Parents' Experiences of Newborn Hearing Screening and Early Intervention

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Abstract

Universal newborn hearing screening and early intervention programmes (UNHSEIPs) plays a vital role in the identification of congenital deaf and hard of hearing (DHH) children, and the provision of interventions to facilitate appropriate language development. Parental involvement has been identified as a modifiable factor in the language development of DHH children. Parents are also expected to become experts in their child's hearing abilities, navigation of services, and habilitation options. This makes parents' experiences an important consideration in UNHSEIP. The aim of this study was to explore the ways parents constructed their experiences of UNHSEIP in NZ. This included any associated support systems, as defined by the parents involved. Fifteen parents completed an online qualitative survey, that asked about their experiences. Two of those parents also participated in a semi-structured interview. All responses were collated and analysed using reflexive thematic analysis (Braun & Clarke, 2006), within a social constructionist epistemology and relativist ontology. Three distinct themes were generated. These were related to each other to form the overarching theme that parents' experiences were constructed by how the demands of the process were created or mitigated; (1) "A very stressful journey, even with the right support it was hard"; (2) "Who is organising?", navigating the process; (3) family-clinician interactions. Clinicians and surrounding support networks should be aware of the effect that they have in creating or mitigating demands during the process, ultimately affecting parent's perceptions of UNHSEIP.

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Abbreviations

ANSD:	Auditory Neuropathy Spectrum Disorder
AoDC:	Advisor(s) on Deaf Children
ASHA:	American Speech-Language-Hearing Association
ASL:	American Sign Language
BTE:	Behind-the-ear
CCM:	Constant Comparative Method
CI:	Cochlear Implant
dB HL:	Decibels Hearing Level
DHBs:	District Health Boards
DHH:	Deaf and Hard of Hearing
EIT:	Early Intervention Teacher
ECE:	Early Childcare Centre (?) Parent used this abbreviation in survey
FCC:	Family Centred Care
HA:	Hearing Aid
LOCHI:	Longitudinal Outcomes of Childhood Hearing Impairment
MELAA:	Middle Eastern, Latin American or African ethnicity
NZSL:	NZ Sign Language
NZ:	New Zealand
PCPs:	Primary Care Physicians
PSQ-NHSP:	Parent Satisfaction Questionnaire with Neonatal Hearing Screening Programme
SLT:	Speech Language Therapists

UNHSEIP: Universal Newborn Hearing Screening and Early Intervention Programme

Terminology

Clinician(s): Doctors, nurses, advisors on Deaf children, speech language therapists, audiologists, support workers, or any associated service personal is indiscriminately referred to as 'clinician in the analysis of the data. This is to ensure anonymity of organisations involved in- or associated with the Universal Newborn hearing Screening and Early Intervention Programme in NZ, as discussed during the ethics process. 'Clinician' was used over the choice of 'professional', as 'professional' had a tendency to appear as an adjective rather than a noun.

DHH person: Many Deaf Adults in NZ prefer to use identity-first language. This means Deaf and hard of hearing (DHH) individuals will be referred to as DHH adult, or DHH child/ren.

Parent(s): The term parent will be used to signify parents, caregivers, and guardians.

Introduction

Nearly all newborns in New Zealand (NZ) are screened to identify conditions that could lead to adverse developmental outcomes. This includes the universal newborn hearing screening and early intervention programme (UNHSEIP) (National Screening Unit, 2014). UNHSEIP involves identifying infants who may have, or are at risk of a hearing impairment, and provides newborn hearing services for deaf and hard of hearing (DHH) infants. The aim of UNHSEIP is to facilitate language and communication development. Appropriate language acquisition plays a vital role in childhood academic and psychosocial outcomes (Chamberlain & Mayberry, 2008; Hoffman et al., 2015; Laugen et al., 2016; Shojael et al., 2016). UNHSEIP in NZ assists with supporting children with language delays, increasing educational outcomes, reducing isolation of DHH children in their families, and decreasing parental stress (Ministry of Education & Fitzgerald and Associates, 2019).

UNHSEIP in NZ, global paediatric audiological practices, and much of paediatric audiological literature focuses on family centred care (FCC). FCC is an inter-disciplinary term that relates to placing each unique family at the centre of services and to provide individualised care. Findlen et al. (2019) noted that as FCC requires family involvement, and it is crucial to understand parents' perspectives and experiences to evaluate and improve services. This study aims to explore the experiences and interactions of parents with UNHSEIP, including any associated support networks as defined by NZ parents of DHH children.

This chapter outlines services, programmes, and information NZ parents of DHH children interact with. The breadth of information and situations parents may be exposed to include the hearing system, various hearing devices, interventions, modes of communication, and services available to parents in NZ. This demonstrates the information and services parents must navigate to understand and make informed decisions regarding their child's care.

