect (Hall et al., 2019). However, undiagnosed or untreated deaf children are at much higher risk of language deprivation (Nicholas and Geers, 2007). This can cause permanent deficits in their language skills – and even if some language is acquired later in life, it is unlikely that they will reach fluency (Friedmann and Rusou, 2015; Hall et al., 2019). By age two, most normally-hearing children can understand simple sentences, produce several consonants (*e.g.* /m/, /p/, and /w/), and use approximately 50 words (Feldman, 2019). And by ages five to seven, and their speech is typically 90% intelligible, and they should show a rudimentary grasp of social communication features like humour, rules, and negotiating (Feldman, 2019; Tyszkiewicz, 2013).

Historically, deaf children have been delayed in meeting these milestones. Research from Blamey et al. (2001) followed the speech and language outcomes of 87 deaf children with hearing aids or cochlear implants for three years. The study used multiple linear regression to model the groups' development, and concluded that by age 12, the children would have an average language delay of four to five years (Blamey et al., 2001). Whilst it must be taken into account that the children in this study were implanted later than what is common today, the study still demonstrated a large disparity in language development between deaf and normally hearing children.

2.2.2.1. Potential benefits of sign language

As mentioned previously, many parents of deaf children have limited awareness of Deaf culture and the benefits of sign language. This may lead to a delayed uptake of sign language for children who struggle to acquire spoken language skills even with a cochlear implant (Hall et al., 2019). The potential developmental stunting caused by language deprivation has led to a call for increased sign language exposure for deaf children, regardless of their habilitation path. For much of the 20th century, sign language exposure was thought to be detrimental to spoken language development in deaf children. Whilst unfavourable terms such as "visual takeover" and "language contamination" are still present in the literature (Gordon et al., 2011; Lyness et al., 2013; Moriarty, 2020), more research is emerging that questions the prior critiques of sign language (Humphries et al., 2014; Murray et al., 2019;

Sanzo, 2022; Stropahl et al., 2015).

A study from Geers et al. (2017) is among the body of literature claiming that sign language can detract from the auditory-verbal skills of deaf children. The authors asserted that children without sign exposure were almost twice as likely to have age-appropriate speech recognition and spoken language skills than those with sign exposure (Geers et al., 2017). Whilst this may sound compelling, there were fundamental flaws in the study design that undermine the authors' claims. Namely, there was no differentiation between exposure to sign-assisted speech and *natural* sign languages, which are linguistically complex with their own lexicons and grammatic rules (Murray et al., 2019; Newport and Meier, 1985). All children in the study were from non-native signing families (Geers et al., 2017), which makes it unlikely that the sign-exposed children were receiving a high quantity and quality of sign input. This is a considerable oversight as the developmental benefits of natural sign language are tantamount to those of natural spoken language (Murray et al., 2019). By contrast, sign-assisted speech lacks the linguistic complexity that is required to develop fully-fledged mastery of a language (Hall et al., 2019). Additionally, there may have been a self-selection effect where sign language was adopted by families of children who already struggled to acquire spoken language (Hall et al., 2019). This would subvert the implied causal relationship between sign exposure and poorer language outcomes. Furthermore, the presentation of findings from Geers et al. (2017) appeared to gloss over the fact that children with cochlear implants were still frequently exhibiting language delays regardless of their signing status.

The potential benefits of signing emphasise the need for children with hearing loss to master *language* over speech. For those who will receive cochlear implants, learning sign from an early age can create the necessary foundation for the development of spoken language skills. Not only does this bridge the gap in language input between pre- and post-implantation, but it also reduces the risk of language deprivation in instances of unsuccessful implantation, which occurs in 5-10% of paediatric cases (Ozer et al., 2021; Ulanovski et al., 2017; Wang et al., 2014). These unsuccessful cases can be due to incomplete insertion or activation of electrodes, post-surgical device failure, or other errors. However, it is also important to recognise that embracing Deaf culture and sign language will still require ongoing commitment and engagement from families, and some families may find it overwhelming to simultaneously attempt spoken- and signed-language acquisition. This further emphasises the need for comprehensive parental education surrounding the potential implications of each different habilitation path.

2.2.3. Impacts of deafness: The bigger picture

The impacts of deafness on speech and language outcomes tend to take precedent in research efforts surrounding deaf children. Whilst these are undoubtedly important, the wider psychosocial impacts of deafness can feel overlooked – the causes of which are often multifaceted and compounding.

The speech and language delays seen in deaf children can hinder their academic performance in school (Michael et al., 2019; Thagard et al., 2011). Research from Niclasen et al. (2016) found a significant association between hearing loss and academic difficulties; children with hearing loss were almost twice as likely to struggle with reading and spelling than their hearing peers, even after adjusting for parental education levels (Niclasen et al., 2016). Additionally, it takes considerable effort for children with hearing loss to listen in a class environment as they do not have access to full, natural auditory input; this can cause listening-related fatigue that impedes classroom learning (Hornsby et al., 2021). Poor academic performance can also flow on to affect vocational opportunities for deaf individuals in adulthood (Schley et al., 2011).

Because many deaf children struggle to acquire speech and language skills at the rate of their peers, their understanding of more sophisticated linguistic features, such as sarcasm or humour, can also lag (Marschark et al., 2019). Moreover, they may struggle to express themselves and communicate effectively with peers. In turn, these language delays can contribute to difficulties with socialising and quality of life (Tsou et al., 2021; van der Straaten et al., 2020). Compared to hearing children, deaf children are considered less popular (Peterson et al., 2016) and are more likely to have fewer or no friends, regardless of whether they use spoken or signed language (Terlektsi et al., 2020; Wauters and Knoors, 2008). These difficulties with peer relationships are the most significant hindrance for quality of life among deaf children, and can contribute to antisocial behaviours in adolescence or adulthood (Stevenson et al., 2015). One large scale survey of teenagers in mainstream schools found increased signs of anxiety, depression, substance use, and truancy among those with hearing loss – particularly for boys (Brunnberg at al., 2008).

Connecting with other deaf children may ameliorate some of the negative social impacts of deafness, but many still face discrimination from normal hearing peers (Bouldin et al., 2021; Tertlektsi et al., 2019). Bullying is unfortunately experienced by a substantial amount of children, with recent global research estimating that almost one-third of all children experience some degree of bullying (Biswas et al., 2020). However, due to the stigma surrounding disabilities and deafness, children with hearing loss are particularly vulnerable (Bouldin et al., 2021). Lund and Ross (2016) found that over 90% of children with hearing loss had been victims of bullying within the past two months, and approximately 70% were experiencing bullying at least once a week. Moreover, deaf children are less likely to be perpetrators of bullying than their normally hearing peers, which only heightens the injustice of their victimisation (Bouldin et al., 2021; Niclasen et al., 2016; Pinquart and Pfeiffer, 2015).

Having a strong sense of identity can enhance self-esteem and self-worth (Chapman and Dammeyer, 2017). However, some deaf children with cochlear implants can struggle with their sense of identity, as they feel like they aren't part of the hearing world or the Deaf community (Mauldin, 2019). Some deaf children may also identify with hearing culture themselves, but do not feel accepted by their hearing peers – this internal conflict can lead to feelings of social isolation (Terlektsi et al., 2020). Additionally, most deaf children are born into hearing families, which can limit their exposure to Deaf culture and may stunt their identity development (Mauldin, 2019). Following the Deaf cultural movement of the 1970s, Glickman (1996) proposed four distinct deaf identities that have become widely used and accepted in Deaf research: 1) culturally Deaf, 2) culturally hearing, 3) bicultural *i.e.* identifies with both hearing and Deaf culture, and 4) culturally marginal *i.e.* identifies with neither hearing nor Deaf culture. There is considerable evidence demonstrating the negative effects of a lack of Deaf culture immersion (Chapman and Dammeyer, 2017). For example, Bat-Chava (2000) found that deaf individuals with hearing or marginal identities consistently had lower self-esteem than those with Deaf or bicultural identities.

The aforementioned factors can all reduce the quality of life for deaf children, and can give rise to poor mental health and other adverse outcomes in adolescence or adulthood (Bouldin et al., 2021). Overall, it is clear that many deaf children are in need of additional support and acceptance to enable them to reach their potential in all facets of life.

2.3. Cochlear implants

In cases of severe to profound hearing loss, cochlear implants are a common intervention choice. The conception of the cochlear implant can be traced back to the late 18th century when Italian physicist Alessandro Volta observed a "crackling" sound after inserting metal rods into his ears and connecting them to an electrical circuit (Deep et al., 2019). This is the earliest known demonstration that the auditory system can be electrically stimulated. Over 150 years later, the first modern CIs were developed using the same principles discovered by Volta (Chen et al., 2019).

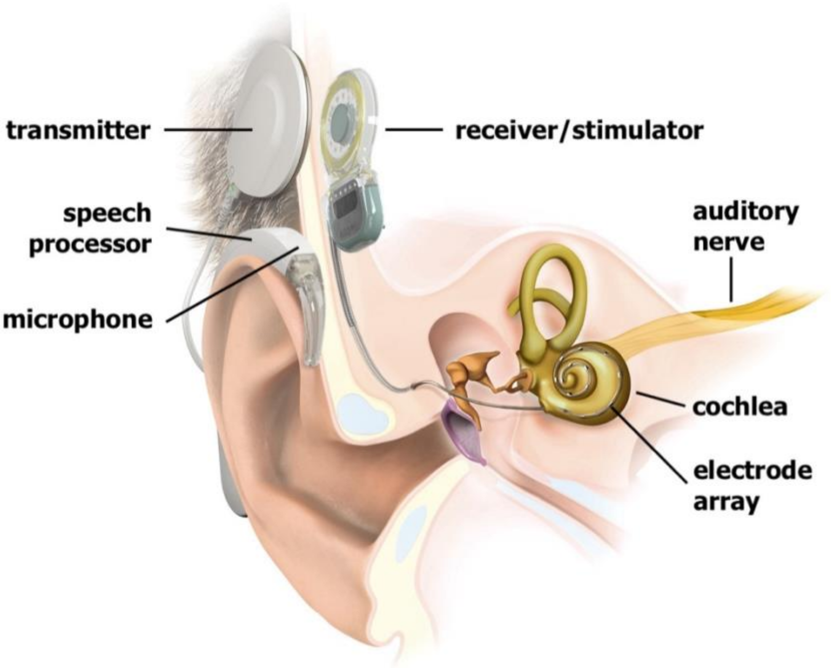

Figure 1. Diagram of a cochlear implant. Adapted from *Diagram of a cochlear implant*, by Hear hear!, 2022. CC BY-SA.

Today, cochlear implants are commonly implanted in people with severe to profound hearing loss to provide them with access to sound. They work by bypassing the ear and directly stimulating the auditory nerve with electrical stimuli (Buchman et al., 2020). Cochlear implants have both internal and external components. The external components include a speech processor and microphone that sits on the ear, and a transmitter that sends signals to the internal components (Figure 1) (Deep et al., 2019). The internal aspects of the CI are surgically implanted and involve a receiver/stimulator that sits under the skin behind the ear, and an electrode array that is inserted into the cochlea (Figure 1) (Deep et al., 2019).

While cochlear implants can provide severe to profoundly deaf children with unparalleled access to sound compared to other hearing devices, the auditory input is still inferior to that of hearing aids or natural sound. The 30,000 tonotopically arranged auditory nerve fibres of the cochlea enable highly-specific frequency discrimination (Musiek and Baran, 2020; Pickles, 2015). By contrast, most modern cochlear implants have 22 active electrodes, meaning they can only stimulate auditory nerve fibres at 22 locations along the cochlea (Garaycochea et al., 2020; Peters et al., 2018). This low fidelity input creates an unnatural and often unpleasant auditory experience (Dorman et al., 2020). Whilst it is difficult for children to chronicle their post-implantation experiences, adult patients have likened it to "robotic Donald Duck" or the sound of someone "talking with [their] mouth tightly closed" (Hallberg and Ringdahl, 2009, p. 119 and Dorman et al., 2020, p. 8, respectively). In addition, many patients have reported physically *feeling* sounds, which can be uncomfortable and distressing (Snell, 2015). Fortunately, patients typically adapt to these novel sensations over time and the input begins to sound clearer (Hallberg and Ringdahl, 2009). Nevertheless, a significant amount of time and effort must be invested before the cochlear implant's input sounds natural (Mauldin, 2009).

2.3.1. Cochlear implant habilitation in paediatric populations

The rise of cochlear implants has led to improved speech and language development in children with severe to profound hearing loss. However, cochlear implants have oft been touted as an infallible panacea for deafness. In reality, the post-implantation habilitation process is intensive and comes with no guarantees of auditory-verbal aptitude (Murray et al., 2019).

One unique feature of the paediatric cochlear implant habilitation process is that most recipients are pre-lingually deaf, meaning that they have had no prior access to sound before implantation (Petersen and Willems, 2006). This poses particular challenges as children must use the compromised signal from their implants to learn to listen and understand spoken language from the ground up; this is the rationale for the use of the term "habilitation" over "*re*-habilitation" when referring to paediatric cochlear implantation – the latter being more apt for cases of post-lingual deafness (McConkey, 2017).

The overall objective of cochlear implant habilitation is to develop the child's language skills by manually recreating the natural process of language acquisition (Feldman, 2019). The process of post-implant habilitation can look vastly different between cases and can entail a range of therapy styles or auditory training techniques. Speech-language therapy is often used for children with cochlear implants and can be started prior to implantation (Jeyaraman, 2013). This approach typically involves weekly to monthly sessions with a therapist, while the remaining efforts are primarily taken on by parents or educational figures (Feldman, 2019). Speech-language therapists aim to support a child’s development by individualising therapeutic approaches to suit their strengths and learning style (Paul and Roth, 2009). They also encourage learning in the child’s natural environments, often the home, to facilitate the transfer of newly learned skills to everyday contexts. Home-based, parent-implemented speech-language therapy has been shown to improve delays in expressive language capabilities (Suttora et al., 2021; Zuccarini et al., 2020) – although, the potential effects on receptive language skills remain undetermined (Heidlage et al., 2020; Tosh et al., 2007) Overall, parental input appears to contribute significantly to the efficacy of speech-language therapy, and interventions administered by parents appear to be equally as effective as those administered by clinicians, given that parents receive sufficient guidance and training (Law et al., 2004). However, the demands of home interventions can be overwhelming for parents – particularly those who have competing work or family demands (Huttunen and Välimaa, 2012; Zaidman-Zait and Most, 2006). Many have also expressed surprise at the workload required for speech-language therapy (Zaidman-Zait, 2008).

Another branch of speech-language therapy involves working with an auditory-verbal therapist (now known as Listening and Spoken Language Specialists). This approach is highly analytical and specific – the term Listening and Spoken Language Specialist has even been trademarked by the Alexander Graham Bell Association (Tyszkiewicz, 2013). The schedule for auditory verbal therapy is markedly intensive (Dornan et al., 2020; Hayes et al., 2009), and can come at a considerable financial cost to families in countries without public healthcare (Brennan-Jones et al., 2014). The philosophy that guides the auditory-verbal approach is that listening skills need to be developed in isolation, so that children can build their auditory abilities without relying on visual or other contextual information (Rhoades, 2006). Auditory-verbal therapists often use a variety of techniques to exclude visual cues during auditory training, which is thought to promote listening skills (Brennan-Jones et al., 2014; Rhoades, 2006). Another hallmark of auditory-verbal therapy is its emphasis on parental involvement. It is the only habilitative approach that explicitly requires parents to be the primary therapists for their child (Brennan-Jones et al., 2014). The auditory-verbal approach is firmly grounded in linguistic development theory, and several studies have shown that children who undergo the therapy can meet speech and language milestones at similar rates to hearing children (Dornan et al., 2010; McCaffrey et al., 2000; Pappas et al., 1994; Warner-Czyz et al., 2005). Despite this, there is still some debate in the literature regarding its advantages over other therapeutic approaches. One recent retrospective analysis of speech and language outcomes in children with cochlear implants demonstrated that recipients of auditory-verbal therapy consistently outperformed children who followed other habilitation models (Oral- or Total-Communication) (Thomas and Zwolan, 2019). However, the children in the auditory-verbal group had comparatively higher socio-economic status (SES) and significantly earlier ages of implantation (19 months) compared to the other groups (32 and 41 months) – these asymmetries unfortunately detracted from the validity of the study (Thomas and Zwolan, 2019). Although most research of auditory-verbal therapy supports its efficacy, it is important for future studies to confirm whether it is a worthwhile endeavour compared to less onerous approaches.

A less common yet equally valid approach to post-implantation habilitation is to incorporate sign language into the child's linguistic repertoire. Sign can be used as a primary communication mode or in parallel to speech-focused habilitation (Fitzpatrick et al., 2016). When signed and spoken language are learned concomitantly, this is referred to as the bimodal-bilingual communication approach (Humphries et al., 2014). There are an array of factors contributing to the infrequent uptake of sign language. Foremost are the practical barriers for parents. Because most parents of deaf children are non-signing, there would be a substantial learning curve for parents hoping to learn how to sign with their child (Napoli et al., 2015). Many parents are also concerned for their child's social wellbeing and may fear that learning sign language will inhibit their spoken language development; in turn, this could lead to social isolation or ostracism – particularly in a mainstream educational setting (van der Straaten et al., 2020). Additionally, clinicians are overwhelmingly in favour of spoken language over sign language, and may not suggest sign-inclusive habilitation to parents until other avenues have proved fruitless (Murray et al., 2019). For those who do employ bilingual-bimodal communication, there are some distinct advantages over speech-focused approaches. Whilst it does not appear that signing itself can *improve* spoken language outcomes (Fitzpatrick et al., 2016), having an established knowledge of sign will ensure that a child does not go without language skills if spoken language acquisition is not successful in the long-term (Humphries et al., 2014). It also gives deaf children a means of communication for when their implant is temporarily unavailable. There are obvious safety benefits to this, as non-signing deaf children could quickly become vulnerable if their device was lost or ran out of battery.

Throughout their early years, most paediatric cochlear implant users will also receive support from other professionals. These can include deaf educators, such as Advisors on Deaf Children or Resource Teachers of the Deaf, who work closely to support children in their educational settings. Children and families may also work with psychologists or counsellors to address the emotional challenges that can arise during the habilitation process.

Regardless of which habilitation path is chosen for a child, substantial long-term input will be required from both the child and family. It is apparent that families need to be better informed of the ongoing responsibilities involved in the habilitation process, as therapy is often continued for years after implantation (Huttunen and Välimaa, 2012). Furthermore, the later therapy is started, the longer it may be needed (Paul and Roth, 2011).

2.3.2. Early intervention in paediatric cochlear implant habilitation

In relation to hearing loss, the concept of “early intervention” refers to the practice of beginning habilitation, such as cochlear implantation, as early as possible. Early intervention is naturally dependent on early diagnosis, hence, the implementation of newborn hearing screening has made early intervention much more accessible. Before newborn hearing screening, the average age of diagnosis was between 18 and 24 months, meaning that many deaf children showed significant language delays (Yoshinaga-Itano, 1999). Now, many countries, including New Zealand, follow the “1-3-6” goals for early intervention; this entails aiming to have all children screened by one month old, diagnosed by three months old, and starting habilitation by six months old (Digby et al., 2021). In 2019, the Joint Committee on Infant Hearing (JCIH) even proposed that early intervention programs that are currently meeting the 1-3-6 goals could aim for 1-2-3 goals (JCIH, 2019).

The importance of early intervention can be explained by the “critical period” of language development, which is the timeframe wherein languages can be effortlessly acquired to a fluent degree (Friedmann and Rusou, 2015; Sharma et al., 2002). For many adults, learning a new language would be a mammoth undertaking. Yet, it is a seamless and largely subconscious process for most normally-hearing children. This is because the brain is highly plastic during early childhood, allowing new neuronal connections to be established at a rapid rate (Karl and Sharma, 2012). When young children are exposed to sensory input such as speech, various regions of the brain are activated and neuronal connections are formed between them (Sharma et al., 2020). Any of these connections that are simultaneously activated will go on to forge larger neuronal networks that create the foundation for higher-level cognitive processes, such as receptive language skills (Feldman, 2019). In fact, children as young as eight months old have demonstrated the ability to detect distinct phonological units of speech, and can use them to identify word boundaries in a constant stream of speech (Saffran, 2001). Time estimates for the critical period of language development are varied in the literature, but it is generally thought to end after the first few years of life (Hall et al., 2019; Nicholas and Geers, 2007). There is also evidence to suggest that language acquisition can begin in the womb, with neonates being shown to prefer languages they were exposed to *in utero* (Mehler et al., 1988). This further emphasises the importance of early access to language which, for many deaf children, is contingent on strong family engagement from early on in the habilitation process.

It is well known that early intervention can improve speech and language outcomes for deaf children (Yoshinaga-Itano, 1999). Language outcomes, such as vocabulary, reading, and articulation, can be improved by 20 to 40 percentile points if habilitation is started by six months of age, compared to children who started later in life (Yoshinaga-Itano, 2003). Newer evidence supporting the benefits of early intervention continues to emerge. An ongoing prospective study of deaf children in Australia has demonstrated clear links between early intervention and improved speech and language outcomes. This research, called the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study, is currently following the progress of over 400 children with hearing loss, including 111 cochlear implant users (Cupples et al., 2018). Interestingly, the benefits of early intervention appear to be greater for children with cochlear implants compared to those with hearing aids (Ching et al., 2013; Cupples et al., 2018). At five years of age, the average global language scores of children who received their implants at six months was 1.4 standard deviations (SD) higher than those who received their implants at 24 months (Cupples et al., 2018). Similar positive effects of early intervention were also observed at three years of age (Ching et al., 2013). The language outcomes seen in LOCHI study participants are highly encouraging compared to earlier studies of children with hearing loss; on average, the scores of LOCHI participants were 1 SD below their normal hearing peers – this is considered the lower end of the normal range (Cupples et al., 2018). By comparison, similar research from 2006 found a 2 SD discrepancy in language scores between deaf and normally-hearing children, which is indicative of severe language delays (Kennedy et al., 2006). At the time of the study, "early diagnosis" was considered nine months old, and intervention was not started until 15 months on average (Kennedy et al., 2006). This delayed timeframe is a stark contrast to the 1-3-6 and 1-2-3 goals that are used today, and is a likely factor in the poorer language scores reported by Kennedy et al. (2006).

The findings from the LOCHI study are indeed promising, and appear to demonstrate clear benefits of earlier implantation ages and technological advances in cochlear implant habilitation. However, it should not be overlooked that many children with cochlear implants are still struggling to match the language development skills of normally-hearing children.

2.3.3. Controversy of paediatric cochlear implantation in the Deaf community

Many members of the Deaf community firmly believe that deaf children should be immersed in Deaf culture and use sign language as their primary mode of communication (Putnam, 2020). In light of this, controversy naturally arose when cochlear implantation became a routine intervention for deaf children – especially given that access to spoken language was touted as the main benefit.

Before the age of Deaf activism, anti-deaf discrimination was prevalent in society and deaf people were forcibly upheld to the standards of the hearing world (Harmon, 2021). Alexander Graham Bell, who is primarily known for inventing the telephone, also unintentionally played a sizeable role in the oppression of deaf people (Greenwald, 2014). Bell, whose own mother was deaf, was hoping to encourage the assimilation of deaf people into the hearing world. However, his views were misguided and ultimately gave rise to decades of mistreatment towards deaf individuals (Harmon, 2021; Trussel, 2021). Bell fiercely advocated for "oralism" in deaf education, which is the intentional suppression of sign language in favour of spoken language and lip-reading (Greenwald, 2014; Hall, 2017). He was also considered an esteemed member of society following his invention of the telephone, so his views on oralism were swiftly adopted by deaf educators (Greenwald, 2014; van Cleve, 2007). Alongside oralism, Bell also firmly endorsed eugenics, and notoriously penned an essay calling for the prevention of deaf people marrying or procreating together (Greenwald, 2014; Trussel, 2021). There is still progress to be made towards Deaf acceptance. Still today, many Deaf people have been victims of disability-related hate crimes. In 2015, the British Deaf Association (BDA) surveyed Scotland's Deaf community and found that over half of participants had experienced a hate crime before – 84% of victims also reported experiencing hate crimes on multiple occasions (BDA, 2015).

In light of the numerous adversities that Deaf communities have faced, it is understandable that Deaf people are often staunch in their disapproval of cochlear implants.

While the concerns of the Deaf community must not go unheard, it is difficult to ignore the fact that approximately 95% of deaf children are born into hearing families (Mitchell and Karchmer, 2004). In an ideal world, all family and community members surrounding a deaf child would be proficient in sign language so the child could communicate and feel included. However, that is far from the present reality of our society where only ~1% of the general population use sign language (Mitchell et al., 2006). It is an unfortunate truth that denying a deaf child access to sound would likely result in them being ostracised from their own family and community.

In recent times, the Deaf community's perception of CIs has shifted into a more favourable light (Putnam, 2020). This coincides with the increasing popularity of bimodal-bilingual communication, which allows children to be exposed to Deaf culture whilst still working towards spoken language proficiency (Humphries et al., 2014). There is increasing evidence that Deaf and hearing cultures need not be mutually exclusive, and there is room for deaf children in both worlds (Bat-Chava, 2000; Chapman and Dammeyer, 2017).

2.4. An introduction to family-centred care

Modes of healthcare delivery have varied widely over time. Traditional healthcare models tend to be patient-focused and address the varying needs of a patient in isolation. What traditional models of healthcare have failed to recognise is that patients and their needs do not exist in a vacuum. Rather, they are strongly affected by their environment and the people in it (Bamm and Rosenbaum, 2008). The shortcomings of traditional healthcare delivery have slowly come to light in recent decades.

In the 1950s, the term “family-centred care” was coined by American social workers who were studying a community in St. Paul, Minnesota. The researchers noted that a small number of families with complex needs were placing a disproportionately large burden on the community’s social services (Birt, 1956). These families were described by social work staff as “difficult to treat” or even “hostile” (Birt, 1956, p.42). However, further investigation revealed that these families had been receiving fragmented, disorganised care that was centred on individual family members rather than acknowledging the needs of the family as a whole. Not only was this frustrating for the families to navigate, but it also created an unnecessary strain on the social services, with almost 50% of resources going to these families (Birt, 1956). The researchers recognised the need for a holistic, multidisciplinary approach that centred the family unit and their collective needs. In the following years, family-centred care gained traction in many areas of healthcare including nursing, speech language pathology, and audiology (Ball et al., 2021; Hammer, 1998; Kokorelias et al., 2019; Maluleke et al., 2021). But, family-centred care has not been immune to criticism. Some practitioners worry that involving parents in the decision making processes can be too stressful for them (Barker et al., 2021; Shields, 2010). Others are concerned about practical barriers to implementing family-centred care, as it requires a high staff-to-patient ratio to be delivered effectively (Paliadelis, 2005; Shields, 2010).

Today, family-centred care can be defined as a method of service delivery that acknowledges and collaborates with the whole family, and is integrated with other relevant healthcare disciplines (Jolley and Shields, 2009). It is now widely embraced in paediatric care, with many providers in developed countries already claiming to be family-centred. Despite this widespread acceptance, few clinical settings have yet to properly implement family-centred practices. So, what does it look like to be family-centred? Is family-centred care really practicable or an unattainable ideal? True family-centred care must be supported by a strong social welfare system (Duffy et al., 2018). Without this, parents from disadvantaged or marginalised backgrounds often lack the time and resources to fully participate in the care of their child. Tackling systemic issues is, of course, extremely challenging and resource intensive. However, it would break down many of the social barriers to equitable healthcare, which may reduce strain on the healthcare system in the future.

In the implementation of family-centred care, clinicians must also be mindful of negative bias toward families. Historically, some healthcare staff have excluded low-income parents from decision-making processes due to negative assumptions about the parents' capacity to understand or contribute to the treatment of their child (Alsop-Shields, 2002; Shields, 2010). Furthermore, health staff tend to view working with children in a more positive light compared to working with parents (Shields, 2010). This unfavourable perception of parents creates a barrier to achieving family-centred care, as parents must be involved and embraced throughout the treatment process for family-centred care to be properly implemented (Moeller et al., 2013). Parents have expressed that mutual trust and open communication with clinicians is critical when it comes to providing the best care for their child (Moeller et al., 2013; Shields, 2010) – this further highlights the need for clinicians to start viewing parents as allies rather than adversaries, because both parties ultimately have the child's best interests at heart.

2.4.1. Family-centred care in paediatric cochlear implant habilitation

Family-centred care can be applied to any area of healthcare, but it has proved particularly useful in paediatric settings as parents and family are an integral part of most children's lives (Bamm and Rosenbaum, 2008; Matziou et al., 2018). Given the extensive role of parents in the cochlear implant habilitation process, it follows that family-centred care is now the standard in many habilitation centres (Paul and Roth, 2011).

Traditional models of cochlear implant service provision were far removed from the principles of family-centred care. These models primarily followed a prescription-based approach, wherein the clinician would prescribe a treatment plan based on what they felt is best for the child – it was then the family's responsibility to comply with their prescribed plan (DesJardin, 2006; Kokorelias et al., 2019). Whilst clinicians undoubtedly had the child's best interests at heart, prescription-based models did not leave room to honour any cultural, religious, or other boundaries that families may have had. In instances where a family's boundaries were in conflict with their prescribed treatment, they may have found themselves being criticised for poor compliance. Oftentimes, this would result in disengagement with their service provider and could create feelings of distrust and alienation. The field of cochlear implant habilitation has since moved away from this mode of practice, and greater efforts are made to collaborate with families in decision-making processes (Ciciriello et al., 2016; Porter et al., 2018).

Incorporating family-centred care into the post-implant habilitation of a child can entail a variety of techniques. Foremost, families must be sufficiently educated and feel empowered to take part in the habilitation process. This enables the family and clinician to collaboratively outline the course of action for their child – which is often done via joint goal-setting sessions (Zaidman-Zait and Young, 2008). The daily life of families must also be considered throughout the habilitation process; this creates a meaningful context for therapy techniques for the child whilst centring the values of the family (Alduhaim et al., 2020). Additionally, it is important for clinicians to recognise and build upon the strengths of each individual family (Moeller et al., 2013). This, of course, requires a foundational knowledge of each family's unique dynamics, which can be deepened as the habilitation process progresses. Family-centred care also necessitates emotional support for families, which can be provided through a variety of avenues. Namely, counselling is often integrated into habilitation, however, emotional support can also be fostered through inter-family connections (Moeller et al., 2013).

2.5. Family engagement in paediatric cochlear implant habilitation

One major aspect of family-centred care is family engagement. Whilst the principles of family-centred care in paediatric cochlear implant habilitation are certainly relevant to family engagement (e.g. Moeller et al., 2013; McConkey-Robbins, 2017), they rarely address engagement itself. If family engagement is not distinctly highlighted in these guidelines, the level of awareness regarding the importance of engagement may wane – this could lead to adverse impacts on outcomes for children with cochlear implants.

The term “family engagement” can be used to describe a family’s level of active participation in habilitation, advocacy for their child, and informed decision making (Erbasi et al., 2016; Moeller et al., 2013). Paediatric cochlear implant habilitation is a long-term commitment with a strong focus on the family throughout all stages. It is also important to note that simply undergoing cochlear implantation surgery does *not* provide access to sound – this can only be achieved whilst the external device is being worn. Hence, a child’s access to sound and language input is highly dependent on family engagement, as the families are most able to enforce device wear-time. It is crucial that families are firmly on board with the habilitation process and form reciprocal connections with their habilitation providers.

Although early diagnosis and intervention are largely available for deaf children, outcomes can vary widely between cases. Some children are able to develop their speech, language, and executive function skills at rates comparable to normally hearing children, while others still show considerable deficits. Many investigations into the causes of this variation have focused on intervention- or child-based factors such as age of implantation or additional disabilities (Ching et al., 2013; Chu et al., 2019; Harris et al., 2017; Thomas and Zwolan, 2019). These factors are of course worthy of recognition, but researchers have also posited that family engagement can play a considerable role.

To appreciate the significance of family engagement, Bronfenbrenner’s (1979) *Ecological Systems* theory of child development must also be understood. This theoretical framework postulates that the process of a child’s development is embedded in the social and cultural “ecosystems” surrounding them, such as the family, school setting, and peer groups

(Bronfenbrenner, 1979; Fivush and Merrill, 2016). These ecosystems have complex, dynamic relationships with each other and also function under the influence of higher-level systems, like local governments and the economy (Bronfenbrenner, 1979; Mizuki et al., 2021). The family ecosystem (*i.e.* parents, siblings, and extended family) is regarded as the most influential aspect of a child's development (Bronfenbrenner, 1979). This is because children spend considerable amounts of time with their family, and the family is often one of the most stable and persisting ecosystems (Fivush and Merrill, 2016).

For a child with cochlear implants, the time spent per week in therapy dwarfs in comparison to the time spent around family – particularly the parents (McConkey-Robbins, 2017). This situates the parents in a prime position to support healthy development for their child. It follows that children with well engaged parents often fare better than those without. There is now substantial evidence illustrating the benefits of strong family engagement (Bierbaum et al., 2019; DesJardin, 2006; Garung et al., 2020; Hogan, 2021; Holzinger et al., 2020; Le Roux et al., 2016; Maluleke et al., 2021; Moshtaghi et al., 2019; Verdon et al., 2015; Yanbay et al., 2014; Zaidman-Zait and Young, 2008). Research from Moeller (2000) reported that levels of family engagement can account for approximately 35% of variation in language scores among children with cochlear implants,

In a matched case-study of two children with cochlear implants, Davenport and Holt (2019) found marked discrepancies in speech, language, and psychosocial outcomes. The two children had almost identical audiological history, including age of diagnosis and intervention, and were primarily varied in their family characteristics, such as household income and family cohesion (Davenport and Holt, 2019). The child with a favourable home and family environment was able to meet age-appropriate speech and language milestones, and demonstrated advanced social skills for his age. In contrast, the second child was over 1 SD below the mean for language outcomes, showed little mastery of speech, and had more behavioural problems (Davenport and Holt, 2019). It was noted that the first family was able to provide their child with greater home enrichment and support to promote speech and language development. This was theorised to be one of the key influences on the children's varying outcomes (Davenport and Holt, 2019). A similar, larger scale study from Holt et al. (2020) illustrated similar trends between outcomes and family characteristics. These findings highlight the impact that external stressors, such as financial issues or family conflict, can have on a family's ability to engage with the habilitation process.

When discussing families who show poor engagement, it is important not to individualise the issue and perceive it as a personal shortcoming or flaw on the family's part. Rather, the wider systemic issues that underpin a family's capacity to engage must be both acknowledged and addressed. In 2013, Moeller et al. updated the best practice principles for family-centred care in children with hearing loss, with several of the principles highlighting the importance of family engagement. In particular, providers were urged to understand how oppression, discrimination, and implicit bias against families may impact the quality of the services they receive and, therefore, their ability to effectively engage (Moeller et al., 2013).

2.5.1. Barriers to family engagement

It is clear that family engagement can have a significant impact on the outcomes of children with cochlear implants. Consequently, it is important to understand the barriers to family engagement as this insight can be applied when developing strategies to encourage engagement. There are currently several structural issues within the field of cochlear implant habilitation that may contribute to barriers to family engagement. Firstly, the concept of family engagement is yet to be formally defined, this makes it difficult to monitor engagement effectively. Further, there is a lack of frameworks or guidelines that are specific to engaging families.

Many studies have previously demonstrated the importance of family engagement, however, they rarely investigate the specific barriers and facilitators of engagement. There is currently only one original article directly investigating the barriers and facilitators of family engagement in the habilitation process of children with hearing loss. In 2020, Alduhaim et al. conducted a qualitative investigation into parent-identified barriers and facilitators of family engagement in intervention services for children with hearing loss. While this study was not specific to the cochlear implant habilitation process, 71% of participants were parents of cochlear implant users (Alduhaim et al., 2020). It must also be noted that this study was based in Kuwait, and was focused on the specific challenges faced by families in developing countries. Hence, many of the identified barriers were related to the lower quality of habilitation services and are unlikely to be applicable to the countries that are addressed in the present study. Regardless, the study provided insight into parental opinions and identified several relevant facilitators of engagement. Other studies have identified broader barriers and facilitators that can be applied to family engagement. Mytton et al. (2014) investigated the barriers and facilitators to family engagement in parenting programmes. While parenting programmes are not identical to cochlear implant habilitation process, they are similar in that they require ongoing commitment and attendance of sessions.

Several emotional or behavioural factors from families may act as barriers for family engagement. Namely, grief and denial about the child's hearing loss can delay or reduce a family's involvement in the habilitation process (Bierbaum et al., 2019). A study of factors impacting the speech and language development of deaf children found that ongoing family grief could contribute to poorer outcomes (Fulcher et al., 2015). Denial has been shown to delay cochlear implant uptake (Bierbaum et al., 2019).

Many families also experience logistical barriers to engagement. For those who live far from their habilitation provider (e.g. rural families), attending in-person appointments is a significant burden, often taking hours out of their day. This can be further complicated for some rural families who do not have sufficient connectivity for telehealth (Noblitt et al., 2018). Several studies have identified these practical issues as barriers (Bierbaum et al., 2019; Ravi and Gunjawate, 2020; Noblitt et al., 2018). On average, children from rural families have also been shown to have later ages of implantation (Li et al., 2016) – this finding demonstrates the impact that practical barriers can have on a child's habilitation process. Furthermore, one parental survey found that the practical burdens associated with habilitation (e.g. travel and time off work) were the most commonly reported barrier to implantation (Yang et al., 2018). For these families who face logistical barriers, the lack of access can be both disappointing and demotivating, and may cause them to disengage with habilitation services (Alduhaim et al., 2020).

Numerous studies have documented the correlation between low SES and poorer outcomes in paediatric cochlear implant habilitation (Noblitt et al., 2018; Schuh and Bush, 2021; Smith et al., 2019; Stern et al., 2005). Research from Kirkham et al. (2009) also demonstrated that 78% of audiologists who work with children with cochlear implants perceive a negative impact of low SES on post-implantation outcomes. Participants also believed that low family engagement was the main contributor to the poorer outcomes in low SES families (Kirkham et al., 2009). Low SES families are also less likely to be able to afford extra private therapy, and may struggle to keep up with costs related to habilitation, such as petrol for appointment attendance (Kirkham et al., 2009). These examples are just some of the countless ways that low SES can contribute to poor engagement and outcomes.

Language differences between families and providers can be a barrier to family engagement. The effectiveness of habilitation relies heavily on strong communication between clinicians and families (Alduhaim et al., 2020). Clinicians also do a significant amount of educating so that families can be informed of the habilitation process and take part in decision making. It follows that language barriers can adversely affect a family's understanding of the habilitation process and, therefore, their engagement (Grandpierre et al., 2018).

Additionally, cultural differences between families and providers can have a negative impact on family engagement. Grandpierre et al. (2020) found that cultural mismatches between a family and their provider can lead to struggles building trust and rapport within their relationship. Furthermore, cultural diversity often intersects with other barriers to family engagement such as low SES, stigma or shame associated with disability, and language barriers (Grandpierre et al., 2018). The intersection of various barriers can have a compounding effect on a family's ability to engage in habilitation.