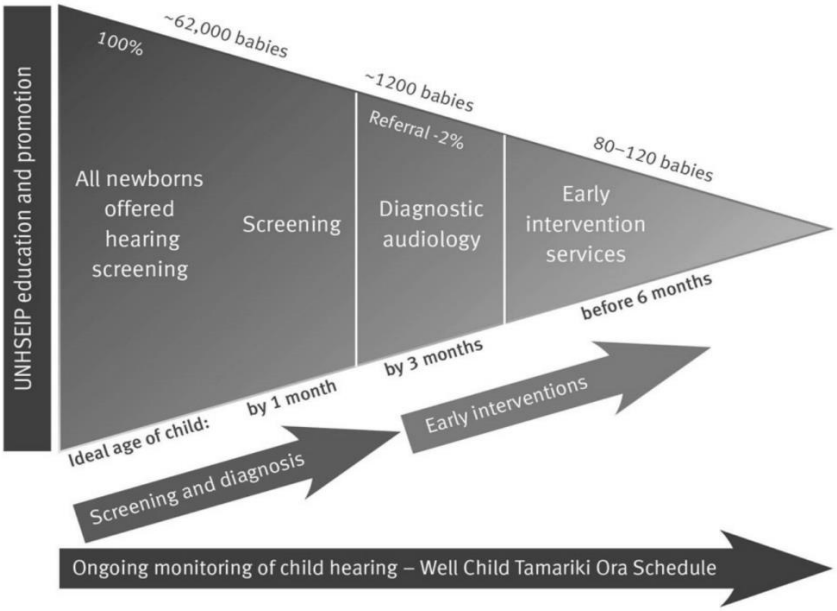
Universal Newborn Hearing Screening NZ

Universal newborn hearing screening rolled out across district health boards (DHBs) in NZ between 2007-2010, with the intention of identifying all DHH infants (Ministry of Health, 2016). Every newborn in NZ must be offered the opportunity to receive newborn hearing screening. The daily management of UNHSEIP services are run under different DHBs, including the delivery of audiological screening, diagnosis, and audiological care (unless the child is referred onto other services) (Ministry of Health, 2016). Thus, families may have different experiences across the different regions in NZ.

The goals of UNHSEIP are described as '1-3-6', as shown in *figure 1*. The intention is that all infants are screened within the first few weeks of birth. This allows for referral to audiological services proper, and the first diagnostic appointment within 4 weeks of referral or 44 weeks gestational age. Ideally, any permanent congenital hearing impairment is diagnosed by 3 months-old and the first audiological aid and/or intervention to be implemented by 6 months (Ministry of Health, 2016). Infants may be screened at the hospital, outpatient, and/or outreach programmes (Ministry of Health, 2016). A DHH diagnosis through UNHSEIP can warrant further investigations into other related abnormalities or a syndromic diagnosis, for example, ophthalmological abnormalities (Brown & Smith, 2013). Thus, early identification of DHH allow for earlier identification and medical intervention for other health related problems (Madell & Flexer, 2014).

Other infants may be identified as possessing certain 'risk factors' that are associated with delayed, progressive or fluctuating hearing impairment. These infants are placed into a hearing surveillance programme. Risk factors can include in-utero infections, craniofacial anomalies, and certain syndromes (Ministry of Health, 2016; National Screening Unit, 2015b). The specific process of appointments will relate to different risk factors identified. This will typically involve ongoing support or appointments, with at least one full diagnostic audiological assessment, regardless of the initial screening result (Ministry of Health, 2016).

Figure 1. *UNHSEIP 1-3-6 Goals*



Note. From "Universal Newborn Hearing Screening and Early Intervention Programme: National Policy and Quality Standards" by Ministry of Health, 2016, p. 3, https://www.nsu.govt.nz/system/files/page/unhseip-national-policy-and-quality-standards-2nded-2016.pdf. Reprinted with permission.

In other countries, parents did not divide UNHSEIP into discrete steps or services. The United Kingdom has a similar protocol to NZ UNHSEIP. Despite clinicians in the United Kingdom dividing the process into screening, diagnosis, and early intervention, most parents viewed it as a continuous series of appointments rather than discrete steps (Tattersall & Young, 2006). In Western Australia, parents did not differentiate audiological or other health professionals. All events around this time were linked to diagnosis (Schulian & Lind, 2020).

Parental Expertise

In order to support their child, parents must learn a lot of new information skills. For example, understanding their child's hearing, navigating services, and deciding between a

variety of audiological aids and modes of communication (Jean et al., 2018; Vukkadala et al., 2019). Parents of DHH children were required to become experts at navigating services to achieve their desired outcomes (Erbasi et al., 2018). Parents in South Australia identified that they had a lack of awareness and knowledge surrounding hearing-impairments prior to their child being diagnosed. Over time parents gained expertise from their experiences, and information provided from other parents of DHH children and clinicians (Roberts et al., 2015). This section will cover information parents would likely be required in NZ, including the function of the auditory system, diagnosing and monitoring hearing impairments, types of hearing impairments, audiological aids, modes of communication, and early intervention programmes. This will provide insight into the complexity of information and options provided to parents.

The Hearing System

Hearing impairments occur due to anomalies in the auditory system and/or functioning. Hearing involves sound being collected by the pinna and directed down the external auditory meatus towards the middle ear. The middle ear includes of the tympanic membrane and the ossicles (malleus, incus, and stapes). It is an impedance matching system, to facillitate sound waves to travel through the fluid in the cochlea (Madell & Flexer, 2014). In the cochlea, sound waves travel along the organ of Corti, which acts as a filter to splits sound into its frequency components. There are two types of hair cells embedded along the organ of Corti; outer hair cells locally amplify the wave and increase the frequency selectivity (and thus frequency resolution) in a particular region (Dallos, 1992; Moore, 2013), and inner hair cells detect the sound wave and convert the mechanical energy into electro-chemical energy. This allows for the communication of sound stimulus to the auditory neurones. Each neurone conducts the signal down its length, connects to and communicates with further neurones via electro-chemical energy and various neurotransmitters. This creates circuits to process the sound information, as well as pass the signal to the auditory cortex for the stimulus to be consciously recognised (Northern & Hayes, 2014). All the

components from the pinna to the cortex must be intact and functioning appropriately to detect and use sound information appropriately.

Audiological Assessment

Audiological testing in infants under 6 months of age relies on objective test measures, as infants cannot consistently behaviourally respond down to threshold level. For example, tympanometry, auditory brainstem response, and otoacoustic emissions, (Madell & Flexer, 2014). Objective tests do not provide a true reflection of what a child can or cannot hear. There are more testing options available as the child develops their motor and cognitive abilities. This includes the ability to test children behaviourally to determine hearing threshold or to test their speech and language development. However, even with the inclusion of more testing options as the child grows, each test still only provides a fragment of information about the child's auditory functioning (Cole & Flexer, 2020; Madell & Flexer, 2014). This means audiological tests must be discussed in conjunction with each other to depict the child's audiological functioning.

Types of Hearing Impairments

The impact of a hearing impairment on a DHH child depends on a number of factors. This includes the location of lesion within the auditory pathway. The lesion is broadly categorised into four main types: conductive, mixed, sensorineural, and auditory neuropathy spectrum disorder (ANSD).

A conductive hearing impairment is related to the attenuation of sound to the cochlea. Typically, they are acquired and transient, but congenital hearing impairments can result from structural abnormalities or deformities (Madell & Flexer, 2014). Some conditions, such as Down's Syndrome or cleft palate, can also place children at a higher risk of recurrent or fluctuating conductive components due to abnormal anatomical structures (Madell & Flexer, 2014).

A sensorineural hearing impairment affects the ability to transform the mechanical forces of the sound wave into electrical neural impulses that send the signal onto the brain. This may be due to gross structural abnormalities, or subtle anomalies, including imbalances to the ionic composition of cochlear fluids. This can result in decreased frequency resolution of the sound signal, decreased sensitivity to sound, and/or reduced dynamic range (Madell & Flexer, 2014). Mixed hearing impairments are when a conductive and sensorineural hearing impairment co-occurs. These add together to further decrease sensitivity to sound (Madell & Flexer, 2014).

Auditory neuropathy spectrum disorder (ANSD) is characterised by absent or diminished auditory brainstem response, absent acoustic stapedial reflexes, and poor speech perception, with preservation of some cochlear function (Madell & Flexer, 2014). ANSD may be sensory, in which there is failure to conduct signals to the auditory nerve, or neural, in which there is loss of synchrony or inability of the auditory neurones to fire.

The degree of hearing impairment severity is determined by the hearing threshold. It can range from slight impairment (almost normal hearing) to a profound hearing impairment (struggle with extremely loud sounds) (Madell & Flexer, 2014). Severity may be classified using Clark American Speech-Language-Hearing association (ASHA) scale (Clark, 1981); normal (-10 to 15 dB HL), slight (16 to 25 dB HL), mild (26 to 40 dB HL), moderate (41 to 55 dB HL), moderate-severe (56 to 70 dB HL), severe (71 to 90 dB HL), and profound (>91 dB HL). However, the age of intervention first implemented or amount of family involvement are better predictors of vocabulary development than hearing severity or type of hearing impairment (Moeller, 2000). It is also important to remember that parents of children with permanent moderate impairment will have the same concerns as parents of children with profound impairment in regard to adjusting to habilitation (McCracken et al., 2008).

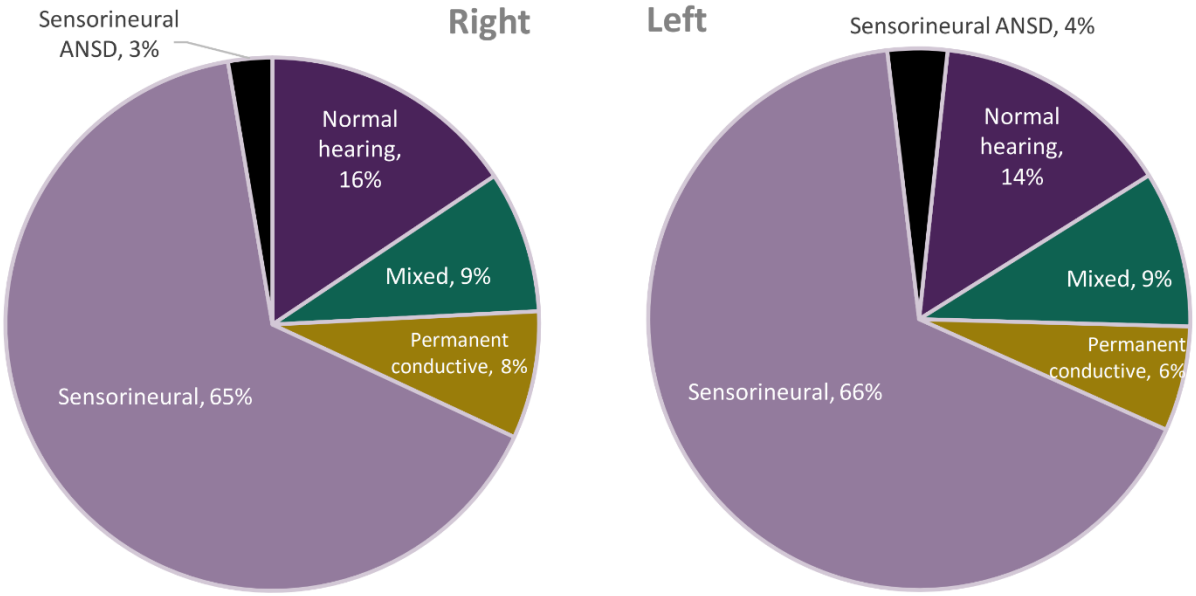
Hearing Impairment Statistics

The Deafness Notification Database produce annual reports on all DHH children with a hearing impairment that is 26 dB HL or greater and are under 19 years old at diagnosis (Digby et al., 2019). It noted that one in five children diagnosed with a hearing impairment in NZ will have one or more additional disabilities (sometimes referred to as 'deaf plus') or medical problems (Digby et al., 2019). *Figures 2* and *3* depict the proportion of type and severity of hearing loss in NZ. Notifications between 2015-2018 show that between 17-22% of children with a permanent hearing impairment also have an immediate DHH family member (Digby et al., 2019).