Other child- and family-related factors can inhibit family engagement, such as additional disabilities of a child or having multiple siblings within a family. The effects of additional disabilities are most often mentioned for their potential negative impacts on speech and language outcomes (Cupples et al., 2018). Likewise, larger family size is a predictor of poorer speech and language skills for children with cochlear implants (Davenport and Holt, 2003; Geers et al., 2003). However, similarly to low SES, these factors can impact engagement due to the additional demands they place on a family.

It is evident that there is an abundance of potential barriers to family engagement, all of which can intersect and interact with each other. However, there are fortunately many ways that these barriers can be overcome or circumvented to assist families throughout the habilitation process.

2.5.2. Facilitators and strategies for improving family engagement

As with the barriers of family engagement, the facilitators of engagement are scarcely discussed in the literature. Much of the existing research that is relevant to family engagement is predominantly focused on barriers. This issue is not exclusive to the cochlear implant habilitation process. A systematic review of the barriers and facilitators to rehabilitation services, including physical therapy and occupational therapy, found that facilitators were less frequently mentioned than barriers (Grandpierre et al., 2018). Furthermore, the review noted that studies of clinicians' perspectives were less likely to report on facilitators compared those which recruited patients or caregivers. The authors suggested that future research should focus on identifying feasible solutions to known barriers (Grandpierre et al., 2018). Despite the limited literature, several facilitators of family engagement have still been identified.

Firstly, building strong, trusting relationships between families and providers can facilitate family engagement. Alduhaim et al. (2020) found that almost 80% of parents feel that there needs to be mutual trust with clinicians for them to be able to fully engage with habilitation services (Alduhaim et al., 2020). This healthy relationship with providers allows families to be honest about their experiences with habilitation, so they can comfortably express their needs and concerns (Alduhaim et al., 2020). Clinicians are encouraged to create a safe, non-judgemental, and non-stigmatising environment with their families to help build this relationship and facilitate engagement (Mytton et al., 2014).

Group experiences have also been identified as a facilitator of family engagement. Interestingly, Mytton et al. (2014) found that parents were twice as likely as providers to indicate that group experiences were important for encouraging engagement. Likewise, Alduhaim et al. (2020) noted that increased family participation beyond the clinical setting can facilitate engagement. These wider group experiences can create opportunities for parents to meet others who are going through similar experiences. Through this, they can exchange ideas and provide emotional support to one another (Mytton et al., 2014). The bonds formed between families may also provide motivation to stay engaged with the habilitation process, as the groups can become a source of enjoyment and fulfilment for families.

Cultural differences between families and clinicians have been established as a barrier to engagement. It follows that providing culturally safe care can facilitate engagement. In other rehabilitation fields, cultural awareness amongst clinicians has been shown to improve patients' perceptions of their service (Grandpierre et al., 2018). Families of children with hearing loss have also expressed that they appreciate when their culture is integrated into their habilitation activities (Alduhaim et al., 2020). Not only does this make their therapy techniques easier to apply to daily life, it also fosters a sense of trust and rapport with their providers.

Having accessible services is another way to facilitate family engagement. Whilst it would be ideal for all families involved in cochlear implant habilitation to live near their service providers, this is, of course, impracticable. Mytton et al. (2014) found that being flexible with session times can ease the burden of poor accessibility. Furthermore, the increased uptake of telehealth in light of COVID-19 had made habilitation more accessible for rural families – this may also facilitate engagement. Interestingly, providers appear to be less cognizant of the practical barriers to family engagement compared to parents (Mytton et al., 2014). It is important for clinicians to be aware of these barriers so that they can work with families to overcome them, which in turn will encourage their engagement.

Finally, the use of incentives and compensation has been identified as a facilitator of family engagement (Mytton et al., 2014). These most commonly include providing free meals/food during sessions, or giving petrol/taxi vouchers to assist families with the cost of attending habilitation. Whilst these incentives have clear material value, they can also facilitate engagement in a more figurative way. Families may view these gifts as an acknowledgement of the time and effort they invest in habilitation, which then encourages them to stay engaged.

2.5.2.1. The role of the clinician in facilitating family engagement

As the field of cochlear implant habilitation has shifted towards family-centred care, the role of the clinician has become more focused on engaging families (Moeller et al., 2013). With previous approaches to service provision, the onus has been on the families to ensure that they stay engaged and active throughout habilitation. Moreover, a lack of engagement could be perceived as a failure on the family's part. As the barriers to family engagement have become increasingly understood, clinicians have begun to take on the responsibility of engaging families (Moeller et al., 2013).

2.5.3. Clinicians' views on family engagement

Unfortunately, very little research has been done to determine clinicians' views towards family engagement. The value of the clinicians' perspective is twofold: 1) clinicians can serve as a proxy measure of family perspectives due to their ongoing, close-working relationships with families, and 2) it is important to determine whether there are discrepancies between families' and clinicians' views so that any asymmetries can be addressed as needed. Based on research in other fields, it appears that clinicians and families generally hold similar views

(Grandpierre et al., 2018). However, there are certain things that are important to families that clinicians may be less aware of, and vice versa (Grandpierre et al., 2018).

Currently, research from Kirkham et al. (2009) provides the best insight into clinicians' views on family engagement. Kirkham et al. (2009) surveyed 103 audiologists regarding their perspectives on SES-related health disparities in paediatric cochlear implantation. While the study did not directly investigate family engagement, many of the findings are still relevant to the present study. Low SES was perceived as being linked to poorer post-implantation outcomes by most audiologists (78%). Furthermore, low parental involvement in habilitation was identified as the most common factor impairing the outcomes of low SES children. Additionally, clinicians felt that increasing parental involvement in habilitation was the most effective strategy for improving outcome disparities (Kirkham et al., 2009). This demonstrates a strong degree of awareness of the impact of family engagement among audiologists involved in the cochlear implant habilitation process.

2.6. Summary of the literature

It is evident that deafness can have profound impacts on a child's language development and their wider psychosocial wellbeing. By providing auditory access to deaf children via cochlear implants, many of the impacts of deafness can be reduced or eliminated. However, ongoing engagement with the post-implantation habilitation process is required for children to be able to develop the language and psychosocial skills needed for a fulfilling life. Many families of paediatric cochlear implant users face barriers to engagement, and this can have serious downstream effects on the outcomes of the child. Currently, there is a need for an improved understanding of the barriers and facilitators of family engagement.

3. Chapter 3: Methods

The overall goal of the present study was to explore the views around family engagement from clinicians involved in the paediatric cochlear implant habilitation process, with a particular focus on uncovering the strategies that clinicians are currently using to facilitate family engagement. Gaining insight into clinicians' perspectives of family engagement may help to identify the most effective strategies for facilitating engagement, whilst also uncovering any weaknesses in the field that currently act as barriers to engagement.

3.1. Research aims

1. **Aim 1**: Investigate clinicians' views towards family engagement.
    a. Hypothesis: Clinicians are aware of family engagement and its potential impacts on outcomes
        i. Poor family engagement is encountered frequently by clinicians
        ii. Clinicians perceive families from underprivileged social groups as being more prone to poor engagement

2. **Aim 2**: Explore clinicians' views towards the barriers of family engagement
    a. Hypothesis: Clinicians are aware of a wide range of barriers to family engagement
        i. Clinicians perceive low SES and cultural differences as barriers to family engagement
        ii. Clinicians are aware that many families face access-related barriers to family engagement

3. **Aim 3**: Investigate whether clinicians' currently use strategies or resources to facilitate family engagement, and whether these strategies are effective
    a. Hypothesis: Clinicians do use strategies for improving family engagement
        i. Many clinicians rely on informal strategies for engaging families, rather than strategies guided by frameworks
        ii. Clinicians perceive a need for more effective strategies for facilitating family engagement
        iii. Clinicians feel there is a lack of resources for engaging families

3.2. Design

This study was designed to fill gaps in current knowledge surrounding family engagement in the paediatric cochlear implant habilitation process. A mixed-methods study design was used, with information collected through an online cross-sectional survey (with quantitative and qualitative questions) and semi-structured interviews (qualitative only).

3.2.1. Ethical considerations

The survey used in this study was designed to be anonymous, however, some clinicians who were eligible for the study are personally known to the student researcher and Principal Investigator. This created a risk that these participants could be inadvertently identified by the research team from the demographic information collected in the survey. Participants were advised of this risk through the Participant Information Sheet so that they could make a fully informed decision regarding their desire to partake in the study. Additionally, information regarding age and years of experience was collected in 10-year brackets to minimise the risk of participant identification.

The present study was approved by the Auckland Health Research Ethics Committee (reference number: AH22780). All research was conducted in accordance with the proposal approved by the Auckland Health Research Ethics Committee.

3.3. Participants

All participants met the following inclusion criteria: 1) have experience working with children with cochlear implants, 2) are proficient in written English, 3) work at a centre affiliated with the First Voice group. The First Voice group is a multinational consortium of evidence-based early intervention centres who offer post-implant habilitation to children with hearing loss (First Voice, n.d.). Clinicians with experience working with children with cochlear implants were selected as the target population due to their proximity to families who are involved in the cochlear implant habilitation process. There would be significant ethical and cultural considerations to navigate if the families themselves were recruited – hence, the clinicians' perspective was the most accessible proxy measure of families' opinions. It is also important to understand the views of clinicians themselves. Individuals without English literacy were excluded from the study as they would be unable to give fully informed consent to partake, and may also be unable to meaningfully interpret and answer the survey questions. Participants were also required to work at a First Voice centre for recruitment purposes.

3.3.1. Recruitment

All participants were recruited through their workplace. There were eight First Voice centres who were invited to take part (five in Australia and one each in New Zealand, South Africa, and the United Kingdom). Lead clinicians at each centre were contacted and sent an email invitation with the Participant Information Sheet for Lead Clinicians (Appendix A) attached. Lead clinicians could then consent for their centre to take part in the study and distribute the Participant Information Sheet (Appendix B) and survey link to their team members.

At the end of the survey, there was a link to provide contact details to volunteer for the interview. This link was not traceable to their survey answers. Participants had to consent to taking part in the interview and having their identity revealed to the research team before they could provide any contact information. Participants were contacted by the student researcher via email to schedule a time for the interview.

3.4. Survey development

The survey was specifically developed by the student researcher to fulfill the aims of the study. The survey development process was done in collaboration with the Principal Investigator, who has many years of experience working with children with cochlear implants, to ensure that all questions were appropriate and relevant to the research topic. A draft version of the survey was also distributed to the paediatric team at The Hearing House, a First Voice centre, to gain feedback and suggestions. Main refinements included rewording of some questions, and suggestions for available options in the multi-choice and ranking questions. The final draft consisted of 24 questions, including seven demographic questions. The final survey was sent for ethics approval before being distributed (Appendix C).

The final version of the survey included a mix of multi-choice, ranking, and short open-ended questions. The survey was kept brief to maximise recruitment, given that the pool of potential participants was already quite limited (estimated ~60 clinicians across the various First Voice centres). Multi-choice questions were used as often as possible to encourage completion of the survey. Open-ended questions were used in instances where it would be difficult to create a closed set of answers that represented the true scope of the question; for example, when asking clinicians to describe the strategies they use to encourage engagement.

3.4.1. Survey section I: Consent and participant characteristics

The first page of the survey contained an online consent form which summarised the rights of the participants. Consent needed to be given before participants could continue further with the survey.

Demographic questions were used to obtain information regarding participants' age, gender, ethnicity, occupation, years of experience, and localities. Participants could select "*prefer not to say*" for questions regarding age, gender, and ethnicity to enable participants to withhold this personal information at their discretion. The demographic information was gathered to assess how well the survey population represented the current clinical population working with children with cochlear implants.

3.4.2. Survey section II: Defining engagement

This section (Q9 - Q12) explored the views of clinicians towards family engagement, including how often clinicians feel they encounter families with poor engagement, and who they believe is prone to poor family engagement. It also included two ranking questions: firstly, regarding what clinicians think the key indicators of poor engagement are, and secondly regarding what clinicians think the barriers to engagement are. These questions had a list of suggested items (and two "Other" options with a text entry box for specification) which participants could rank according to how important they felt the items were. Item lists for ranking questions were developed by the student researcher in collaboration with the Principal Investigator, and were informed by relevant literature and clinical experience of the research team.

3.4.3. Survey section III: Resources and strategies for family engagement

This section (Q13 - Q24) focused on what resources and strategies clinicians are currently using to encourage family engagement, and what they believe could help to further improve engagement. In addition, this section aimed to assess whether information about the habilitation process is accessible for diverse families. A ranking question was also included regarding what resources clinicians think would be helpful for improving engagement.

3.5. Interviews

The interviews were intended to delve further into clinicians' views around family engagement and the strategies they use to facilitate engagement. Given the current gap in the literature regarding facilitators and strategies for family engagement, this was a core element of the research aims. However, the survey alone was unlikely to provide rich information for this topic as survey participants gave very brief answers to the open-ended questions regarding engagement strategies.

All interviews were conducted by the student researcher and took place over Zoom. Interviews were semi-structured and designed to take approximately 30 minutes. Participants were sent a copy of the topic guide before the interview to allow them to prepare (Appendix D). There were four topic sections to be covered: 1) demographics, 2) description of strategies used to engage families, 3) discussion of effectiveness of these strategies, 4) suggestions for other strategies/resources that may help engagement. Interview topics were not covered in any particular order as participants would often speak in relation to several topics at once. Care was taken by the interviewer to avoid leading questions, which allowed participants to direct the conversation. Follow-up questions were asked at the discretion of the interviewer to ensure that all topics were covered adequately. As the interviews were semi-structured, participants were also given the freedom to bring up other topics they felt were relevant to family engagement. Audio recordings were taken for all interviews, and these were used in the transcription and subsequent thematic analysis of interview data. Participants were sent copies of their transcripts and were given one week to make any amendments or corrections they felt were necessary.

3.6. Analyses

3.6.1. Quantitative statistics

Descriptive statistics for quantitative survey data were gathered using Qualtrics Stats iQ. There was no further analysis of quantitative data (please refer to COVID-19 Impact Statement).

3.6.2. Weighting of ranked survey data

Static cell weighting was applied to ranked data, using Qualtrics Weighting. This was done to account for the rate of selection of options in a ranking set, and thus gave *more* weight to the *most frequently* selected options. This method of weighting is best for non-overlapping data and involved applying a specified multiplier to ranks, based on the rate of non-selection (Kalton and Flores-Cervantes, 2003). Note – all ranking questions had a text-entry "*Other*" option available. This data was excluded from weighting and relevant figures because each participants' answer was different, hence, comparing the mean ranks of "*Other*" data to the other options would not be meaningful. For brevity, only weighted mean ranks were included in the results chapter. Unweighted data can be found in the appendices (Appendix E).

3.6.3. Quasi-quantitative analysis of qualitative survey data

Several open-ended questions were included in the survey for instances where closed-set questions would impede the breadth and quality of responses. For example, attempting to create a closed-set question about the strategies clinicians use for engaging families would have significantly limited the range of responses – this would conflict with the exploratory aims of the study. However, the brief answers to the open-ended questions did not lend themself to in-depth qualitative analysis, with many answers consisting of only a few words or clauses. Following a consultation with an independent statistics advisor, the decision was made to conduct a quasi-quantitative analysis of this data, with the intention of coding and quantifying answers into digestible topic summaries. The term "quasi-quantitative" is used here because the output of this analysis was *quantitative* (*i.e.* a quantified tabular display of topic summaries), but there was not sufficient richness in the qualitative data to develop coherent qualitative-style themes across the dataset. The coding and categorising processes were informed by Phase I of the General Inductive Approach, as outlined by Thomas (2006). This particular coding method was chosen for its focus on condensing varied text data into brief topic summaries (Thomas, 2006). Coding was done using Qualtrics Text iQ. Codes were then exported to Microsoft Excel for quantification.

3.6.4. Thematic analysis of interview data

A reflexive thematic analysis, as outlined by Braun and Clarke (2006) was carried out for interview data. This analysis allowed for an in-depth exploration of the data to create a meaningful understanding of underlying themes across the interviews. Reflexive thematic analysis was favoured over alternative approaches to thematic analysis as these are often founded on positivist theory, where it is believed that there are objective "truths" that will "emerge" from the data. For example, the coding reliability approach uses multiple coders as an attempt to extinguish researcher bias based on the assumption that researchers may inadvertently mask or taint the "true" themes of the data. By contrast, Braun and Clarke emphasise the value of researcher subjectivity, viewing it as "not just valid but a resource" (Braun and Clarke, 2019, p. 848). This philosophy aligns well with the aims of the present study, as it focuses on exploratory topics that are innately subjective. Hence, the values of the researcher offered richness and insight into the wider concepts underpinning many of the interview themes.

There were six key phases of the thematic analysis:

1. *Familiarisation with the dataset*

The first stage of analysis began during transcription of the interviews. All transcribing was done by the student researcher. Following initial transcription, transcripts were re-read several times to build familiarity with the data. Audio recordings of interviews were also listened over and, where necessary, notes were made in the transcripts to reflect nuances from the speaker (*e.g.* sighing, hesitation, laughing). This allowed the researcher to form an idea of the key messages of each interview, and look for early connections between interviews.

2. *Coding*

After the familiarisation phase, coding was completed in NVivo 12. Generating codes involved more detailed and thoughtful engagement with the data than in the previous phase. An inductive approach was used, meaning that codes were developed openly throughout the coding process, rather than being predetermined before coding began. This approach was deemed most appropriate for the present study as it is an exploratory topic, and there are no established analysis matrices to use for a deductive coding approach. Coded excerpts were typically 2-3 sentences long, however, sometimes single sentences were used if it related to one code in isolation. This approach of longer coded excerpts was used because often a single sentence did not capture the full meaning of what was being said. Most codes were semantic, meaning they were based on the explicit content of the data. However, some latent codes were created further into the coding process as some participants' implicit beliefs became evident (e.g. "engagement is the *families'* responsibility"). In an earlier guide to reflexive thematic analysis, Braun and Clarke suggest using these questions as prompts during coding: "How does this participant make sense of their experiences? What assumptions do they make in interpreting their experience? What kind of world is revealed through their accounts?" (Braun and Clarke, 2012, p.61). These questions had strong influence on the development of the latent codes in this analysis. Towards the end of the coding phase, several redundant codes were condensed into single codes (e.g. "remote care" was merged with "telehealth").

3. *Generating initial themes*

The coding process of all seven transcripts generated 1,157 coded excerpts which were nested into 97 unique codes. These codes were organised into nine rudimentary “themes”. The initial themes were more akin to topic summaries, where codes were organised by their semantic content (e.g. “Resources”, “Barriers”) rather than their *underlying* concepts. “Topic summary” style themes are discouraged in reflexive thematic analysis due to their lack of depth and cohesion. Well-developed themes should have a defined central organising concept that underpins the theme and brings meaning to the analysis (Braun and Clarke, 2019).

4. *Reviewing and developing themes*

Several weeks of revisiting and reworking the data were required to graduate from the initial “themes” to coherent, fully-realised themes. Codes were reviewed and re-organised into different versions of themes until the central organising concepts felt clear enough to outline and discuss – visual mapping was used here to conceptualise the codes as the “building blocks” of their themes. This process also involved reflecting on the aims of the study to ensure that the analysis remained pertinent to the research questions. At the end of this phase, five themes had been outlined, with two overarching central organising concepts.

5. *Refining, defining, and naming themes*

After the final central organising concepts and themes were outlined, the themes were further refined. This process involved assessing the codes within each theme and making sure they were well fitted. Theme names were intently developed to ensure that they captured the themes’ message and related to their respective central organising concepts. Themes were also discussed with the Principal Investigator and an independent qualitative research advisor.

6. *Report writing*

Findings from the thematic analysis were divided into two written sections: results and discussion. The results section aimed to outline the overall concept behind each theme and provide supporting quotes, while the discussion section was used for a more in-depth look at the implications of each theme and how it relates to the research aims. Quotes were mostly reported verbatim, however, some small adjustments were made for ease of reading; for example, stuttering or unnecessary word repetitions (*e.g.* “and- and- and”) were removed. The removal of irrelevant or excessive parts of quotes was indicated with a parenthesised ellipsis.

The quantification of code frequencies (*e.g.* “six out of seven participants thought…”) was intentionally avoided for the present write up. This is in line with Braun and Clarke’s

(2021) philosophy that frequency does not determine value, and quantifying responses “misses the point of qualitative analysis” (Pyett, 2003, p. 1174). Additionally, due to the flexible nature of interviewing, the *absence* of a code or theme from a participant’s response has little meaning – *i.e.* if a participant did not mention a particular theme, it cannot be assumed that they oppose it, rather, they simply may not have brought it up. Hence, quantified reporting of themes is not only unnecessary but can be misleading.

4. Chapter 4: Survey Results

4.1. Survey section I: Participant characteristics

There were 41 total participants in the online survey, including 3 partial participants (2 = 50% completed, 1 = 87% completed). Median response time was 15.2 minutes. Participants were most commonly aged 31-40 years old (n = 17) (Table 2). Six participants were <30, nine were 41-50, and nine were 51-60 years old (Table 2). Forty participants (98%) were female (Table 2). The most common ethnicity was European (n = 34; 83%) (Table 2). Other participant's ethnicities were Asian (*n* = 2), African (*n* = 2), Middle Eastern (*n* = 1), and "Other" (*n* = 5) (Table 2). Answers for "Other" ethnicities included "colored", "American", and "South African".

Occupations were varied among participants. There were 18 (44%) auditory-verbal therapists/listening and spoken language specialists, 12 (30%) speech-language therapists, and 9 (22%) audiologists (Table 2). Other occupations included Deaf educators (*n* = 7), psychologists/counsellors (*n* = 5), early interventionists (*n* = 3), and "Other" (*n* = 2) (Table 2). Participants' years of experience were well distributed – 30% had <5 years, 30% had 6-10 years, and 30% had 11-20 years of experience, while the remaining 10% had over 21 years of experience (Table 2). Most participants were based in Australia (n = 26; 63%) and South Africa (*n* = 10; 25%) (Table 2). Four participants were from New Zealand, and one was from the United Kingdom (Table 2). Participants' primary location of experience was the same as their current location for all but two participants (Table 2).

Table 2. Demographic information of survey participants (*n* = 41)

Characteristic	Number of Participants
Age (years)	
<30	6 (15%)
31-40	17 (41%)
41-50	9 (22%)
51-60	9 (22%)
Gender	
Female	40 (98%)
Male	1 (2%)

Ethnicity(s)	
European	34 (83%)
Asian	2 (5%)
African	2 (5%)
Middle Eastern	1 (2%)
Other	5 (12%)
Occupation(s)	
Audiologist	9 (22%)
Speech-language therapist	12 (30%)
Auditory-verbal therapist/LSLS	18 (44%)
Early interventionist	3 (7%)
Deaf educator	7 (17%)
Psychologist/counsellor	5 (12%)
Other	2 (5%)
Years of Experience	
<5	12 (30%)
6-10	12 (30%)
11-20	12 (30%)
21-30	2 (5%)
>31	3 (7%)
Current Locality	
New Zealand	4 (10%)
Australia	26 (63%)
South Africa	10 (25%)
United Kingdom	1 (2%)
Primary Location(s) of Experience	
New Zealand	5 (12%)
Australia	26 (63%)
South Africa	10 (25%)
United Kingdom	2 (5%)

Note. LSLS = Listening and Spoken Language Specialist.

4.2. Survey section II: Defining engagement

4.2.1. Indicators of poor family engagement

Participants were asked to rank a list of potential indictors of poor family engagement based on how well they indicate poor engagement (Figure 1).

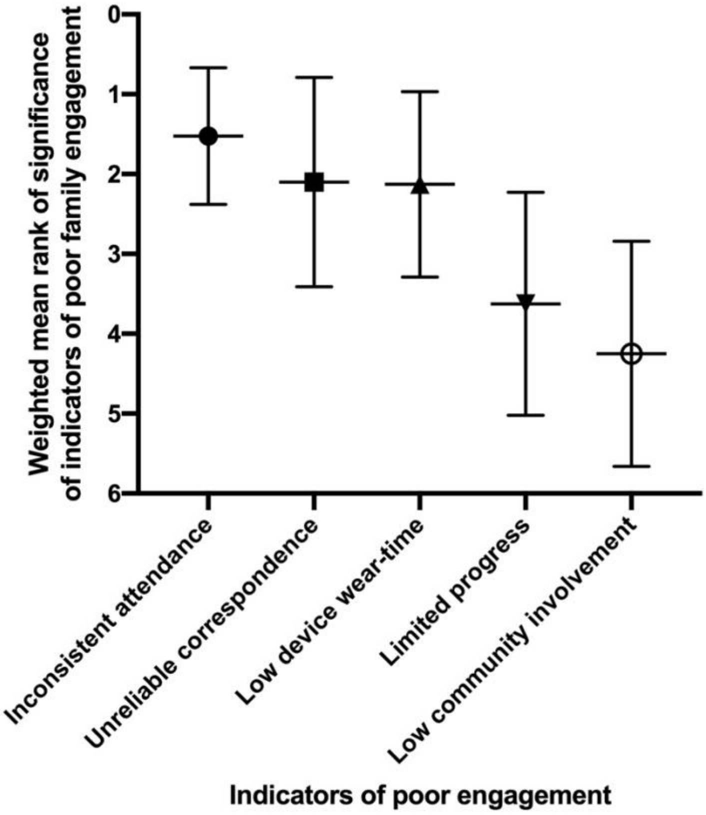

Figure 2. Ranked indicators of poor family engagement. Data show weighted mean (±SD) ranks of various indicators of poor family engagement (1 = highest rank/best indicator). *n* = 38.

Inconsistent attendance of appointments was considered the best indicator of poor family engagement – it was selected by 87% of participants and had a weighted mean rank of 1.5 out of 6 (Figure 2). *Unreliable correspondence* (90%; weighted mean rank = 2.1/6) and *Low device wear-time* (84%; weighted mean rank = 2.1/6) were also considered reliable indicators of poor engagement (Figure 2). *Limited progress in the child's development* (55%) and *Limited wider community involvement* (47%) were less frequently selected, and ranked lower than the other indicators (Figure 2). "*Other*" indicators of poor engagement were selected by 33% of participants, and had a wide range of rankings. Participants' answers for "*Other*" included "limited questions/participation during appointments", "limited signs of home follow-up", and "prioritisation of other activities over therapy".

4.2.2. Frequency of encountering poor engagement

Overall, clinicians appeared to feel that they encounter poorly engaged families fairly frequently. Participants most commonly felt that they encounter families with poor engagement *Several times a week* (32%), *Once weekly* (22%), or *Several times a month* (20%). Several participants (10%) also felt they encounter poorly engaged families *Daily*. Few participants indicated that they encounter poor engagement *Once a month* (5%), *Once every few months* (7%), *A few times a year or less* (2%), or *Never* (2%).

4.2.3. Demographics prone to poor engagement

Participants were asked to describe which demographics they felt were prone to poor family engagement, with most answers listing several different groups (Table 3). A quasi-quantitative analysis of participants answers was conducted, and the most commonly identified groups are displayed below (Figure 3).

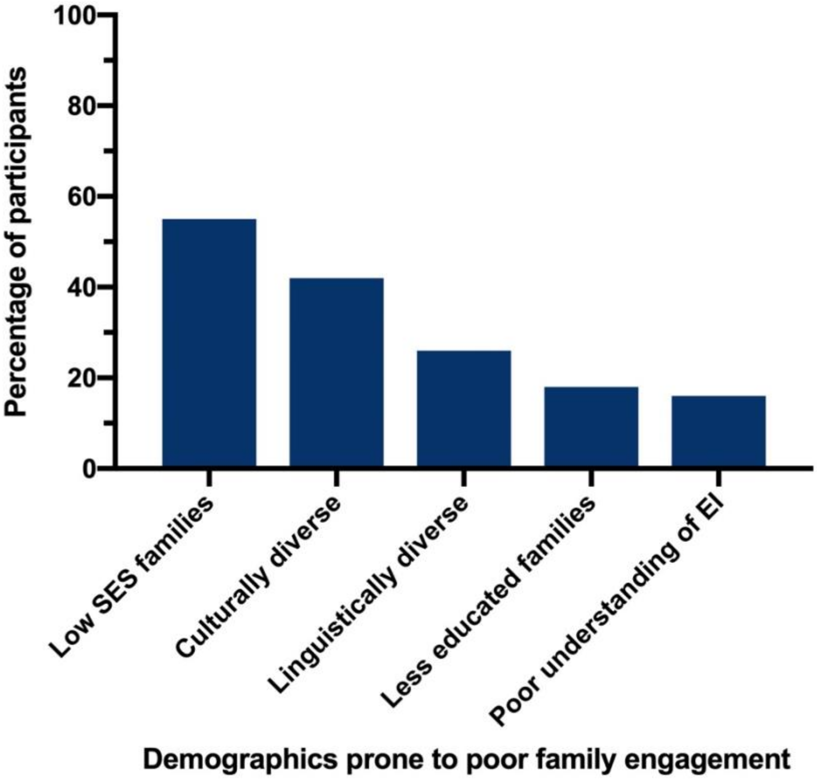

Figure 3. Demographics most commonly identified by clinicians as being prone to poor family engagement. EI = early intervention. SES = socio-economic status. *n* = 38.

Overall, most clinicians perceived families from diverse or underprivileged social groups as being prone to poor engagement. More specifically, the most frequently mentioned demographics were families with low SES (55%), culturally or linguistically diverse families (42% and 26%, respectively), and less educated families (18%) (Figure 3). Families with a poor understanding of habilitation/early intervention were also cited (16%) (Figure 3). Several participants mentioned families experiencing shame/stigma or denial about the hearing loss. Other demographics included families with complex dynamics (*e.g.* family violence), rural families, and families with two working parents (Table 3). Only one participant felt that there were no demographics who were prone to poor engagement (Table 3).

Table 3. Quasi-quantitative breakdown of demographics prone to poor family engagement

Demographics	**Number of mentions (%)**
Low SES families	21 (55%)
Culturally diverse families	16 (42%)
Linguistically diverse families	10 (26%)
Less educated families	7 (18%)
Families with poor understanding of hab/EI	6 (16%)
Families experiencing shame/stigma	5 (13%)
Families in denial	5 (13%)
Complex family dynamics e.g. conflict/violence	5 (13%)
Families with both parents working	4 (11%)
Rural families	2 (5%)
Very young parents	1 (3%)
Very high SES families	1 (3%)
None	1 (3%)

Note. EI = early intervention. Hab = habilitation. SES = socio-economic status. *n* = 38.

4.2.4. Barriers to family engagement

Participants were asked to rank a list of potential barriers to family engagement based on how significantly they impact engagement (Figure 4).

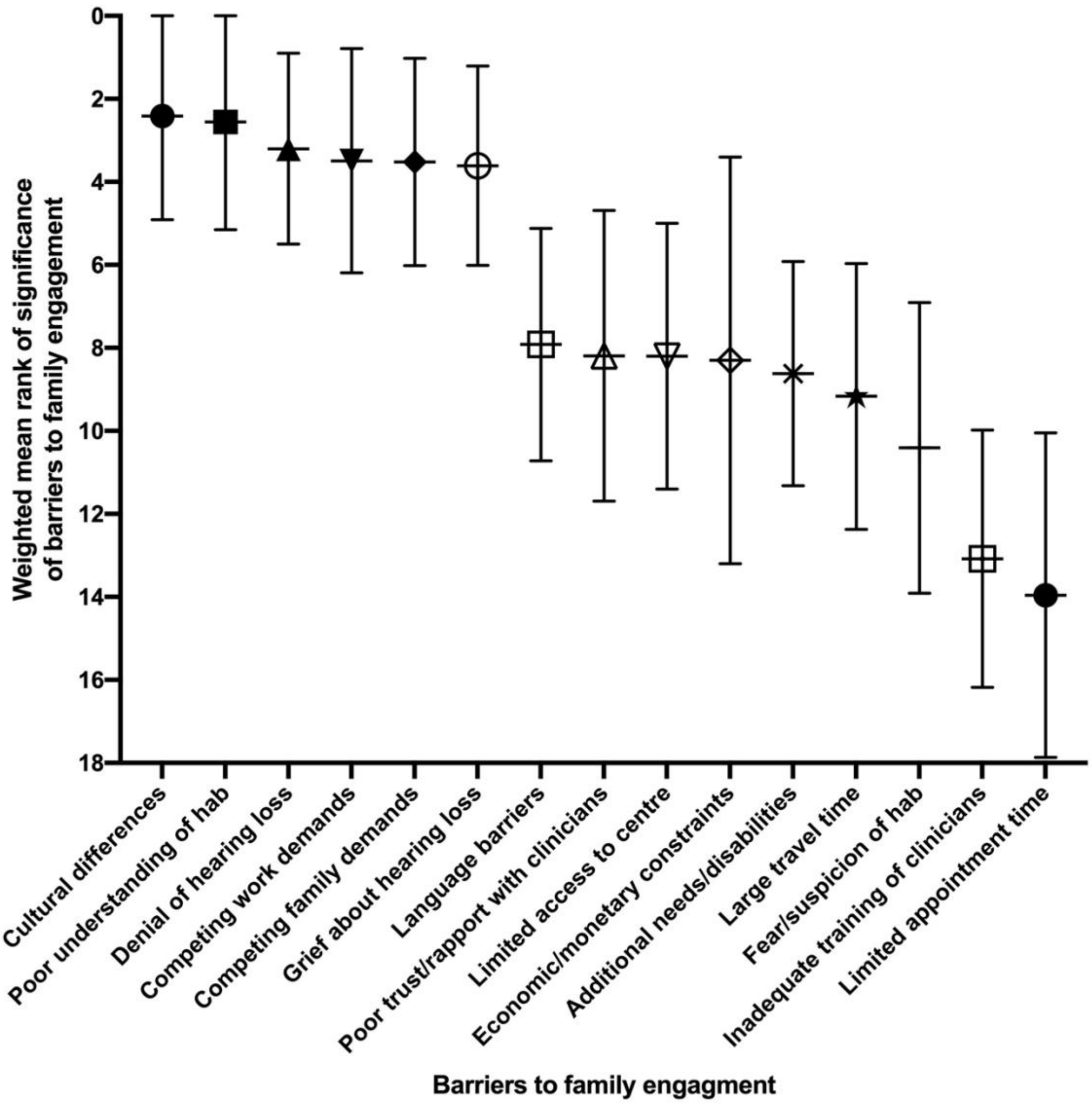

Figure 4: Ranked barriers to family engagement. Data show weighted mean (±SD) ranks of various barriers to family engagement (1 = highest rank/largest barrier). Hab = habilitation. *n* = 38.

Cultural differences between families and clinicians was the most commonly selected and highest ranked barrier – it was selected by 76% of participants and had a weighted mean rank of 2.4 out of 16 (Figure 4). *Limited understanding of habilitation process* was also highly ranked (71%; weighted mean rank = 2.6/16) (Figure 4). Other highly ranked barriers included *Denial of hearing loss* (63%; weighted mean rank = 3.2/16), *Competing work demands* (71%; weighted mean rank = 3.5/16), *Competing family demands* (68%; weighted mean rank = 3.5/16), and *Grief about hearing loss* (61%; weighted mean rank = 3.6/16) (Figure 4). *Economic/monetary constraints* were selected as a barrier by 39% of participants (weighted mean rank of 8.3/16) – this barrier also had the greatest variability (SD = 4.9) (Figure 4).

Participants rated access-based barriers with mid-to-low importance; *Limited access to centre* was selected by 53% (weighted mean rank = 8.2/16), and *Large travel time* was selected by 47% (weighted mean rank = 9.2/16) (Figure 4). Some of the lowest ranked barriers included *Fear/suspicion of habilitation process* (34%), *Inadequate training/skills of clinicians* (18%), and *Limited appointment time* (13%) (Figure 4). "*Other*" barriers were selected by 13% of participants, with answers including "overwhelm", "low parental education", and "therapy model doesn't fit family's needs".

4.3. Survey section III: Resources and strategies for family engagement

4.3.1. Delivering information about habilitation to families

Participants demonstrated that they deliver information about the habilitation process using multiple modes. Verbal information delivery was the most common method of informing families; all participants offered meetings with clinicians to discuss the habilitation process, and 88% of participants also offered meetings with other families. Physical brochures were offered by many participants, with 63% offering written informational brochures, and 54% offering picture-based brochures. Links to online information (54%) and online informational videos (44%) were also offered. "*Other*" modes of information delivery were selected by 12% of participants, with answers including "device demonstrations", "providing research articles", and "voice notes via cellphone".

4.3.2. Current workplace practices regarding family engagement

Participants were given a list of statements regarding various practices for family engagement and asked to select all that apply to their current workplace.

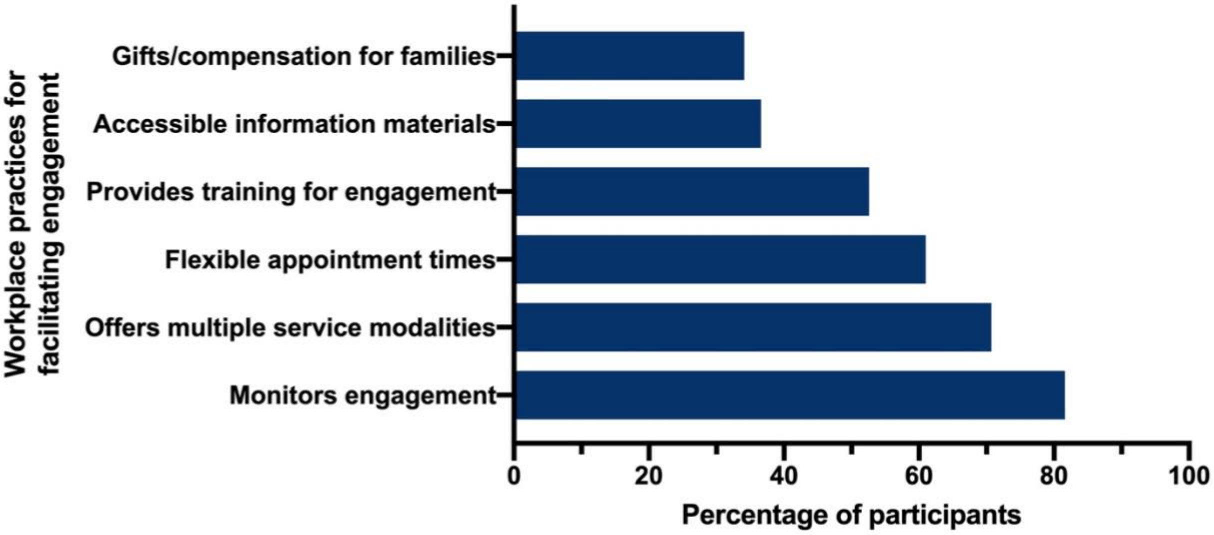

Figure 5. Prevalence of workplace practices for facilitating family engagement. *n* = 38.

Most participants indicated that their workplace *Consistently monitors family engagement* (82%), *Provides multiple service modalities* (*e.g*. telehealth, home visits) (71%), and *Offers flexible appointment times* (61%) (Figure 5). Approximately half of participants indicated that their workplace *Provides training to improve family engagement* (53%) (Figure 5). The least common practices were *Offers informational materials that are accessible to families with limited English literacy* (*e.g.* translated materials or picture-based/video information) (37%), and *Offers gifts/compensation to engage families* (*e.g.* compensation for travel expenses) (34%) (Figure 5).