Since 2013, 60% of permanent DHH childhood notifications have been from UNHSEIP, and in 2018 alone, 80% of notifications came from UNHSEIP (Digby et al., 2019). UNHSEIP has significantly decreased the age of diagnosis in NZ, however, Māori and Pacific infants are less likely to be screened than other ethnicities. Within Māori and Pacific infants that were screened, there existed a higher referral rate but were less likely to complete or meet the 1-3-6 targets of UNHSEIP (Digby et al., 2019, 2020; Ministry of Education, 2017). This leads to concern that Māori and Pacific needs are not being meet. There are also a higher proportion of Māori children identified with permanent bilateral hearing impairments compared to those of other ethnicities (Digby et al., 2019, 2020). DHH Māori children may also be underreported due to mild hearing losses that are more likely to be undiagnosed or later diagnosed. This may be due to disparities in access to health care services or having a mild hearing impairment that is not severe enough to meet the criteria for the Deafness Notification Database from 2010 (Digby et al., 2014).

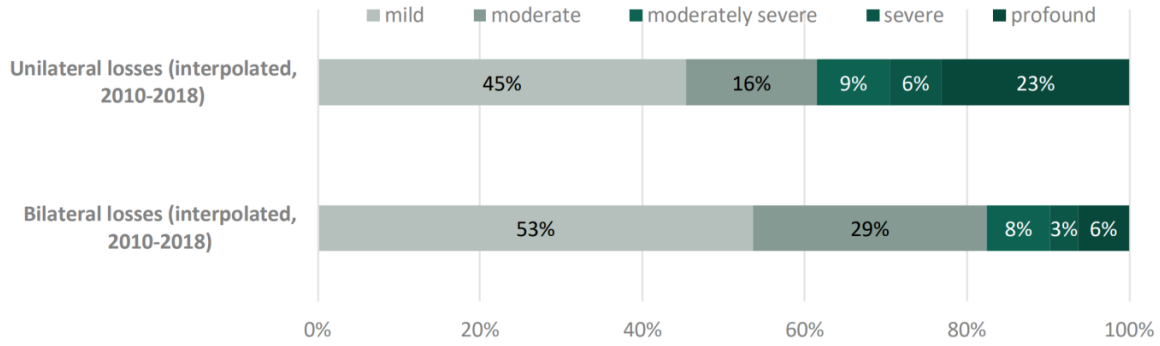
NZ has similar rates of DHH children compared to other countries, including United Kingdom, Finland, United States, and Australia. However, across NZ there are a higher proportion of mild to moderately severe profiles and a lower proportion of severe or profound severities compared to overseas (Digby et al., 2019, 2020). This likely reflects the higher proportion of mild to moderate bilateral hearing impairments in Māori DHH

Figure 2. *Types of Hearing Impairments in NZ Children between 2010 to 2018.*



Note. The diagram depicts the proportion in the right or left ear. From *"Deafness Notification Report (2019) Hearing Loss (not Remedial by Grommets) in New Zealanders under the age of 19,"* by J.E. Digby et al., p. 22, CC-BY 3.0 NZ.

Figure 3. *Proportion of NZ Hearing Impairment Severities for Unilateral and Bilateral Childhood Hearing Impairment Notifications between 2010-2018.*



Note. Severities are based on Clarke ASHA Scale (Clark, 1981). From *"Deafness Notification Report (2018) Hearing Loss (not Remedial by Grommets) in New Zealanders under the age of 19,"* by J.E. Digby et al., 2019, p. 52, CC-BY 3.0 NZ.

children, and the relatively lower proportion of severe or profound hearing impairments, or unilateral hearing impairments in other ethnic groups (Digby et al., 2019, 2020).

Different Interventions Depend on Severity and Pathology

Irrespective of the type or severity of hearing impairment, the primary goal of UNHSEIP is to provide the opportunity for appropriate language development. If spoken language is the primary goal, then there must be adequate auditory stimulation for the auditory pathways to develop appropriately (Cole & Flexer, 2020). Audition can be supplemented or provided through various audiological aids.

Hearing aids (HAs) are the most prescribed audiological aid. Between 2010 and 2019, 78% of NZ DHH children with bilateral hearing impairments, and 66% of unilateral hearing impairments used at least one HA (Digby et al., 2020). HAs are the most versatile in providing amplification across a range of severities and types of hearing impairments (Dillon, 2012). A behind the ear (BTE) HA involves an ear level device that picks up environmental sound, amplifies it, and conducts the sound down the infant's ear canal (Dillon, 2012).

BTE HAs are not always suitable for infants with fluctuating conductive pathologies or microtia/atresia (Madell & Flexer, 2014). Bone conduction hearing aids pass the signal through the skull, bypassing the ear canal and middle ear system. This can be worn on a headband, or when old enough, surgically implanted (bone anchored hearing aid). Due to attenuation of the skin and skull, bone conduction devices struggle to aid more than a moderate to moderate-severe sensorineural hearing impairment (Dillon, 2012).

Surgical interventions can partially or fully correct various middle ear pathologies. Grommets or tympanostomy tubes are temporarily placed into the tympanic membrane to allow fluid to drain from the middle ear (Cole & Flexer, 2020). Reconstructive surgeries (e.g. for microtia, atresia, ossicular abnormalities) can result in improved thresholds or be purely cosmetic. These typically occur after the child had started school (Cole & Flexer, 2020).

When a child has ANSD or acoustic amplification cannot provide sufficient amplification, and the child is not obtaining benefit from acoustic amplification, then a cochlear implant (CI) may be considered. Cochlear implantation includes an electronic device implanted under the skin and an electrode array placed into the cochlea. The electrode directly stimulates auditory neurones. An external component (speech processor) powers the implant and processes the environmental sound for the implant to activate corresponding electrodes (Grayden & Clarke, 2006). In 2019, 100 publicly funded CI, or 45 DHH children, and 2 privately funded CIs were implanted in NZ (Digby et al., 2020). If there is no or insufficient auditory nerve present, then an auditory brainstem implant may be used instead of a CI (Fisher et al., 2018).