The 31 participants who indicated that their workplace consistently monitors family engagement were asked to briefly describe their monitoring processes. Most answers mentioned multiple processes.

Table 4. Quasi-quantitative breakdown of methods for monitoring family engagement (*n* = 31)

Monitoring strategy	Number of mentions (%)
Monitoring appointment attendance	19 (61%)
Case discussions/team meetings	14 (45%)
Check-ins/feedback from families	8 (26%)
Engagement monitored via counsellor/social worker	6 (19%)
Annual family surveys	3 (10%)
Monitoring correspondence	2 (6%)

Monitoring data logging	2 (6%)
Tracking entry/exit to program	2 (6%)
Monitoring outcomes	1 (6%)

Monitoring appointment attendance was the most frequently mentioned method of monitoring family engagement (61%) (Table 4). Common methods also included having case discussions/team meetings (45%) and checking in with/getting feedback from families (26%) (Table 4). Several participants indicated that their workplace monitors engagement via counsellors/social workers who work with the families (19%). Less common methods included using annual family surveys, monitoring correspondence between families and clinicians, monitoring a child's datalogging hours, tracking entry/exit to habilitation programmes, and monitoring a child's outcomes (Table 4).

The 20 participants who indicated that their workplace provides training for improving family engagement were asked to briefly describe any training processes. Most answers listed multiple processes.

Table 5. Quasi-quantitative breakdown of family engagement training methods (*n* = 20)

Training method	**Number of mentions (%)**
Professional development sessions	11 (55%)
Family engagement-related seminars/webinars	7 (35%)
Mentoring from counsellors	7 (35%)
Regular team discussions around engagement	6 (30%)
Cultural training sessions	4 (20%)
Training from external organisations	4 (20%)

Training for family engagement was most commonly provided through professional development sessions (55%) (Table 5). Approximately one third of responses mentioned attending engagement-related seminars, mentoring from counsellors, or team discussions about engagement. Cultural training sessions were included in four responses. There were also several mentions of training from external services or organisations, including "child protection agencies" and "family dynamic specialists".

4.3.3. Resources for facilitating family engagement

Clinicians were asked whether they feel they currently have enough resources to fully engage families, and responses were fairly divided. Just under half of participants responded *Definitely* or *Probably* (5% and 37%, respectively). *Maybe* was selected by 17% of participants. Approximately one third of participants selected *Probably not* or *Definitely not* (29% and 2%, respectively).

Participants were then asked to rank a list of potential resources for family engagement based on how helpful they would be (Figure 4).

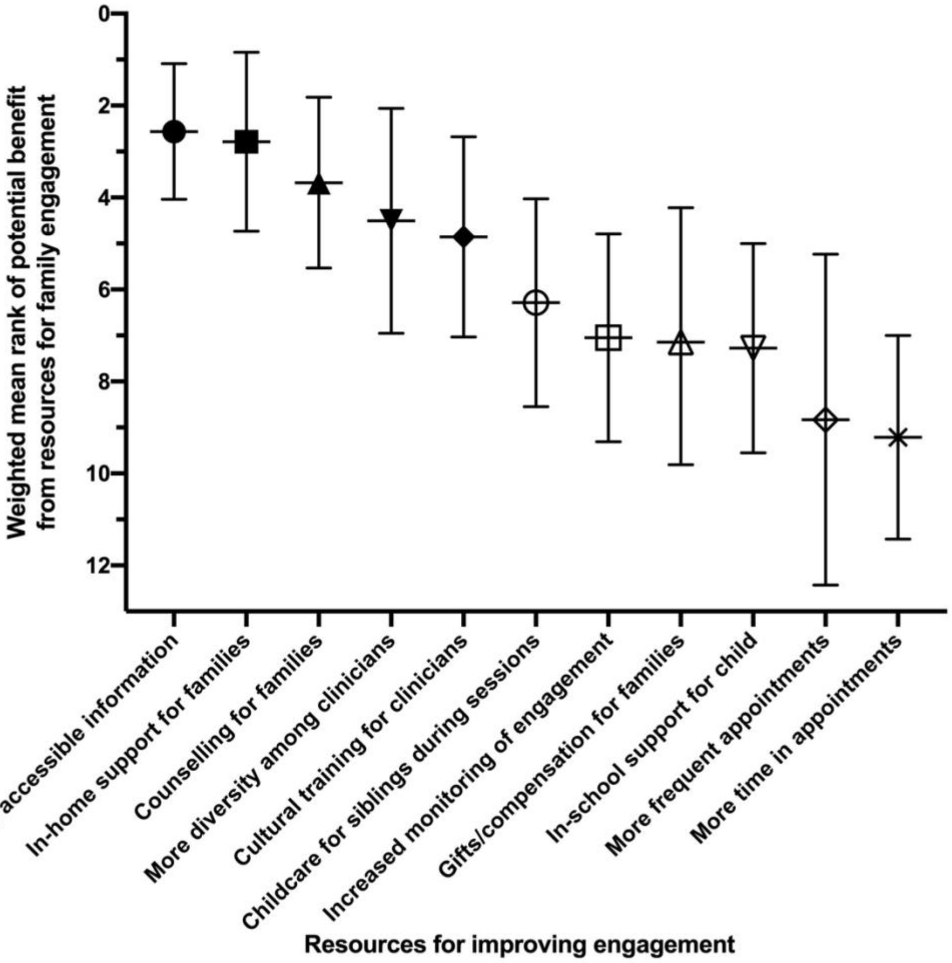

Figure 6. Ranked potential resources for family engagement. Data show weighted mean (±SD) ranks of potential resources for family engagement (1 = highest rank/most helpful). *n* = 38.

More accessible information for families (e.g. translated or non-written information) was selected by 66% of participants and was the highest ranked potential resource with a weighted mean rank of 2.6 out of 12 (Figure 6). *More in-home support for families* (*e.g.* home visits) was most frequently selected (71%), but was ranked slightly lower overall (weighted mean rank = 2.8/12). Other highly ranked resources included *More counselling for families* (55%; weighted mean rank = 3.7/12), *More diversity among clinicians* (55%; weighted mean rank = 4.5/12), and *More cultural training for clinicians* (53%; weighted mean rank = 4.9/12) (Figure 6). Approximately one third of participants selected *More monitoring of family engagement, More gifts/compensation for families* (*e.g.* travel compensation) (weighted mean ranks = 7.1/12 and 7.2/12, respectively). The lowest ranked resources were *More frequent appointments* (16%) and *More time in appointments* (11%) (weighted mean ranks = 8.8/12 and 9.2/12, respectively) (Figure 6). "*Other*" resources were selected by 5% of participants, with answers including "better psychosocial assessment of families" and "greater knowledge among professionals of the AV [auditory-verbal] approach".

4.3.4. Current strategies for facilitating family engagement

Participants were asked whether they had previously used strategies to facilitate family engagement. Almost all (95%) participants indicated that they have previously used strategies to encourage family engagement. The remaining two participants did not respond to this question. Those who indicated that they have used engagement strategies were asked to briefly describe them. Most answers listed multiple strategies.

Table 6. Quasi-quantitative breakdown of clinicians' strategies for engaging families (*n* = 39)

Engagement strategy	**Number of mentions (%)**
Offering remote care/telehealth	15 (38%)
Setting up meets with other families from the centre	11 (28%)
Gifts, compensation, and incentives	11 (28%)
Offering home visits	11 (28%)
Offering flexible appointment times	10 (26%)
Involving in-centre support services	9 (23%)
Offering interpreter/translator	8 (21%)
Family-lead goal setting	7 (18%)
Meeting at casual environments (*e.g.* cafes)	7 (18%)
Casual communication (*e.g.* text/social media)	5 (13%)
Referring to external support services	5 (13%)

Switching clinicians as needed	5 (13%)
Involving extended family	4 (10%)
Focusing on building rapport	4 (10%)
Hosting group sessions/events	2 (5%)
Integrating cultural values into habilitation	1 (3%)
Using counselling techniques (as a clinician)	1 (3%)

The most frequently mentioned strategy for engaging families was offering remote care or telehealth (38%) (Table 6). Other common strategies included offering home visits (28%), offering flexible appointment times (26%), arranging meetings with other families from the centre (28%), and using gifts or compensation (mostly food or transport related) (28%). Several responses mentioned involving in-centre supports (mostly counsellors) (23%) or referring to external support services (13%), and one clinician also mentioned using counselling techniques during their appointments. Eight responses mentioned offering interpreter or translator services for families with limited English; in a similar vein, one clinician mentioned integrating families' cultural values into the habilitation process. Two strategies were related to family-centred care: using family-lead goal setting (18%), and involving extended family in the habilitation process (10%). Several responses mentioned the use of casual communication methods (13%) or casual environments (18%) to facilitate engagement. Other strategies included switching to a different clinician (13%), focusing on rapport over habilitation (10%), and hosting group sessions or events (5%) (Table 6).

The majority of participants felt that their engagement strategies were *moderately effective* or *very effective* (56% and 30%, respectively). Two participants found their engagement strategies *extremely effective*, and three participants found their strategies either *slightly effective* or *not effective at all*.

5. Chapter 5: Interview Results

5.1. Interview participant characteristics

There were seven interview participants, all of whom had also taken part in the survey. Mean interview time was 30 minutes. Most participants were female, European, and aged 31-40 years (Table 6). The most common occupation was speech-language therapist (*n* = 3), however there was also representation from other clinical roles (Table 6). Two participants had <5 years of experience, four had 6-10 years of experience, and one had >31 years of experience (Table 6). All participants were from either New Zealand (*n* = 3) or Australia (*n* = 4).

Table 7. Demographic information of interview participants (*n* = 7)

Characteristic	Number of participants
Age (years)	
<30	1
31-40	4
41-50	1
51-60	1
Gender	
Female	6
Male	1
Ethnicity(s)	
European	6
Asian	2
Occupation(s)	
Audiologist	1
Speech-language therapist	3
Auditory-verbal therapist/LSLS	2
Deaf educator	1
Psychologist/counsellor	1
Regional Manager	1
Years of Experience	
<5	2
6-10	4

>31	1
Current Locality	
New Zealand	3
Australia	4

Note. LSLS = Listening and Spoken Language Specialist.

5.2. Reflexive thematic analysis

The reflexive thematic analysis of interview data resulted in five themes and two overarching central organising concepts. The first three themes, which fall under the central organising concept of *connectedness*, are: 1) *It takes a village:* the importance of fostering wider community connections in paediatric cochlear implant habilitation, 2) *Prioritising rapport:* cultivating meaningful connections between clinicians and families, and 3) *Keep it casual:* the power of removing pressure on families. The remaining two themes, which are underpinned by the central organising concept of *systemic barriers*, are: 1) *Systemic failures:* how our society enables poor engagement, and 2) *Aiding accessibility:* the need for increased service flexibility.

5.2.1. ***It takes a village:*** **the importance of fostering wider community connections in paediatric cochlear implant habilitation**

This theme encompasses the families' need for an extensive support system throughout the habilitation process. The old adage "it takes a village to raise a child" holds true even for typically developing children, and the extra demands of the cochlear implant habilitation process only heighten the need for an expansive support network.

The theme became evident as clinicians noted that families who engage in wider community groups felt more connected to the habilitation process. Notably, the positive impacts of family support groups and centre-run events were most commonly mentioned. However, play groups, music groups, and one-on-one family meetings were also discussed. The benefits of these wider community connections were often credited to a feeling of connectedness and belonging within the hearing loss and cochlear implant community. Clinicians also reported that families use these connections to exchange or seek advice regarding therapy techniques, or even just general child raising topics. The benefits of these wider community connections were also largely found to be long lasting.

> I think, well no- I *know* that having parent groups, and all of that, really strengthens the bonds of engagement. Not just with the centre but in the whole hearing loss community- and they feel *part of* something. *– Interview participant (IP) 5*

> With the preschool group that we ran in South Auckland once, we had families who came and we hadn't seen them for like *a year* (…) and since then, you know, we've seen those families more regularly. *– IP 1*

Furthermore, it was noted that families who are not involved in wider community groups may be at increased risk of poor family engagement. This was generally thought to be because the inter-family connections can also be a source of emotional support for families. This enhances the family’s support network, and can allow them to maintain their engagement even in the face of adversities or struggles.

> If families do join those things [parent groups, etc], we do find that engagement is much higher and those families that choose not to join are probably those ones that are more vulnerable in terms of disengagement. *– IP 3*

> We do have some families that are very much *on their own*, you know? And it just makes things so much harder. *– IP 2*

5.2.2. ***Prioritising rapport:*** **cultivating meaningful connections between clinicians and families**

In a similar vein to the previous theme, this theme denotes the need for genuine connections between families and their clinicians. Many participants felt that intentionally dedicating time to building rapport was warranted and showed long-term benefits for families’ engagement. This was usually achieved by slowly building trust with a family and creating a safe environment for open, honest communication. Several clinicians also mentioned making effort to be personable or even somewhat vulnerable with families as a means of building mutual trust.

> We also know that engagement is often more around that feeling of *connectedness* with the centre and the therapist. And we know that if families feel engaged, then the outcomes are much better for children. *– IP 3*

> One thing I'm quite big on is building good relationships with my families. (…) I always try and ask them about themselves and check in, because I think building that relationship really helps with further engagement. But I think you have to make

> yourself a little bit vulnerable first too. – *IP 4*

Participants spoke of the importance of rapport not only as a preventative strategy, but also as a response to noticeable disengagement. In these instances, clinicians felt that it was necessary to step back from clinical goals or therapy and focus on maintaining the relationship with the family. This, in part, was because clinicians noticed that families tend to lose engagement when there are other external stressors present, such as a separation or bereavement. Clinicians hoped that by focusing on rapport during times of hardship, families would be find it easier to re-engage once they were ready.

> For those families where I'm not seeing a lot of progress, when I *do* see them, it is more around relationship building and keeping in touch- so we don't just lose the family or that connection. – *IP 2*
>
> [When a family is disengaging] I just try and like pull back a bit from too much clinical stuff, and go back to just trying to get up like a positive relationship, and then celebrating little wins or, you know, being really positive if they just, like, come to an appointment. – *IP 7*

Another facet of this theme was the use of gifts or compensation (*e.g.* food, petrol/taxi vouchers) to help families who were struggling to engage. This was mentioned by almost all participants, and was viewed not only as a material favour but as a symbolic gesture to acknowledge the efforts made by families and foster a trusting relationship.

> …with families who struggle to come into the centre for practical reasons, we have paid for some petrol vouchers and, yeah, just little ways of trying to help recognise that this is a real commitment for families. – *IP 3*
>
> I always bring, like, a little toy or some sort of food [to the sessions]- just little gifts here and there. I think when you bring something, it helps the family be less guarded [sic] and they don't feel as judged, and it’s a way to break those barriers. – *IP 1*

Counselling for families was also mentioned by every participant as a strategy for strengthening the connection between families and their habilitation centre. About half of participants’ workplaces had a dedicated counsellor to work with families. Those whose workplaces did not offer routine counselling often suggested implementing more counselling or having a “family liaison” who can focus on building rapport between families and providers. Furthermore, some clinicians spoke of consciously taking on a counselling role alongside their work as habilitation clinicians – again, this was done with the intention of building trust and rapport with families.

> Their very first contact is always with a family counsellor, so we really try to build connections with the parents right from the start (…) And we really aim for the counsellor to be throughout all parts of their work – *IP 6*

> As a service, I think we need more counsellors available. Just somebody that can look at these families go, "What does this family need to be able to achieve their goals more? And what are the barriers? What can we break down?" It's just *so* needed – *IP 7*

Furthermore, some participants illustrated the potential negative impacts of not having counselling integrated into the habilitation process. For example, one mentioned that families who are struggling to engage can feel confronted by counsellors if they have not been a consistent part of their habilitation. Another said that families who may benefit from counselling will sometimes decline the offer, and speculated that this was due to the a sense of stigma around accepting support. Additionally, one participant, whose workplace does not routinely offer counselling, also noted that for some families the positive relationship built with the clinician can begin to overshadow therapy. They suggested that a dedicated family counsellor could help the families build trust with the centre, while allowing habilitative therapists to maintain healthier professional boundaries.

> They trust us, but then they just see you as a friend and they don't see the importance (…) I wonder if it's better if we actually have a family liaison person to do what I've done [in terms of rapport]. Whereas right now, I feel like for some parents it's a bit *blurred* and they don't understand... – *IP 1*

5.2.3. *Keep it casual:* the power of removing pressure on families

This theme was created after many participants mentioned that they intentionally maintain a casual "feel" to the habilitation process as a means of building trust with families. This strategy was developed by clinicians in response to reports from families feeling a sense pressure around the habilitation process. Again, this theme stems from the central organising concept of *connectedness* as the purpose of the casual communication/environments was to enhance the connection between families and the habilitation providers and community.

Several participants described how they create a casual environment during their sessions to allow families to feel comfortable and relaxed. This was primarily done by spending the first part of an appointment focusing on informal conversations with parents, and play for the child.

> I always make sure the first session is just play, like no expectations, and the family gets to know me - then they're less guarded. *– IP 1*
>
> In my sessions, I always like the first part to be really informal, just because I think building that relationship really helps with further engagement and building trust. *– IP 2*

The theme of removing pressure also came up regarding communication styles. Several clinicians noted that many families respond better to informal communication methods, as there is less pressure to respond in a particular way. Namely, the use of social media and texting was frequently mentioned. One participant described their use of a work-related Facebook account as their primary means of communication with many families.

> I just use [my work Facebook] like it's not a professional account. Like, I'll post a few pictures that are personable enough to make it feel like "ah, it's not a *formal* photo, it's just her with the dogs" [sic] I also don't use any more formal tools, like I wouldn't then go and email them. *– IP 1*

Several clinicians also noted that families respond well to casual environments. This was primarily evidenced as play-groups for families, which create a judgement-free informal environment for children and families. Some clinicians also described the benefits of having a casual feel to the habilitation centre itself. This can reduce the stress associated with attending appointments and makes the habilitation process more enjoyable for children and families, which can then facilitate engagement.

> We've set up casual playgroups (…) so there's no pressure on them to do therapy or be hounded about kids wearing their devices and it just creates a different space to build that relationship with the families. *– IP 7*
>
> So if there's outdoor space [at the centre], it's really good for family engagement because it's less formal. It means parents aren't as self-conscious about children's behaviour and so on. *– IP 3*

5.2.4. *Systemic failures:* how our society enables poor engagement

This theme stemmed from discussions around wider social issues that hinder family engagement. Whilst the interviews conducted for the present study were primarily focused on strategies and facilitators for engagement, many clinicians also gave insight into the various barriers that families face.

One thing that was commonly identified by participants is that for many poorly engaged families, their low engagement is not caused by a lack of concern for their child. Rather, they simply do not have the resources to fully engage with the habilitation process due to multiple external stressors, such as poverty or inadequate support systems.

> You do see those families that you're like "Oh my gosh, you've just not got a lot left to give, do you?" (…) but when they're at that level of just *surviving* every day, I can totally see how teaching your child how to communicate and to speak is just too much. – *IP 2*
>
> I think so often it's [poor engagement] that they don't have that, like, "*social currency*" (…) And then they don't have the capacity to engage. – *IP 7*
>
> It just seems like for some families, a lot of things compound on one another- those external factors, you know? – *IP 4*

Another aspect of this theme was the current lack of cultural safety throughout habilitation centres. Some clinicians mentioned a lack of cultural safety training, or implied that the training they had received was not very helpful. Clinicians spoke of their difficulties with engaging culturally diverse families, and how they are working on building stronger connections to them. To do this, many centres appear to be working alongside other groups or organisations that have already established connection with these diverse communities. This allows clinicians to gain cultural knowledge that they can apply to their own caseloads.

> Some of the work that we do with Indigenous Australians, I think we need to improve on. (…) Particularly as they really are represented in the world of hearing loss. So we really know we need to make stronger connections with the Aboriginal communities in order to service them better. – *IP 3*
>
> At [a previous workplace], they had a kaitakawaenga [Māori liaison], and for some Māori families that actually really helped them engage. And then you could also tap into them for like, cultural knowledge. – *IP 7*

Almost all clinicians recognised the importance of diversity in the workplace – especially for connecting with culturally diverse families. Clinicians noted that there is currently a lack of diversity in the habilitation workforce. They also expanded on how this largely stems from the barriers that culturally diverse people face in accessing higher education.

> We definitely are targeting clinicians that have other cultural backgrounds, because we know that that is important for connectedness with those families. – *IP 3*

> [in speech-language therapy] you kind of get your 20-to-25-year-old Pākehā [*te reo Māori term for white New Zealanders*] females, no kids usually, that maybe haven't had much different life experiences [sic]. – *IP 7*

Finally, many participants expressed that family engagement should be the *clinicians'* responsibility, and clinicians need to focus on the whole family unit. However, they also mentioned how others in the field still felt that poor engagement is the *families'* fault, rather than a symptom of their limited social resources. The participants called for an increase in empathy and a change in attitude from clinicians, as these outdated mindsets are currently holding back family engagement.

> Well, I think there's got to be a 'philosophy shift' or a 'mindset shift' [sic] (…) you have to consider the whole *family* as the client, not just the child. – *IP 6*

> For some of them, I get the impression that when a family is not engaging, they think it's like, the *family's* fault – *IP 5*

> When it comes to engagement, it needs to be a *family-centred* conversation. There's just little comments that you hear other therapists making, like "ugh, why don't they get it? How hard is it?" and I think that really needs to change. – *IP 2*

Several participants also discussed how clinicians in the field can show signs of bias against families who may be prone to poor engagement. There were multiple mentions of resistance from other clinicians when it came to working with families who struggle with the current model of service provision. Others spoke of need to examine their own implicit biases and work to overcome them, so that they can provide for equitable care.

> And some therapists are not- they- ah, how can I say it? They prefer to work with a *certain* demographic… – *IP 1*

> I’m always checking my own biases. More from a cultural perspective, too, like looking at your own culture and being able to identify those biases within yourself. – *IP 2*

Although not explicitly mentioned by clinicians, it important to address the strong bias that many clinicians have towards spoken language-based habilitation. This aspect of the present theme was evident in the way some clinicians referred to sign language as a last resort.

> Fortunately, I haven't had the experience where it's gotten to the point where a child *needs* to use sign [sic]. But I know a lot of my colleagues have had to deal with that situation. – *IP 5*

5.2.5. *Aiding accessibility:* the need for increased service flexibility

This theme addresses how the standard model of service provision is inaccessible for many families, which leaves them disadvantaged in the habilitation process. Many participants discussed the toll that centre-based habilitation can take on a family – especially if they live far from the centre, or if both parents are working. Some clinicians told how families may have to spend hours in travel time getting to appointments, often with multiple young children too.

As mentioned in the theme of *Prioritising rapport*, several clinicians stated that they provide families with gifts and compensation, such as petrol or taxi vouchers. These can certainly provide a temporary solution to access-related barriers. However, clinicians were wary that they do not address the underlying cause of the issue.

Several clinicians expressed a desire to do more home visits, as this can make habilitation much more accessible for families who struggle to get to the centre. Participants were also aware of the additional resources required to do home visits. But ultimately, they felt that it could be of tremendous benefit for families with access barriers. Clinicians also felt that increasing access would improve family engagement, as it reduces the burden of the habilitation process.

> I think home visiting resources would be helpful for engagement. That's something we need to look into for those more vulnerable families, and those that really have *multiple* barriers to accessing us. – *IP 2*

> A lot of my kiddies don’t really respond well to coming into a clinic, and a lot of my families also really struggle doing that. And I do believe that it's better to have therapy

> in the home or their natural environments to help them learn. – *IP 1*

> For some families, it's a *very* big visit to come to us face-to-face for therapy. – *IP 3*

In addition, the widespread implementation of telehealth during the COVID-19 lockdowns was often framed almost as a "silver lining" of the pandemic. However, the shortfalls of telehealth were not overlooked, and several clinicians mentioned that it can be difficult to form proper connections with families through telehealth. Hence, many participants said they preferred using home visits or satellite clinics to improve accessibility.

> COVID has also made a little bit easier in that, previously, if you were sick, your session would be cancelled, right? Now, we can just easily convert it to being online so we can maintain seeing them, and that does maintain their engagement – *IP 4*

6. Chapter 6: Discussion

Through both the survey and interviews, this study was able to provide a broad overview of clinicians' perspectives on family engagement, while the interviews also brought additional depth and insight to these views.

6.1. Overview of key findings

Several key beliefs from clinicians were identified in the present study. These findings may inform the development of engagement strategies and have implications for future clinical practices.

1. Clinicians feel that low SES and culturally/linguistically diverse families are more prone to poor family engagement
    a. Increased efforts should be made to provide culturally safe care to these families
2. Feelings of connectedness are critical for family engagement
    a. Increasing families' connections with the wider hearing loss community can facilitate family engagement
    b. Increasing rapport between families and clinicians can facilitate engagement
3. Systemic flaws in the healthcare system are hindering family engagement
    a. Wider social issues are often the root of poor engagement
    b. Current modes of service provision are not accessible for many families

6.2. Study participants

Overall, the participant demographics in the present survey appeared to be fairly representative of the current workforce in paediatric cochlear implant habilitation. A 2018 assessment of the paediatric audiological workforce in New Zealand reported a relatively young age profile with the average age being 40 years, and most audiologists being between 25-44 years (Valentine and Rahiman, 2018). Present survey participants followed a similar age distribution, with most being between 31-40 years (Table 2). Females were overrepresented in the present study with 98% of participants being female (Table 2), compared to 86% of the current workforce (Royal College of Speech and Language Therapists, 2019; Valentine and Rahiman, 2018). For ethnicity, it is difficult to accurately determine representation of ethnic minorities as participants were distributed across four countries with varying ethnic breakdowns and Indigenous populations. Hence, comparisons will be simplified into European and non-European groups. Data from audiologists and speech-language therapists in New Zealand and the United Kingdom, estimate that 70-75% of the workforce is European (Royal College of Speech and Language Therapists, 2019; Valentine and Rahiman, 2018). In South Africa, the workforce appears to be slightly more diverse, with only 59% of audiologists and speech-language therapists being European (Pillay et al., 2020). Ethnicity estimates could not be found for Australia as Speech Pathology Australia does not collect ethnicity information (O'Hara and Rowlandson, 2010). With 83% of participants in the present survey being European (Table 2), it is likely that European clinicians have been slightly overrepresented, while non-European ethnicities were underrepresented. Further, there were no participants of Indigenous heritages (*e.g.* Māori or Australian Aboriginal). The scope of recruitment for the present study was also limited to clinicians working at a First Voice centre. As such, the findings will be most representative of paediatric cochlear implant habilitationists from private clinical settings in developed countries. Despite some discrepancies, the survey population is largely in alignment with the current paediatric cochlear implant workforce. Interview participants had a similar demographic distribution to the survey participants (Table 7). However, due to the small sample size (*n* = 7), it is difficult to assert whether their views would be representative of the wider workforce.

6.3. Clinicians' perspectives on family engagement

Overall, this survey demonstrated that poor family engagement is a prevalent issue for clinicians, with over half of participants indicating that they encounter poor engagement at least once a week. This is the first known reporting of the frequency that clinicians encounter poor family engagement. This highlights the need for an increased understanding of the barriers to engagement, and improved strategies for engaging families. The need for improved strategies is especially true considering that most survey participants indicated that their current strategies are only moderately effective. This was also evident in the interviews: "I would say that our efforts have improved engagement with some families, but nothing we've done has really like… *fixed* it" (IP 2).

Several indicators of poor family engagement were identified in the survey. Most prominently were inconsistent attendance, unreliable correspondence, and low device wear-time/datalogging (Figure 2). This was corroborated by the reported methods of monitoring family engagement – monitoring appointment attendance was the most frequently mentioned method, followed by regular case discussion/team meetings (Table 4). These findings show that clinicians and their workplaces are competent in recognising and monitoring poor family engagement. In particular, increased device wear-time is a known predictor of improved language outcomes for children with cochlear implants (Gagnon et al., 2020; Walker et al., 2013). However, having high wear-time requires significant daily effort from parents, as devices can often fall off if a child is lying down, sitting in a car seat, or having a tantrum (Gagnon et al., 2020). This is a likely explanation for the value of device wear-time as a reliable indicator of family engagement.

6.4. Discussing clinician-identified barriers to family engagement in paediatric cochlear implant habilitation

Throughout the present study, many various factors were identified that can have an impact on a family's engagement. Much of the prior literature surrounding family engagement has focused on the impacts of engagement, but the underlying barriers and facilitators of engagement have rarely been explored. Thus, the present findings contribute significantly to the understanding of family engagement in the paediatric cochlear implant habilitation process.

6.4.1. Cultural and linguistic barriers to family engagement

The impact of cultural differences on family engagement was evident throughout many areas of this study. Firstly, in the survey, cultural differences between families and clinicians were ranked as the most significant barrier to family engagement (Figure 4). Additionally, when survey participants were asked which demographics are prone to poor family engagement, culturally diverse families were the second-most frequently mentioned group. Moreover, several interview participants discussed the barriers that culturally diverse families face throughout the paediatric habilitation process, as seen in the theme of *Systemic failures*. The impacts of linguistic diversity were also evident throughout the study, although they were typically regarded as less slightly significant than the impacts of cultural diversity. These findings are in agreement with previous literature. Alduhaim et al. (2020) reported a lack of cultural safety in intervention services for children with hearing loss. Furthermore, although not directly related to cochlear implant habilitation, Grandpierre et al. (2018) and Mytton et al. (2014) both reported that cultural differences can impact on engagement with services.

The mechanisms underpinning the impacts of cultural differences are diverse and multifaceted. However, it is likely that there are a wide range of factors that compound on one another to create a far-reaching effect on engagement and outcomes. To attempt to understand these varying factors, it is important to consider the cultural ecosystems within which they occur (Fivush and Merrill, 2016). In most developed countries, societal norms are largely built on Euro-centric standards. These standards are woven into the fabric of society and have shaped the systems surrounding healthcare, education, legislation, and government bodies. Meanwhile, culturally diverse families have historically been marginalised and are expected to assimilate with the cultural norms of the countries they reside in. This creates an imbalanced power dynamic wherein European families and their values are viewed as the “default”, which make it easier for them to interact with public services such as healthcare, as the system already caters to their cultural needs. Conversely, culturally diverse families may hold values that conflict with their environment. This can lead to confusion and frustration as they navigate the different systems in society. Furthermore, healthcare providers may have implicit biases against culturally diverse families that can affect the quality of care that is given (Dehon and Weiss, 2017). Over a lifetime of receiving fragmented care or feeling unheard by the healthcare system, culturally diverse families may develop a sense of distrust towards healthcare workers. Hence, if these families have had unfavourable experiences with the healthcare system in the past, this could hinder their motivation to engage with the paediatric cochlear implant habilitation process. And, as demonstrated by the literature, this can lead to poorer outcomes for their child (Yanbay et al., 2014). Many culturally diverse families also face language barriers that can compound on the cultural barriers. This naturally impedes a family’s ability to engage, as the habilitation process relies heavily on communication between families and providers. This communication is critical not only for therapeutic and educational purposes, but also for building rapport. Hence, language barriers can increase the risk of poor family engagement.

6.4.2. Low socio-economic status as a barrier to family engagement

Throughout many areas of the present study, clinicians identified low SES as a barrier to family engagement. Families with low SES were the group most frequently identified as being prone to poor engagement (Figure 3). Interestingly, economic/monetary constraints were not highly ranked as a barrier to family engagement, being ranked 10th out of 16 barriers. However, this barrier also had the largest variation in ranks compared to the available options (Figure 4). This may be because the participants were spread across different countries where the costs of habilitation are varied. Additionally, the choice of wording in the ranking question (*i.e.* “economic/monetary constraints”) could have caused confusion among participants as it has slightly different connotations to “low SES”. Nevertheless, these results indicate that clinicians perceive a negative effect of low SES on family engagement. The SES-related findings of the present study are in alignment with findings from Kirkham et al. (2009). While Kirkham et al. (2009) did not directly assess whether clinicians felt that low SES affected family engagement, 33% of participants felt that low parental engagement was the main contributor to SES-related outcome disparities (Kirkham et al., 2009).

However, viewing low SES itself as a predictor of poor outcomes is overly simplistic. Rather, low SES limits a family’s resources in multiple ways which, in turn, impedes their capacity to engage with the habilitation process. For example, in low SES families, both parents often need to work full-time to cope financially. This means that on top of being materially disadvantaged, they are also “time-poor”. The concept of time poverty refers to a lack of leisure time (Giurge et al., 2020). In the present study, parents’ competing work demands were ranked 4th out of 16 potential barriers to family engagement (Figure 4). Whilst high work demands are not exclusive to low SES families, these families are more likely to require a dual income to meet their financial needs. Time poverty can be further exacerbated by long commutes for families who cannot afford to live close to their workplace (Giurge et al., 2020). Being time-poor limits the time that can be spent working on speech-language therapy exercises at home and makes it difficult to attend appointments. This concept was touched in the theme of *Systemic failures* where clinicians noted that some families have poor engagement due to an overall lack of resources. This leaves the families overwhelmed and unable to be fully engaged in habilitation.

6.4.3. Access-related barriers to family engagement

The notion of limited accessibility was another prominent theme in the present study. Interestingly, access-related barriers to family engagement, such as limited access to centre and large travel time, were not highly ranked by survey participants (9th and 12th out 16, respectively) (Figure 4). However, the need for increased accessibility was discussed by all interview participants. Overall, it appears that clinicians perceive limited access to services as a barrier to family engagement, but it is considered less significant than other barriers. Mytton et al. (2014) suggested that compared to parents, clinicians may be less aware of access-related barriers – however, this study was not specific to cochlear implant habilitation. Further research of families’ perspectives would be required to determine whether service accessibility is truly a less significant barrier, or whether clinicians have underestimated the impact of poor accessibility on family engagement.

Findings from the interviews may be able to offer some explanation. Interview participants suggested that limited accessibility may not often be a significant barrier on its own, but it does increase the overall demand of the habilitation process for families. Hence, for families with sufficient resources, limited accessibility may not be a significant issue. However, for those who are already affected by other barriers, such as time poverty or complex family dynamics, the added strain of limited accessibility can have a profound impact on a engagement. This perspective may also explain why access-related barriers were not ranked as highly important, yet access-related facilitators were viewed as very beneficial.

6.4.4. Emotional barriers family engagement

Throughout the present study, many participants identified emotional barriers to family engagement, namely, grief and denial. Denial of hearing loss was ranked 3rd out of 16 barriers, and grief was ranked 6th out of 16 (Figure 4). Moreover, families who feel shame and stigma related to their child's deafness were identified as being prone to poor engagement (Table 3). These findings demonstrates that clinicians recognise that families must be accepting of the hearing loss before they can properly engage with the habilitation process. The effect of emotional barriers has also been evidenced in the literature. Fulcher et al. (2015) found that emotional barriers such as ongoing grief can lead to poorer outcomes for children with cochlear implants. Bierbaum et al. (2019) also found that denial can hinder a family's willingness and ability to opt for a cochlear implant for their child.

There are many ways that grief and denial may inhibit family engagement. Firstly, a child's hearing loss diagnosis comes unexpectedly for most families, as they are typically from a hearing background (Huttunen and Välimaa, 2012). The subsequent process of grieving about their child's hearing loss can take time, and many parents may not feel ready to move towards habilitation until they have accepted it. For parents who do begin habilitation before fully accepting the diagnosis, they may feel conflicted and overwhelmed, meaning they do not have the mental capacity to fully engage in the process. The stigma surrounding deafness can also contribute to delayed acceptance of a diagnosis, and may cause parents to be in denial about their severity of their child's hearing loss. Being in denial can stunt any sense of urgency regarding intervention and cause parents not to follow up on referrals or recommendations

(Bierbaum et al., 2019).

6.4.5. Limited understanding of habilitation as a barrier to family engagement

Having a poor understanding of the habilitation process and early intervention was also identified as a significant barrier to family engagement – survey participants ranked it 2nd out of 16 barriers (Figure 4). Furthermore, several participants identified families with a poor understanding of habilitation or early intervention as being prone to poor family engagement (Table 3). These findings show that clinicians understand the importance of families being well educated on their role in the habilitation process and the importance of early intervention. This supports previous studies who have stated that a family's understanding of the habilitation process is important for their ability to engage (Alduhaim et al., 2020; Kirkham et al., 2009). If families are not sufficiently educated on the habilitation process, they may not feel inclined to be actively engaged in their child's journey.

It is also important for clinicians to ensure that they inform families of *all* habilitation options – including those which integrate Deaf culture or sign language. As mentioned in the theme of *Systemic failures*, clinicians are overwhelmingly in favour of spoken language-based goals for deaf children, and often view reliance on sign language as an indicator of failure. This could mean that clinicians portray the use of sign language in a negative light when speaking to families. This may create a barrier for families and children who would prefer or benefit from sign language, as they are not fully informed of their options. Clinicians should work to address their own implicit biases regarding Deaf culture so that they can meet the needs of families who opt for sign language.

6.5. Discussing clinician-identified facilitators and strategies for family engagement in paediatric cochlear implant habilitation

Many facilitators and strategies for family engagement were identified throughout this study. Note that for the purpose of this section, a "facilitator" describes an abstract concept that can help to improve a family's engagement, whereas a "strategy" is an actionable technique or resource for encouraging engagement. For example, providing culturally safe care has been identified as a *facilitator* of family engagement, thus, increasing diversity in the workforce is a *strategy* for engaging families.

It became evident throughout the study that most clinicians are relying on informal strategies to improve family engagement. Only half of survey participants stated that their workplace provides training for facilitating engagement (Figure 5). One interview participant, whose workplace does not provide training, stated that “we all just kind of try our own things” (IP 1). This means that families may be receiving inconsistent service quality, as some clinicians could incidentally have more effective strategies for engagement than others. Many clinicians also expressed that their current strategies for engaging families are only moderately effective. Thus, there is a clear need for evidence-based strategies to be developed for facilitating family engagement to ensure that all families have access to a high standard of care.

Additionally, clinicians indicated that they are not confident that they have sufficient resources to engage families, with only 2 out of 41 survey participants stating that they “definitely” have enough resources. This may be seen as a call to action for habilitation centres to increase their awareness of engagement-related issues, and dedicate resources to implementing strategies for family engagement.

6.5.1. Building connections with families to facilitate engagement

This study has demonstrated that strong connections are a significant facilitator of family engagement. These connections can be built between families and their habilitation providers, or with other families from the habilitation centre. Further, *connectedness* was considered the central organising concept of three of the themes in the thematic analysis.

One clinician-identified strategy for increasing connectedness is fostering supportive relationships between families, as mentioned in the interview theme *It takes a village*. In the present study, arranging meetings with other families was one of the most commonly mentioned strategies for facilitating engagement (Table 6). Many interview participants also spoke of centre-run parent groups and events, which they reported to be beneficial. These strategies are supported by research from Mytton et al. (2014), in which group experiences were found to be a facilitator of family engagement. This shows that clinicians have an awareness of the benefits that inter-family connections can have for engagement. Inter-family connections may encourage engagement by providing a source of emotional support and belonging for families – this was discussed in the interviews and was also hypothesised by Mytton et al. (2014). The sense of solidarity between families who are going through similar experiences may help families to cope with the stress of the habilitation process. This, in turn, may help them to become more engaged.