Early Intervention Services

A multidisciplinary team will care and manage the infant's hearing loss and related conditions. The composition of the team will reflect the specific child's needs, but can include medical and allied health professionals, including otorhinolaryngologists, paediatricians, audiologists, Advisor on Deaf Children (AoDC), speech language therapists (SLTs), cochlear implant specialists, ophthalmologists, radiologists, and genetic services (Ministry of Health, 2016).

Most early intervention programmes are provided by the Ministry of Education, and are coordinated regionally across NZ. In 2018, the Ministry of Education provided services for around 1,850 children under eight years old, including 723 infants and young children diagnosed through UNHSEIP (Digby et al., 2019). Services specific to early intervention include AoDCs, SLTs, Early Intervention Teachers (EIT), Ko Taku Reo Deaf Education NZ, the Northern and Southern Cochlear Implant programmes, First Signs Facilitators, and Deaf Children NZ Tamariki Turi o Aotearoa (Ministry of Health, 2016).

AoDCs work alongside families, educators, and professionals, to provide advice, information, and organise a range of supports as appropriate. Support can include guidance on communication modes and language development to ensure that children are meeting

developmental needs. AoDCs are involved from birth (or diagnosis) until the DHH child is in year three at school (Ministry of Education, 2020). SLTs work with children, families, teachers, and schools to aid in developing and understanding language, good communication, basic social development, and overcome speech errors (e.g., articulation errors, sentence building) (Ministry of Education, 2015, 2019). EITs support children with learning and language needs, develop age-appropriate social skills, and meet milestones. SLTs and EITs can be with the Ministry of Education, or through Ko Taku Reo Deaf Education Centre (Ministry of Education, 2015).

Ko Taku Reo Deaf Education Centre (formally Kelston Deaf Education Centre and Van Asch Deaf Education Centre) is a provider of education services for DHH families. There are primarily two hubs, Auckland and Christchurch, which provide a range of opportunities including a bilingual (New Zealand Sign Language (NZSL) and English) preschool for DHH children, their siblings, or children of Deaf adults, provide bilingual schooling or support for students that attend mainstream schools, various group sessions for children and families, and wholistic residential assessment visits prior to starting primary school. Ko Taku Reo employs an audiologist, and works closely with AoDCs, DHB audiologists, school teachers, and First Signs Facilitators. However, specific services provided depend on the location in NZ (Ko Taku Reo, n.d.-a, n.d.-b).

The Northern and Southern Cochlear implant Programmes complete referrals and assessments of CI candidates, facilitate surgery and implantation, CI programming, and (re)habilitation to teach individuals to listen, speak, and use the implant after implantation. They are based both in clinics and outreach services (Southern Cochlear Implant Programme, n.d.).

First signs facilitators are employed by Deaf Aotearoa Tāngata Turi. They work with children, parents, and families, to teach NZSL and for children to meet language milestones (Ministry of Education, 2015). This service is provided from birth or identification of the DHH child, until the child is five years old. Deaf Aotearoa Tāngata Turi work with and

represent Deaf people in NZ, work with Deaf communities and government agencies, and promote the use of NZSL. They also provide information, advice, and assessment for assistive equipment, help people find employment, and help employers understand more about employing Deaf people, and provide NZSL interpretation (Deaf Aotearoa Tāngata Turi, n.d.). Roughly 17% of families that receive AoDC services also receive First Signs Services (Ministry of Education & Fitzgerald and Associates, 2019)

Deaf Children NZ Tamariki Turi o Aotearoa (formally the NZ Federation for Deaf Children Incorporated) is a volunteer organisation that focuses on enabling DHH children to have appropriate access to education or social opportunities, provide social/parent support groups, and financial assistance for families. It is run by parents, for DHH families (Deaf Children New Zealand Tamariki Turi o Aotearoa, n.d.).

The day-to-day management and commitment of using audiological aids and providing adequate environment for language development is mostly reliant on the parents and family. There are also frequent, ongoing appointments parents must attend to ensure the hearing devices are functioning optimally and to monitor hearing and child development.

New Zealand Sign Language (NZSL)

Parents must also decide on the language and/or mode(s) of communication for their child to use. This includes a purely auditory/oral approach, auditory with natural gestures, bilingual spoken language and NZSL, or NZSL only (Ministry of Education, 2015). Families found that NZSL was helpful even in DHH children that were aided and had good speech (Ministry of Education & Fitzgerald and Associates, 2019).

NZSL has a controversial history, and did not become formally accepted in education and legislation until the early 1990s (McKee, 2017). It was not until after 1979, that Australasian Signed English was introduced into deaf classrooms, and replaced many of the older NZSL signs (McKee, 2017). Now, there are many programmes and organisations that expose DHH children/families to NZSL, with additional funding towards NZSL classes. The

mode of communication used is ultimately decided by the parent, regardless of any clinicians preferred intervention.

Benefits of Early Diagnosis and Intervention

The primary benefit of early diagnosis and early intervention is to facilitate for appropriate language development (in any communication mode). Of those identified through UNHSEIP in NZ, 47% of infant's language abilities are at or above their current age level, and 63% of infants did not have significant language delay (Digby et al., 2019). Prior to newborn hearing screening programmes, even the most advanced DHH preschool child would likely be in the 10th percentile of the normal distribution for developmental outcomes (Yoshinaga-Itano, 2003).

Children learning sign language in language-rich environments from birth will acquire their signs, grammatical rules, and meet language milestones comparable to the trajectory of hearing children with spoken languages (Anderson & Reily, 2002; Bellugi & Klima, 2001; Woofle et al., 2010). Late sign language learners (prelingually deafened but acquired sign as a first language after 5 years old) have less automatisation in processing American Sign Language (ASL) and Pidgin Signed English compared to early sign language learners (exposed to sign since birth). The proportion of semantic lexical errors decrease, and phonological lexical errors increase the later a child begins to learn sign language. Late sign learners have decreased comprehension compared to early sign language learners (Mayberry, 1993; Mayberry & Fischer, 1989). However, older sign language learners (post-lingually DHH children) show similar linguistic errors as those observed in early sign language learners. This is also observed when comparing early sign language learners, adult sign language learners (post-lingually DHH adults), and late sign language learners (Mayberry et al., 2002). Though it is interesting to note that across these groups, the number of signs used and rate of sign production were not significantly different, but later sign language learners were more likely to produce ungrammatical responses (Mayberry,

1993). These suggest that the timing of language acquisition has an important role on language processing skills (Mayberry, 1993).