The connection between families and their providers is also important for facilitating engagement. This was discussed in the interview theme *Prioritising rapport*. This aligns with the principles of family-centred care outlined by Moeller et al. (2013), in which family/provider partnerships were considered a key aspect of the habilitation process. In the present study, the main reported strategy for building this connection was to dedicate time in sessions to getting to know the families on a personal level. Furthermore, several interview participants reported pulling back from clinical work and focusing on their relationship with families if they started to notice that they were struggling or disengaging. This was found to be effective as it created a sense of trust in the clinicians, meaning that families could seamless re-engage with habilitation once they were emotionally ready.

6.5.2. Providing emotional support to facilitate family engagement

It is known that the habilitation process can be an emotionally turbulent time for families (Bierbaum et al., 2019). It follows that providing emotional support for families can facilitate engagement. An important strategy for improving the emotional wellbeing of families is to provide them with counselling. Throughout the interviews, many clinicians also spoke of the benefits of family counselling. Increased counselling for families was also ranked 3rd out of 12 facilitators of family engagement (Figure 6), demonstrating that clinicians perceive high potential benefit from counselling. Previous literature has shown that families also feel that counselling is helpful for engagement – some parents have expressed that they wish there was more counselling involved in the habilitation process (Alduhaim et al., 2020).

Some interview participants also advised that counselling should be integrated into the habilitation process, rather than offered as solution once a family has begun to noticeably struggle or disengage. This is because having early and ongoing access to counselling can have a preventative effect for emotional barriers, meaning that families can accept the hearing loss and engage with habilitation in a more timely manner. Furthermore, there is a degree of stigma attached to going through counselling. Interview participant 3 noted that some can families feel confronted or embarrassed when counselling is offered to them *"because it will feel as though it's finding solutions to problems that have been, like, flagged"*. Similarly, Mytton et al. (2014) also found that non-stigmatising service was a facilitator of family engagement. This emphasises the need for counselling to be present throughout the entire habilitation process. Several interview participants also mentioned that they often take on counselling roles themselves – one survey participant also cited this as a strategy they use for encouraging engagement (Table 6). Whilst habilitation clinicians should feel comfortable providing some emotional counselling to their families, there are also benefits to having a dedicated counsellor. As mentioned by interview participant 1, if clinicians spend too much time providing emotional support with their families, professional boundaries can become “blurred”, and families struggle to “see the importance” of therapy sessions. This highlights the need for a balanced, multidisciplinary approach to habilitation, so that families have an avenue for emotional support through the centre, but also respect the role of their primary habilitation therapists. In the present study, less than a quarter of clinicians indicated that they offer support services to families who are struggling to engage (Table 6). By contrast, over half of clinicians believed that increased counselling could benefit family engagement (Figure 6).

6.5.3. Removing pressure on families to facilitate engagement

Throughout many of the interviews, clinicians alluded to a feeling of pressure that is often experienced by families in the habilitation process. Whilst this pressure was not necessarily framed as a barrier to family engagement, many clinicians discussed various methods of reducing pressure on families. Hence, the reducing pressure can be viewed as a facilitator of family engagement. This concept was also evident in the survey, as some participants mentioned the use of casual environments and communication styles as a strategy of facilitating engagement (Table 6). These findings are a stark contrast to research from Kirkham et al. (2009), where one of the key strategies suggested by audiologists to improve SES-related outcome disparities was to have stricter programme requirements. Participants from the study said that they “keep pressure on them [families] to comply with us” and “force parents to participate in sessions” (Kirkham et al., 2009, p. 519). One possible reason for this disagreement in the literature is that the research from Kirkham et al. (2009) was conducted over a decade ago. Hence, when comparing their findings to the present study, the differences in clinicians’ attitudes may reflect a change in philosophy regarding how families should be treated. This theory aligns with the ever-increasing adoption of family-centred care, where healthcare practitioners make conscious effort to build rapport and collaborate with families (Moeller et al., 2013).

As seen in the *Keep it casual* theme, several different strategies were suggested for removing pressure on families, including using social media to communicate, maintain a casual demeanour during appointments, and creating a casual environment in the centre. Interview participants said that these strategies help families to feel less judged, and they ultimately feel more comfortable throughout the habilitation process which can then improve their engagement. This demonstrates that clinicians are aware of the power dynamic between themselves and families, which can contribute to feelings of pressure or anxiety for families. Clinicians also showed that they take conscious steps to reduce this pressure and thus, enable families to be more engaged.

6.5.4. Parental understanding of habilitation as a facilitator of family engagement

Findings from the present study have shown that it is important for parents to have a comprehensive understanding of the habilitation process, particularly the importance of early intervention. This aligns with the findings of Kirkham et al. (2009), which showed that audiologists perceived a need for increased parent education throughout the cochlear implant habilitation process. When considering the significant benefits that early intervention can have on outcomes, it is crucial that parents understand the need to engage in habilitation in a timely manner to give their child the best chance to acquire language. Parents also need to be educated on the ongoing nature of their responsibilities from the outset of habilitation.

Providing families with more accessible information was considered the most beneficial potential resource for improving family engagement (Figure 6). All survey participants indicated that they currently deliver information about the habilitation process verbally, either through clinicians or through meetings with other families. It is known that parents can only absorb a limited amount of information that is delivered verbally – particularly if they are still experiencing shock of grief about the hearing loss diagnosis. Hence, it is important for families to have access to permanent copies of information (physical or digital) so that they can refer back to it as needed – this especially holds true for families with limited English skills, who may struggle to keep up with verbally delivered information. However, only approximately half of participants indicated that they provide permanent copies of information, such as brochures or online links. Furthermore, almost two thirds of participants' workplaces do not offer informational material that is accessible to those with limited English literacy, such as translated or picture/video-based materials (Figure 5). This lack of accessible information is likely to disproportionately affect families from linguistically diverse backgrounds, and may compound with the aforementioned barriers that stem from language differences. It is clear that clinicians see a need for more accessible and comprehensive education for parents in the cochlear implantation habilitation process. However, current practices do not seem to meet the needs of many families.

6.5.5. Providing accessible service provision to facilitate family engagement

Improving families’ access to habilitation services has been shown to be an important facilitator of family engagement. Increased in-home support for families, such as home visits, was ranked 2nd out 12 potential facilitators of family engagement (Figure 6). This demonstrates that clinicians are aware that improving service accessibility can have a positive impact on family engagement. In the present study, the main strategies for improving accessibility were home visits and telehealth. The benefits of home visits, specifically, may also extend beyond increasing accessibility. Some interview participants expressed that therapy is best conducted in the home, so that the skills learned during sessions have more context, making them more applicable to daily life. This aligns with multiple studies involving speech-language therapy that have found home-based therapy to be effective (Tosh et al., 2017; Zuccarini et al., 2020).

It is encouraging that some practices for increasing accessibility already appear fairly widespread, with a majority of survey participants indicating that their workplace already offers multiple services modalities (*e.g.* telehealth or home visits) and flexible appointment times (Figure 5). Survey participants also mentioned that they already use several access-related strategies for engaging families – including offering remote care/telehealth, which was the most frequently mentioned strategy overall (Table 6). However, findings from the interviews reveal that there is still progress to be made in terms of making habilitation accessible to all families. While telehealth is often used to increase accessibility, several interview participants highlighted its weaknesses. Namely, clinicians felt that it was harder to form a genuine connection with families via telehealth appointments. As discussed earlier, it is crucial that families form a meaningful relationship with their habilitation providers as this can facilitate engagement. Hence, it may be beneficial for habilitation providers to focus on home visits as a strategy for improving accessibility. While home visits can be resource-intensive, there is evidence to suggest that the relative improvements in a child’s language development resulting from home visits can outweigh the associated costs (Tosh et al., 2017).

Another facet of accessible service provision is ensuring that low SES families have equal opportunities to engage in habilitation. Low SES has been shown to make habilitation less accessible to families, as they often have to work with limited resources. Kirkham et al. (2009) found that 90% of audiologists believed that improving service provision would reduce

SES-related outcome disparities for children with cochlear implants. However, the effects of low SES are particularly difficult to properly address, as it would take large-scale social change to lift low SES families out of their underprivileged position in society. However, the use of gifts or compensation (*e.g.* free meals or petrol vouchers) can help to offset some of the financial stressors that come with the cochlear implant habilitation process. Only approximately one third of survey participants indicated that their workplace offers gifts or compensation to families (Figure 5; Table 6). The potential benefits of gifts and compensation were also mentioned by several interview participants. Although, it appears that clinicians do not feel that gifts and compensation are particularly effective for facilitating engagement, as this was ranked 8th out of 12 potential facilitators and was selected by only one third of participants (Figure 6). This may demonstrate that clinicians recognise that small material gifts ultimately fall short of addressing the underlying issues – that is, that low SES families are both resource- and time-poor. This dilemma was illustrated by Interview Participant 7:

> We might be able to solve one little thing by giving them petrol vouchers, but then they might not have people to look after their other kids, or they're still living in cold houses so they get sick more and have to cancel more often.

In light of this, further research should be conducted to find alternative strategies making habilitation more accessible to low SES families

6.5.6. Providing culturally safe care to facilitate family engagement

Throughout the survey and interviews, it became clear that clinical providers recognise that culturally and linguistically diverse families are disadvantaged in the habilitation process. Clinicians also showed an interest in increasing the cultural safety of their services. This aligns with Alduhaim et al. (2020), which reported that parents appreciated the integration of their cultural values into the habilitation process.

Ensuring that habilitation providers are culturally competent is one strategy for reducing the negative impact of cultural differences. In the present study, 53% of survey participants indicated that increased cultural training for clinicians would be a helpful resource for improving family engagement; it was also ranked 5th overall out of 12 other suggested resources (Figure 6). This shows that some clinicians see a need for improved cultural competence. Although, it is interesting that almost half of participants did not indicate that cultural training would help them to improve family engagement, despite the fact that cultural differences were the most commonly selected and highest ranked barrier to family engagement (Figure 4). Furthermore, only one participant mentioned that they currently integrate families' cultural values into the habilitation process (Table 6). This may indicate a degree of cognitive dissonance amongst clinicians where they are aware of the potential negative impacts of cultural barriers, yet they are less cognizant in their own role in upholding these barriers. After all, it is unlikely that any particular culture is innately more prone to poor engagement. Rather, it is the cultural mismatch between families and clinicians that creates the barrier; one interview participant said "As a European clinician, I do I struggle to engage with Māori and Pacifica families" (IP7). For this reason, increasing cultural diversity amongst clinicians should be more effective strategy for reducing cultural barriers to engagement. This was corroborated by the higher selection rate and ranking of increased diversity as a facilitator of engagement (selected by 55% of participants and ranked 4th overall; Figure 6) compared to increased cultural training. Interview findings further support this, as several clinicians noted that the current workforce is rather homogenous – typically consisting of young, European women from similar social backgrounds. They expressed that increased diversity would bring richness to the workplace and allow culturally diverse families to connect with their habilitation providers more. Unfortunately, increasing diversity amongst clinicians is not an easily implementable solution as there are also cultural barriers for getting into the field of paediatric cochlear implant habilitation. Interview participant 7 recalled an encounter with a Māori single mother of a child with cochlear implants:

> "she actually wanted to become a speech-language therapist, but there were just *so* many barriers. She's a single mum so she still needed to work, right? But then, there's not the option to [study] part-time. And she lived out of Auckland so they'd have to relocate, and then she'd be away from her family and… it would just be too much."

This anecdote also illustrates the various barriers that culturally diverse people can face in their efforts to become clinicians, and thus shows the complexities of attempting to increase diversity in the workforce. Greater diversity among service providers should still be pursued, but this would be a long-term endeavour. In the meantime, providing increased cultural training to clinicians is a more feasible alternative for reducing cultural barriers. However, only 20% of survey participants indicated that they their workplace provided them with cultural training (Table 5). This discrepancy may be seen as a call for action for clinical leads and administrators.

6.6. Strengths and limitations of the present study

Several limitations may have impacted the findings of the present study. Firstly, because participation was voluntary (with no rewards or compensation), the study may have attracted clinicians who already take an interest in family engagement and have an increased awareness of the barriers and facilitators to engagement. This self-selection bias may have impacted the findings of the present study – particularly given that several interview participants discussed the varying attitudes towards engagement from clinicians in the field. Hence, the views expressed by participants may not represent the beliefs of the wider clinical body. However, this does not necessarily detract from the value of the study; the clinicians who took part may have given a more accurate reflection of families' perspectives due to their heightened awareness of the barriers that families face. Additionally, a major aim of the study was to uncover clinician-identified strategies for family engagement, as these may be implementable in future clinical practice. In this regard, the self-selection bias could have resulted in a degree of "expertise" among participants, and may have provided greater insight into effective strategies for family engagement than if a more representative sample population was recruited.

Another limitation of the study is the lack of diversity among participating clinicians. Although the ethnicities of participants largely reflects the active workforce in paediatric cochlear implant habilitation, it is specifically important for research regarding marginalised social groups (*e.g.* culturally diverse families) to be guided by people from these demographics as they have more insight to the experiences of the groups. It may be beneficial for future research in this field to actively recruit culturally diverse participants.

The use of a non-validated survey is another limitation in the present study. Validated surveys are preferable as they have been tested to ensure that resultant findings are reliable (Dowrick et al., 2015). Further, it can be difficult to compare the findings of a non-validated study to other literature, as there is a possibility that the survey itself introduced a degree of bias that could have impacted results. Hence, it is possible that the use of a non-validated detracts from the reliability of the present study.

Another limitation is the lack of statistical analysis of the quantitative survey findings.

Thorough statistical analysis allows for stronger conclusions to be drawn from the data, and can also illustrate correlations within the data. In the present study, survey questions largely had to be interpreted in isolation, meaning that there may have been additional connections or correlations that were missed. Future studies of family engagement should aim to conduct more rigorous statistical analysis to ensure that maximum information is extracted from the data.

Despite these limitations, this study also displays several strengths. This exploratory research is unique in its focus on pragmatic facilitators of family engagement. Prior research has outlined the barriers to engagement (which the present findings also corroborate), but there is scarce literature regarding solutions to these known problems. This distinct approach adds to the value of the study, as the findings may contribute to the betterment of the paediatric cochlear implant habilitation process.

Another strength of the study is the utilization of qualitative methods. There is currently a lack of qualitative research surrounding family engagement, as researchers often view qualitative approaches as less "valid" (Garung et al., 2020). However, qualitative methods can enable a deeper understanding of subject matters as participants have the opportunity to explain relevant context and nuances within the topics (Paliadelis, 2005). This was evidenced throughout the study as the interviews provided a much more in-depth description of engagement strategies compared to the survey.

6.7. Conclusion

The present study revealed clinicians views on the various barriers and facilitators of family engagement in the cochlear implant habilitation process, and several key themes were identified.

Firstly, this study demonstrated that clinicians frequently encounter families with poor engagement, and they are aware of the negative impacts it can have on a child's post-implantation outcomes. Clinicians also showed awareness of the indicators of poor engagement, and many were consistently monitoring family engagement. The significance of building wider community connections was also established in this study. This can be achieved through parent groups, centre events, or meetings with other families. These connections help families to develop a sense of belonging within the cochlear implant community, which motivates them to engage. Clinicians also believed that building strong, trusting relationships with families was crucial for engagement. These relationships can be fostered by creating a casual, non-judgemental environment in appointments, and dedicating time to building rapport with families. In this study, clinicians also saw the need for increased education and emotional support for families. Many clinicians indicated that providing more accessible information for families would improve their understanding of the habilitation process. For emotional support, clinicians often suggest counselling – however, inter-family connections were also identified as a source of emotional support. Finally, the importance of culturally safe care was a major theme throughout this study. Clinicians demonstrated a strong awareness of the cultural barriers to family engagement, and felt that increased cultural training and diversity in the workplace could help to break down these barriers.

Overall, the findings of this study have contributed significantly to the current understanding of family engagement and its barriers and facilitators throughout the cochlear implant habilitation process. However, as this study is founded on clinicians' opinions, it is possible that families would have differing perspectives. Hence, it is important for future research to investigate families' opinions so that a more balanced view of family engagement can be developed.

7. Chapter 7: Appendices

7.1. Appendix A: Participant Information Sheet for Lead Clinicians

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Auckland, New Zealand

PARTICIPANT INFORMATION SHEET FOR LEAD CLINICIANS

Project Information:

Your centre is invited to take part in a study: *Family engagement in paediatric cochlear implant habilitation: the clinicians' perspective*. Whether or not you choose to share this invitation with your team is your choice. If you decide not to, you don't have to give a reason.

This Participant Information Sheet will help you decide if you'd like your team to take part. We are happy to answer any questions you may have before, during, or after the study. You do not have to decide today whether or not you will participate. Before you decide you may want to discuss the study with others – please feel free to do this. We encourage you to keep a copy of this Participant Information Sheet for your future reference.

There are two key elements of this study: an online survey, and an online interview. Participants are welcome to take part in the survey *only*, and not the interview. While we need your permission for the research to take place at your centre, each team member has the right to individually decide whether to participate or not, and their participation or non-participation will be kept confidential.

We ask that you read and understand all parts of this Participation Information Sheet before deciding whether or not to share this study with your team.

What is the purpose of this study?

The study is focusing on family engagement throughout the habilitation process for paediatric cochlear implant recipients. The clinicians' perspectives are being used as a proxy measure of family opinions, as there would be significant ethical and cultural sensitivities to navigate if these families were to be recruited directly – especially given that the population of interest are difficult to engage.

Both the survey and interview aim to understand the clinicians' opinions on how family engagement can best be measured, what the barriers to family engagement are, and what strategies could be implemented to improve family engagement. However, the interviews will have a more in-depth focus on the strategies that clinicians use to engage families, and how effective they are.

We hope that findings of this study will help to further our understanding of the barriers to family engagement and uncover strategies that can be implemented, so that we can work to overcome the barriers and improve outcomes for all children with hearing loss.

Research team:

This study is being performed by Sophie Wong - a Master of Audiology student from the University of Auckland and the Principal Investigator, Holly Teagle - an Associate Professor at the University of Auckland and Clinical Director at The Hearing House.

Sophie Wong

Holly Teagle

What will participation in the study involve for my team?

Your team has been invited to this study as you are a group of clinicians who works with paediatric cochlear implant recipients, and you are employees of a First Voice Consortium centre. If an individual decides to take part, they will answer an online questionnaire – this should take 15-20 minutes to complete. It will ask about their opinions on what the barriers to family engagement are, what they are currently doing to encourage family engagement, and what they think could be used to improve family engagement. No health information will be collected from them. They will not be asked to identify themselves but we will ask for some demographic information (e.g. age, gender).

At the end of the survey, there will be an opportunity for participants to volunteer for an interview that will be conducted via Zoom. If they wish to volunteer, they will follow a link where they can give consent to the interview and provide a contact email address. Providing contact details will mean that their identity will become known to the researchers. However, their identity will remain confidential in the publishing of findings. If a participant volunteers for the interview, we will get in touch to arrange a time that suits them. The interview will take approximately 20 minutes, and will be an opportunity for them to describe and discuss any strategies they use to engage families. They will not be asked to comment on their employers, colleagues, or workplace.

You are welcome to contact the research team with questions or concerns at any point in the study.

Benefits and risks of participation:

There are no direct benefits from participating in the study. However, information gained from the study may indirectly benefit your team by helping you all to engage families in the future.

While the survey is formatted to be anonymous, we cannot guarantee that participants will remain anonymous to the researchers. If an individual decides to partake in the survey, there is a small risk that the research team will be able to inadvertently identify them by their demographic information, given that there is only a small population who are eligible to participate – some of whom are personally known to the researchers. However, please know that all measures will be taken to ensure that all answers remain confidential. Survey data will be stored and presented without identifiable information. Any answers from your team will not be shared with you.