The timing of first language input affected children's educational outcomes. Late sign language learners had poorer written English ability than early sign language learners, adult sign language learners, and English-as-a-second language learners (Mayberry et al., 2002). Language outcomes were a positive predictive indicator of a child's ability to read and write at school (Shojael et al., 2016). Poor academic achievement in Deaf populations may be due to incomplete language acquisition, irrespective of signed or spoken language (Chamberlain & Mayberry, 2008).

The effect of timing on the provision of interventions to improve access to spoken language has also been studied extensively. Across numerous study designs, there is overwhelming consensus that the earlier the children are identified and receive intervention, the better speech and spoken communication outcomes are compared to DHH children that are identified later. This is demonstrated across receptive and expressive language quotients, phonology, syntax, semantics, and everyday functioning (e.g., Ching et al., 2014; Cuda et al., 2014; Cupples, Ching, Button, Leigh, et al., 2018; Cupples, Ching, Button, Seeto, et al., 2018; Sarant & Garrad, 2014; Shojael et al., 2016; Tomblin et al., 2015; Vohr et al., 2008a; Yoshinaga-Itano, 2003; Yoshinaga-Itano et al., 1998). Later engagement with intervention is related to lower maternal perceived self-efficacy in the ability to develop their DHH child's language skills and lower parental involvement in intervention (Desjardin, 2005).

Children who received HAs early (and CIs if appropriate) were able to 'keep up' with their hearing peers' development, regardless of the degree of hearing severity (in the absence of other medical conditions/disabilities) (Cuda et al., 2014; Fulcher et al., 2012). The degree of hearing severity only had an effect when there was a delay in identification (Cupples, Ching, Button, Seeto, et al., 2018). There is conflicting information whether children can successfully 'catch-up' following a delay in identification. Tomblin et al. (2015) identified

that the difference in language acquisition between earlier and later fitted DHH children decreased between 2 years-old and 6 years-old, hence demonstrating an ability to 'catch up'. However, the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study, noted an increase in difference of language outcomes between children at 3 years-old and at 5 years-old, in those that received later intervention (Ching et al., 2014; Cupples, Ching, Button, Seeto, et al., 2018). Another Australian study noted that DHH children may be unable to learn language faster compared to typically-hearing peers, therefore, DHH children may not catch up with intervention (Sarant et al., 2009).

Appropriate language and communication abilities have an important impact on social interactions and child well-being. Language levels of young children were positively correlated with skills involved with joint attention, imitation and gestural communication, which are important for increasing the complexity of social interactions and enhancing communication skills (Cochet & Byrne, 2016). Language deficits have a negative effect on developing social competence in DHH children (Hoffman et al., 2015), and early identification of DHH children predicts better psychosocial outcomes (Laugen et al., 2016). Behavioural problems in DHH children were not related to the degree of hearing impairment, rather the degree of language acquisition (Stevenson et al., 2010). This means that UNHSEIP can allow for more appropriate language development, either with sign language or with audiological aids, and has a long-term effect on other areas of child development.

Parental Involvement and Self-Efficacy in Habilitation

There still exists a large variation in receptive and expressive language within early identified DHH children, which is correlated with the degree of parental engagement with early intervention programmes (Moeller, 2000). In Australia, family participation was a significant and independent predictor of language development in children (Sarant & Garrad, 2014; Sarant et al., 2009; Yanbay et al., 2014). Increased parental involvement was associated with higher self-efficacy (Brand et al., 2018; Zaidman-Zait et al., 2018).

Poor confidence and perceived self-efficacy in the management of the demands from habilitation affected parents' ability to cope with DHH children and interventions (Punch & Hyde, 2010). Parents with higher confidence levels were more likely to report higher action levels and device usage (Ambrose et al., 2020). Better language outcomes were associated with greater amount of daily HA use and language-rich environments, independent of the severity of hearing impairment (Cupples, Ching, Button, Seeto, et al., 2018; Tomblin et al., 2015). Calderon (2000) noted that it may not be *direct* parental involvement in DHH children's school-based intervention, but various factors that resulted from parental involvement. This could have included parental skills learnt through the engagement with services that influenced children's language, literacy, and socio-emotional development. Mother's involvement and self-efficacy in CI use was not related to maternal linguistic input, but was related to maternal facilitative language skills. Maternal facilitative language skills included recasting and open-ended questions, which were related to DHH children's receptive and expressive language abilities respectively (Desjardin & Eisenberg, 2007). This showed that child language development factors that are related to, but not directly from parental involvement and self-efficacy itself.

This meant that alongside early identification and intervention services, parental involvement and self-efficacy in children's habilitation activities is crucial to DHH child's language outcomes. Due to this, it is important to consider the experiences and perspectives of parents in intervention services.

Family Centred Care

Parental involvement is a significant part of FCC, as it encourages clinicians to collaboratively work together and ensure that services focus on the infant and the families' individual needs (Ministry of Health, 2016; Moeller et al., 2013). The beginnings of FCC trace back to at least the 1950s (Brit, 1956; Scherz, 1953). In 1986, an amendment to the Education of the Handicapped Act in the United States of America, forced American programmes to shift from child-focused education plans, to a partnership between health

professionals and parents, and to develop individualised plans to meet every family needs (Education of the Handicapped Act Amendments, 1986; Degraw et al., 1988). After this, FCC research was purposefully conducted in paediatric audiology (Bailey et al., 1990; Roush et al., 1991), and has continued to be discussed, refined, and referred to amongst paediatric audiological literature.

Allen and Petr (1996) conducted a literature review of greater than 120 articles prior to 1996 across communication disorders, health care, occupational therapy, social work, education, psychology, and sociology. They noted that there was no defined term for FCC, but found common themes related to treating the family as a unit (as opposed to child-directed services), parental involvement, collaboration between professionals and parents, individualised services that address family needs/uniqueness/culture, and empowering families. Following this, Epley et al. (2010) reviewed family-centred service delivery in education, social work, and health between 1996 and 2007. The key principles of FCC identified by Allen and Petr in 1996 remained fundamental to more recent practises, however, the emphasis had changed. There was less focus on treating the family as a unit, and more focus on family choice, strengths, and relationships, how families are treated (choice and relationship), and the family-professional relationship. Epley et al. (2010) suggested there may be a gap between the conceptualisation and implementation of FCC.

An international panel of parents, deaf professionals, early intervention programme leaders, early intervention specialists, and international researchers developed principles and practical implementations for family-centred early intervention for families of DHH infants/children (Moeller et al., 2013). They decided that services should provide balanced family-professional relationships to support language and socio-emotional development of the child. This involved providing individualised informational and emotional support for families, that is respectful and supportive of every family's unique culture, beliefs, and attitudes. Professionals should also connect families to parent support networks for further informational and emotional support. This allows for parents to make informed choices

(Moeller et al., 2013). Providers must be competent in their use of assistive technology and mechanisms in supporting language development, and services should also be delivered in a timely manner with equitable access to appropriate services (Moeller et al., 2013). Regular programme monitoring ensures that all providers follow current best practise guidelines and for quality assurance of programmes (Moeller et al., 2013). UNHSEIP protocols in NZ are centred around FCC.

Summary

UNHSEIP has an important role in identifying and diagnosing congenital DHH children, in order to support appropriate language development. During this process, parents must become experts with a wide variety of information to successfully navigate services and raise a DHH child. While there is no best intervention or mode of communication to facillitate language development, the earlier intervention occurs the better chance of appropriate language development. Parental involvement and self-efficacy also play an important role in language development, particularly as the whole family is valued within FCC audiological practices. This means parents' experiences are a crucial consideration of UNHSEIP.

Literature Review

This chapter explores literature relating to parents' experiences. While summaries from the evaluation of some services in NZ have been published online (Ministry of Education & Fitzgerald and Associates, 2019; National Screening Unit, 2015a; Young Futures, 2014), these shed little light onto the expereinces of parents. Further searches of the internet and databases were unable to locate research explicitly detailing the experiences of parents in NZ. As such, this chapter primarily includes international research findings. It focuses on quantitative studies of parental stress, and qualitative studies relating to parents' experiences.

Stress and Satisfaction Measures in Parents of DHH children

The experiences of parents with DHH children/infants have been studied from various quantitative approaches, particularly in relation to stress. The concept of psychological stress is a product of an individual's ability to cope with their environment. Stress exists as a relationship from any events that exceed an individual's resources to cope with them (Lazarus & Folkman, 1984). However, it is important to note that stress in relation to the human psyche is a relatively recent phenomena. It started to be described in the early to mid-1900s, and become more defined throughout the latter half of the 20th century (Lazarus, 1993). Many of the earlier parenting stress studies in parents of DHH children were born from similar studies that assessed general parenting stress or parenting functioning across a wide variety of life situations, including divorce, incarceration, or other conditions/disabilities.

The Parenting Stress Index (PSI) (Abidin, 1997) has been frequently used to study stress across a range of life situations, and has been translated into many languages with its own norms associated with it. The PSI is based on the premise that the environment, sociological factors, behavioural, and development variables influence parental behaviour and child adjustment. They way parents evaluated and coped with an event produced the stress that parents' experienced. Stress influenced parents' perception as a 'parent', and

subsequent parent-child interactions (Abidin, 1992). The PSI comes in a long form, which divides into two domains of child characteristics and parent characteristics (Abidin, 1992, 1997). There is also a short form that aggregated questions from the long version, with 3 clusters centred around difficult child temperament, dysfunctional parent-child interactions, and parental distress (Abidin, 1997). Most DHH stress-related studies used the PSI short form.

The PSI has been used to compare stress in DHH families with families of typically-hearing children and across various interventions. For example, with the advent of universal newborn hearing screening, studies were used to evaluate the potential harm or undue stress on parents of typically-hearing children from the screening itself (Kolski et al., 2007; MacNeil et al., 2007; Stuart et al., 2000; Tueller & White, 2016; Vohr et al., 2008b). It has also been used in combination with other questionnaires to study many aspects of stress-related phenomena or services. For example, studies looked at social support with the Multidimensional Scale of Perceived Social Support (Åsberg et al., 2008; Dirks et al., 2016), Inventory of Socially Supportive Behaviours (Åsberg et al., 2008), and Perceived Social Support Questionnaire (F-SozU-K-14) (Hintermair, 2006). Other measures of stress included the Parental Psychic Stress (Burger et al., 2005), stress questionnaire (SOEBEK) (Hintermair, 2004), and the Family Stress Scale (Quittner et al., 2010).

Parental stress in parents of DHH children were not clinically different, and often not statistically different, to parents of typically-hearing children (Åsberg et al., 2008; Dirks et al., 2016; Hintermair, 2004; Lederberg & Golbach, 2002; Pipp-Siegel et al., 2002; Quittner et al., 2010; Sarant & Garrad, 2014). Vohr et al. (2008b) suggested there may be increased stress during screening and diagnosis, but stress diminished when families arrived at early intervention centres. Despite most studies saying there is no statistical or clinical difference in the stress in parent of DHH children, the amount of parental stress parents experience was associated with many context-specific factors.