Those who also take part in the interview must provide identifying contact information to the researchers. All measures will be taken to keep their identity confidential to anyone outside the research team. Interviewees will be assigned a number (e.g. Participant 1) and findings will be stored and published in a de-identified manner. Their contact information and consent will be stored separately from survey and interview data on a password-protected database to minimise the risk of any confidentiality breaches.

The rights of the participants:

Participation in this study is entirely voluntary. As the lead clinician, you have the right to withdraw access to your team at any time. However, you do not have the right to withdraw participant data that has already been submitted to the researchers – this can only be done by the participant themselves (in the case of interview data only).

There is no reward or compensation for participation in either the survey or interview, nor will participants incur any costs related to the study. Individuals may decline to partake in either the survey or interview without experiencing any disadvantage. If an individual starts the survey or interview, they may choose not to complete it at any point without giving any reason. If an individual initially volunteers for the interview and then changes their mind, they are not obligated to take part in an interview and may withdraw their consent without providing reason.

Because the survey does not collect identifying information, survey responses cannot be withdrawn by yourself or the participant *after* answers have been submitted. Interview responses may be withdrawn by the participant at any time in the study – they do not have to provide a reason for withdrawing their answers.

What will happen after their participation in the study?

There is no ongoing involvement of participants beyond completion of the survey or interview. Your teams' answers will be stored in a password-protected online database for 10 years before being destroyed by the researchers.

Findings will be disseminated through First Voice newsletters and published as a Master's thesis, which will be available online through the University of Auckland thesis library upon completion of the study.

Contact details, additional Māori support wording, and approval wording

If you have any questions or concerns about the study, please contact Sophie Wong at *swon953@aucklanduni.ac.nz* or Holly Teagle at *holly.teagle@auckland.ac.nz.*

If you require Māori cultural support, talk to your whānau in the first instance. You may also contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324, or contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 4868920 ext 3204 to discuss any questions or complaints about the study.

For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or at 373 7599 x 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.

Approved by the Auckland Health Research Ethics Committee on 03/09/2021 for three years. Reference number AH22780.

7.2. Appendix B: Participant Information Sheet for participants

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The University of Auckland
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PARTICIPANT INFORMATION SHEET

Project Information:

You are invited to take part in a study: *Family engagement in paediatric cochlear implant habilitation: the clinicians' perspective*. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason.

This Participant Information Sheet will help you decide if you'd like to take part. We are happy to answer any questions you may have before, during, or after the study. You do not have to decide today whether or not you will participate. Before you decide you may want to discuss the study with other people, such as family or friends – please feel free to do this.

There are two key elements of this study: an online survey, and an online interview. If you decide to participate, you are welcome to take part in the survey *only*, and not the interview. We ask that you read and understand all parts of this Participation Information Sheet before deciding whether or not to partake. You are welcome to share this Participant Information Sheet with others and keep a copy for your future reference.

What is the purpose of this study?

The study is focusing on family engagement throughout the habilitation process for paediatric cochlear implant recipients. Your perspective is being used as a proxy measure of family opinions, as there would be significant ethical and cultural sensitivities to navigate if these families were to be recruited directly – especially given that the population of interest are difficult to engage.

Both the survey and interview aim to understand the clinicians' opinions on how family engagement can best be measured, what the barriers to family engagement are, and what strategies could be implemented to improve family engagement. However, the interviews will have a more in-depth focus on the strategies that clinicians use to engage families, and how effective they are.

We hope that findings of this study will help to further our understanding of the barriers to family engagement and uncover strategies that can be implemented, so that we can work to overcome the barriers and improve outcomes for all children with hearing loss.

This study is being performed by the student researcher, Sophie Wong - a Master of Audiology student from the University of Auckland and the Principal Investigator, Holly Teagle - an Associate Professor at the University of Auckland and Clinical Director at The Hearing House.

Sophie Wong

Holly Teagle

What will my participation in the study involve?

You have been invited to this study as you are a clinician who works with paediatric cochlear implant recipients, and you are an employee of a First Voice Consortium centre. If you do decide to take part, you will answer an online questionnaire – this should take 15-20 minutes to complete. It will ask about your opinions on what the barriers to family engagement are, what you are currently doing to encourage family engagement, and what you think could be used to improve family engagement. No health information will be collected from you. You will not be asked to identify yourself but we will ask you to provide some demographic information (e.g. age, gender).

At the end of the survey, there will be an opportunity to volunteer for an interview that will be conducted via Zoom. If you wish to volunteer, you will follow a link where you can give consent to the interview and provide a contact email address. Providing contact details will mean that your identity will become known to the researchers. However, your identity will remain confidential in the publishing of findings. If you volunteer for the interview, we will get in touch to arrange a time that suits you. The interview will take approximately 20 minutes, and will be an opportunity for you to describe and discuss any strategies you use to engage families. The interview will be audio-recorded (and optionally video-recorded at your preference) and automatically transcribed by Zoom. We will email you a copy of the transcript and you will have the opportunity to edit it. Edited transcripts must be returned within one week of you receiving the transcript – if it is not returned within this timeframe, we will accept and use the original version. You are welcome to keep a copy of the transcript. Recordings will be owned by and accessible to the researchers only. Recordings will be destroyed by the research team following completion of the study.

You are welcome to contact the research team with questions or concerns at any point in the study.

Benefits and risks of participation:

There are no direct benefits from participating in the study. However, information gained from the study may indirectly benefit you by helping you to engage families in the future.

While the survey is formatted to be anonymous, we cannot guarantee that you will remain anonymous to the researchers. If you decide to partake in the survey, there is a small risk that the research team will be able to inadvertently identify you by your demographic information, given that there is only a small population who are eligible to participate – some of whom are personally known to the researchers. However, please know that all measures will be taken to ensure your answers remain confidential. Survey data will be stored and presented without identifiable information. Your answers will not be shared with your employers.

Those who take part in the interview must provide identifying contact information to the researchers. All measures will be taken to keep your identity confidential to anyone outside the research team. Interviewees will be assigned a number (e.g. Participant 1) and findings will be stored and published in a de-identified manner. Your contact information and consent will be stored separately from survey and interview data on a password-protected database to minimise the risk of any confidentiality breaches.

The rights of the participants:

Participation in this study is entirely voluntary. There is no reward or compensation for participation in either the survey or interview, nor will you incur any costs related to the study. You may decline to partake in either the survey or interview without experiencing any disadvantage. If you start the survey or interview, you may choose not to complete it at any point without giving any reason. If you initially volunteer for the interview and then change your mind, you are not obligated to take part in an interview and may withdraw your consent without providing reason.

Because the survey does not collect identifying information, survey responses cannot be withdrawn *after* your answers have been submitted. Interview responses may be withdrawn at any time in the study before publishing – you do not have to provide a reason for withdrawing your answers.

What will happen after my participation in the study?

There is no ongoing involvement of participants beyond completion of the survey or interview. Your answers will be stored in a password-protected online database for 10 years before being destroyed by the research team.

Findings will be disseminated through First Voice newsletters and published as a Master's thesis, which will be available online through the University of Auckland thesis library upon completion of the study.

Contact details, additional Māori support, and approval wording

If you have any questions or concerns about the study, please contact Sophie Wong at *swon953@aucklanduni.ac.nz* or Holly Teagle at *holly.teagle@auckland.ac.nz.*

If you require Māori cultural support, talk to your whānau in the first instance. You may also contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324, or contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 4868920 ext 3204 to discuss any questions or complaints about the study.

For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or at 373 7599 x 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.

Approved by the Auckland Health Research Ethics Committee on 03/09/2021 for three years. Reference number AH22780.

7.3. Appendix C: Survey

Family engagement in paediatric cochlear implant habilitation: the clinicians perspective

Start of Block: Consent

Q1 *Welcome to the research study!*

You have been invited to participate in a survey of the clinicians' perspective on family engagement in paediatric cochlear implant habilitation. This confidential online questionnaire should take 15-20 minutes to complete. Your participation in this research study is voluntary, and you may withdraw at any time before submission without giving a reason. If you exit the questionnaire before submitting it, your answers will not be saved. If you complete the questionnaire, we cannot remove your response after you have submitted it.

The results of this survey will be used for a Master of Audiology thesis. All data will be stored electronically under password protection by the student researcher and principal investigator. A summary of the results will be given to the First Voice consortium at the end of the study.

If you have any questions about this research, please contact the student researcher, Sophie Wong, at swon953@aucklanuni.ac.nz, or the principal investigator, Holly Teagle, at holly.teagle@auckland.ac.nz.

Please note, we recommend taking this survey on a computer or tablet as some questions will be difficult to view on a phone screen.

By continuing with the questionnaire, you acknowledge that you have read and understood the information above, and you voluntarily agree to participate.

Approved by the Auckland Health Research Ethics Committee on 03/09/2021 for three years. Reference number AH22780.

○ *I consent*

○ *I do not consent*

End of Block: Consent

Start of Block: Demographic Questions

Q2 What is your age?

○ *<30*

○ *31-40*

○ *41-50*

○ *51-60*

○ *61+*

○ *Prefer not to say*

Q3 What is your gender?

○ *Male*

○ *Female*

○ *Other gender (please specify)*

____

○ *Prefer not to say*

Q4 What is your ethnicity?

You may select multiple.

☐ *European*

☐ *Māori*

☐ *Pacific Peoples*

☐ *Asian*

☐ *Middle Eastern*

☐ *Latin American*

☐ *African*

☐ *Other/s (please specify)*

____

☐ *Prefer not to say*

Q5 How long have you been working with children with hearing loss?

○ *<5 years*

○ *6-10 years*

○ *11-20 years*

○ *21-30 years*

○ *31+ years*

Q6 What is your role?

You may select multiple.

☐ *Audiologist*

☐ *Speech Language Therapist*

☐ *Auditory-Verbal Therapist/Listening and Spoken Language Specialist*

☐ *Early Interventionist*

☐ *Deaf Educator*

☐ *Counsellor/psychologist*

☐ *Program Administrator*

☐ *Other (please specify)*

____

Q7 Where is your current workplace?

○ *New Zealand*

○ *Australia*

○ *South Africa*

○ *United Kingdom*

Q8 Where have you spent the most time working with children with hearing loss?

☐ *New Zealand*

☐ *Australia*

☐ *South Africa*

☐ *United Kingdom*

☐ *Other/s (please specify)*

____

End of Block: Demographic Questions

Start of Block: Defining Engagement

Q9 In your current caseload, approximately how often do you encounter families with poor engagement?

○ *Daily*

○ *Several times a week*

○ *Once a week*

○ *Several times a month*

○ *Once a month*

○ *Once every few months*

○ *A few times a year or less*

○ *Never*

Q10 Based on your experience, what do you consider the key indicators of *poor* family engagement?

Please rank items according to how well you feel they indicate poor engagement (#1 being the strongest indicator) by dragging to the labeled box.

If you do NOT feel that a particular item is an indicator of poor engagement, please leave it in the left-hand column.
If there are items not listed that you feel are indicators of poor engagement, please enter these in an "Other" box and rank them accordingly.

Indicators of Poor Family Engagement
. ______ *Limited progress in the child's development*

. ______ *Low device wear-time/datalogging*

. ______ *Inconsistent appointment attendance*

. ______ *Unreliable/low correspondence with clinicians*

. ______ *Little/no involvement in wider community activities (e.g. meets with families of other children with hearing loss)*

. ______ *Other (please specify)*

. ______ *Other (please specify)*

Q11 Based on your experience, what do you think the barriers to family engagement are?

Please select then rank items according to how much you feel they impact engagement (#1 being most significant) by dragging to the labeled box.

If you do NOT feel that a particular item is a barrier to engagement, please leave it in the left-hand column.
If there are items not listed that you feel are barriers to family engagement, please enter these in an "Other" box and rank them accordingly.

Barriers to Family Engagement

. ______ *Poor trust/rapport with clinicians*

. ______ *Fear/suspicion of habilitation process*

______ *Limited understanding of habilitation process*

______ *Inadequate training/skills of clinicians*

______ *Cultural differences between families and clinicians*

______ *Language barriers*

______ *Denial of hearing loss from family*

______ *Grief about hearing loss from family*

______ *Competing family demands (e.g. lots of siblings)*

______ *Competing work demands of parents*

______ *Additional needs/disabilities of child*

______ *Not enough time in appointments*

______ *Large travel time for family*

______ *Limited access to transportation to appointments*

______ *Economic/monetary constraints*

______ *Other 1 (please specify)*

______ *Other 2 (please specify)*

Q12 Based on your experience, do you feel that any particular groups or demographics are more prone to poor family engagement?
If yes, please specify which groups and briefly explain your answer.

____

____

____

End of Block: Defining Engagement

Start of Block: Engagement Strategies and Resources

Q13 How do you deliver information to families to inform them of the habilitation process?

You may select multiple.

- ☐ *Written informational brochures*
- ☐ *Picture-based informational brochures*
- ☐ *Links to online informational resources*
- ☐ *Online informational videos*
- ☐ *Meetings with other families to discuss habilitation process*
- ☐ *Meetings with clinicians to discuss habilitation process*
- ☐ *Other/s (please specify)*

____

Q14 Which of the following statements describe your current workplace?

You may select multiple.

☐ *My workplace provides training to improve family engagement*

☐ *My workplace consistently monitors family engagement*

☐ *My workplace provides incentives to families to engage (e.g. free meals or compensation for travel expenses)*

☐ *My workplace offers informational materials that are accessible to families with limited English literacy (e.g. translated written materials or non-written materials such as videos)*

☐ *My workplace offers flexible appointment times to families*

☐ *My workplace offers multiple mediums for services to families (telehealth, home visits, in clinic)*

Display This Question:

If Which of the following statements describe your current workplace? You may select multiple. = My workplace provides training to improve family engagement

Q15

Please briefly describe how your workplace provides clinicians with training to improve family engagement...

____

____

____

Display This Question:

If Which of the following statements describe your current workplace? You may select multiple. = My workplace consistently monitors family engagement

Q16 Please briefly describe how your workplace monitors family engagement...

____

____

____

Page Break

Q17 Have you previously used any strategies to improve family engagement?

In this context, "strategies" can be defined as taking any action with the intention of facilitating family engagement.

○ *Yes*

○ *No*

Page Break

Display This Question:

If Have you previously used any strategies to improve family engagement? In this context, "strategies... = Yes

Q18 Please briefly describe the strategies you use to encourage family engagement...

____

____

____

Display This Question:

If Have you previously used any strategies to improve family engagement? In this context, "strategies... = Yes

Q19 How effective have you found these strategies?

○ *Extremely effective*

○ *Very effective*

○ *Moderately effective*

○ *Slightly effective*

○ *Not effective at all*

Page Break

Display This Question:

If Have you previously used any strategies to improve family engagement? In this context, "strategies... = No

Q20 Please indicate why you have not previously used strategies to improve family engagement...

☐ *I have never encountered a family with poor engagement*

☐ *I have never felt I needed to improve family engagement*

☐ *I am not confident in recognising poor family engagement*

☐ *I do not know how to encourage family engagement*

☐ *I do not have the time/resources to encourage family engagement*

☐ *Other/s (please specify)*

____

Display This Question:

If Have you previously used any strategies to improve family engagement? In this context, "strategies... = No

Q21 Would you be open to implementing family engagement strategies if provided with sufficient training and resources?

○ *Definitely*

○ *Probably*

○ *Maybe*

○ *Probably not*

○ *Definitely not*

○ *Unsure*

Page Break

Q22 Do you currently feel you have enough resources to properly engage families?

○ *Definitely*

○ *Probably*

○ *Maybe*

○ *Probably not*

○ *Definitely not*

○ *Unsure*

Q23 What resources do you feel would help to improve family engagement?

Please select then rank items according to how much you feel they would help (#1 being most helpful) by dragging to the labeled box.
If you do NOT feel that a particular item would help improve engagement, please leave it in the left-hand column.
If there are items not listed that you feel would help to improve engagement, please enter these in an "Other" box and rank them accordingly.

Resources for Improving Family Engagement
______ *More time in appointments*
______ *More regular appointments with families*

______ *More counselling for families*

______ *More accessible information for families (e.g. translated or non-written materials)*

______ *More cultural competency/safety training for clinicians*

______ *More diversity among clinicians*

______ *More support for the child through school/early childhood education*

______ *More support for families at home (e.g. increased home visits)*

______ *More monitoring of family engagement*

______ *More incentives for families (e.g. free meals or compensation for travel costs)*

______ *Babysitting/childcare services during appointments for families with multiple children*

______ *Other 1 (please specify)*

______ *Other 2 (please specify)*

Q24 Would you be interested in taking part in a ~20 minute interview via Zoom to discuss any engagement strategies you use?

If yes, please follow the link below to provide consent and contact information. We will be in touch to arrange a time that suits you for the interview.

https://auckland.au1.qualtrics.com/jfe/form/SV_4UZZbQAxzCu7nr8

Note: by providing your email address, your identity will become known to the researchers. However, this will remain confidential in the publishing of all study data.

○ *Yes - I have provided my contact information via the link above*

○ *No thank you*

End of Survey

7.4. Appendix D: Interview Topic Guide

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09-373 7599

The University of Auckland
Private Bag 92019
Auckland, New Zealand

Interview Topics for *Family engagement in paediatric cochlear implant habilitation: the clinicians perspective.*

Interviews for *Family engagement in paediatric cochlear implant habilitation: the clinicians perspective* will be semi-structured, and will follow the topics listed below. Appropriate follow-up questions will be asked at the interviewer's discretion.

Interview Topics:

1. Demographic questions (locality, age, gender, ethnicity, years of experience)
2. Description of strategies that clinicians currently use to engage families
3. Discussion of the effectiveness of these engagement strategies
4. Suggestions from participants on other engagement strategies that they believe could be effective.

Approved by the Auckland Health Research Ethics Committee on 03/09/2021 for three years. Reference number AH22780.

7.5. Appendix E: Unweighted ranked data

Unweighted and weighted mean ranks from ranking survey questions are given below.

Table 8. Unweighted and weighted mean ranks with frequency of selection

	Unweighted	**Weighted**	**(%)**
Indicators of family engagement			
Inconsistent appointment attendance	1.8	1.5	87
Unreliable correspondence	2.6	2.1	90
Low device wear-time	2.4	2.1	84
Limited progress	3.4	3.6	55
Limited community involvement	4.3	4.2	47
Barriers to family engagement			
Cultural differences between families and clinicians	4.7	2.4	76
Limited understanding of habilitation process	4.0	2.6	71
Denial of hearing loss from family	3.2	3.2	63
Competing work demands of parents	4.9	3.5	71
Competing family demands	4.5	3.5	68
Grief about hearing loss from family	3.1	3.6	61
Language barriers	5.1	7.9	45
Poor trust/rapport with clinicians	6.1	8.2	47
Limited access to transportation to appointments	7.1	8.2	53
Economic/monetary constraints	4.3	8.3	39
Additional needs/disabilities of child	7.2	8.6	50
Large travel time for family	7.5	9.2	47
Fear/suspicion of habilitation process	6.7	10.4	34
Inadequate training/skills of clinicians	8.6	13.1	18
Not enough time in appointments	10.2	14.0	13
Resources for facilitating family engagement			
More accessible information for families	2.5	2.6	66
In-home support for families	3.4	2.8	71
Counselling for families	2.3	3.7	55
More diversity of clinicians	3.6	4.5	55
Cultural safety training for clinicians	3.7	4.9	53
Childcare for other siblings during appointments	4.9	6.3	45
Increased monitoring of engagement	4.5	7.1	34
Incentives/compensation for families	4.2	7.1	32
In-school support for child	4.5	7.3	32
More frequent appointments	5.2	8.8	16
More time in appointments	4.8	9.2	11

8. Chapter 8: References

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