Parents that experienced higher stress, was associated with higher levels of (deaf-specific) contextual stresses. This included stress related to raising a DHH child (Jean et al., 2018; Quittner et al., 2010), or the amount and intensity of daily hassles (Pipp-Siegel et al., 2002; Zaidman-Zait, 2008). Increased parental stress was also shown when DHH children had additional disabilities or needs (Hintermair, 2006). Parenthood of itself carried demands that had a risk for creating (parenting) context-specific stress (Deater-Deckard, 1998). While there was no clinical difference between parents of DHH child and parents of typically-hearing children populations, there are context-specific stresses related to DHH that increased parental stress.

Increased parental stress was also associated with a lower perceived amount of support (Dirks et al., 2016; Pipp-Siegel et al., 2002). Åsberg et al. (2008) noted that there was a significant negative correlation with perceived social support and parental stress, but there was no correlation between the measured social support received. Social resources, such as support from spouse, family, friends, clinicians, self-help groups etc., were viewed as more important than parent's personal resources, such as their ability to problem-solve, parental self-efficacy, or parent's degree of optimism on life (Hintermair, 2000, 2004). Increased parental contacts with other parents of DHH children reduced parental isolation, and mitigated parental stress. It was also associated with increased parental competence in raising a DHH child and better child behavioural patterns (Hintermair, 2000). Increased amount of measured social support received by parents was correlated with increased parent life satisfaction (Åsberg et al., 2008). Parental support came in a variety of forms, but the perception of adequate support decreased the amount parental stress. Parental support also had implications on family functioning and child behaviour.

Child behaviour problems and communication difficulties increased parental stress (Sarimski et al., 2013). It was not the severity of hearing impairment that impacted parental stress, rather it was child language delays or perceived difficulties in communication that increased parental stress (Hintermair, 2006; Lederberg & Golbach, 2002; Pipp-Siegel et al.,

2002; Sarant & Garrad, 2014). The effect of increased communication difficulties on parental stress was shown in both parents of DHH children and parents of typically-hearing children (Dirks et al., 2016). Contrary to others, Burger et al. (2005) noted increased parental stress with increased speech and comprehension capacity in DHH children pre-and post-CI. However, they wondered if it was due to increased stress around the decision to implant borderline CI cases. The other studies demonstrated that language delays likely affected parental stress via increased behavioural problems (Quittner et al., 2010). Child socio-emotional functioning was also associated with increased parental stress (Dirks et al., 2016; Hintermair, 2006). As discussed earlier, appropriate language acquisition in children is associated with child psychosocial outcomes. Parental stress is related to the interplay between language acquisition, communication competency, and child behaviour.

Other studies have focused more on measures of parental satisfaction than parental stress. Reports of high satisfaction suggested that stresses or demands related to deafness had been mediated (Jackson et al., 2010). Higher satisfaction was also correlated with higher parental competence, decreased daily hassles, and increased parental self-efficacy (Sarimski et al., 2013). Most commonly, satisfaction was used to evaluate local/national services in various programmes and countries. The majority of parents in these studies were satisfied with their services/programmes (Fox & Minchom, 2008; Jackson et al., 2010; Krishnan et al., 2019; MacNeil et al., 2007; Mazlan et al., 2006; Mazlan et al., 2014; Núñez-Batalla et al., 2009; Shojael et al., 2013; Zaitoun & Nuseir, 2020), indicating success within the respected services.

There have been many aspects of parental stress, satisfaction, or experiences that have been studied quantitatively, particularly in combination with the PSI. These have been used to evaluate aspects of services and programmes, or to gain insights to inform future services. In discussing stress-related studies in relation to each other, there is a wide variation of age of diagnosis, age of children in the study, length of time in services, and severity of hearing impairment or language delays. Many of the studies also had a very

heterogeneous sample. This means it is not specific to parents of DHH children diagnosed via newborn hearing screening programmes. However, many of these studies do link to relevant findings from more qualitative or mixed methods research with parents' experiences of newborn hearing screening programmes (discussed in the next section). This included the effect of the clinician's manner and behaviour (Mazlan et al., 2014; Shojael et al., 2013; Zaitoun & Nuseir, 2020), the provision for more of or unbiased information (Krishnan et al., 2019; Larsen et al., 2012; MacNeil et al., 2007; Mazlan et al., 2014; Shojael et al., 2013; Zaitoun & Nuseir, 2020), parental support (Åsberg et al., 2008; Dirks et al., 2016; Hintermair, 2000, 2004; Pipp-Siegel et al., 2002; Vohr et al., 2008b), and parental stress or parental worry about DHH children's futures (Crockett et al., 2005; Green, 2020; Jackson et al., 2010; Tueller & White, 2016; Vohr et al., 2008b).

Experiences of Parents with Newborn Screening and Early Intervention

Newborn hearing screening, diagnosis, and early intervention is a period of intense emotions and important decisions. Parents must navigate a maze of information. Unfortunately, there is often insufficient emotional support, and limited or biased information provided. This journey does not only affect the DHH child, but the entire family (Fitzpatrick et al., 2008; Vukkadala et al., 2019; Young, 2002). Parents have discussed the diagnosis of DHH children in terms of a 'pervasiveness' or an all-consuming adaptation (Davids & de Jager, 2018; Jackson et al., 2010), as it is encountered with almost every aspect of family life. It not only affected big familial decisions such as parental career choices, finances, and the location of residence to access services (Fitzpatrick et al., 2008; Punch & Hyde, 2010), but also everyday life, including the ability to meet the child's therapy or habilitation demands, manage house-hold demands, and balance attention between siblings, particularly as a parent may spend more time with the DHH child over other children (Jackson et al., 2008).

This section predominantly explores findings from qualitative studies examining parents' and families' experiences of newborn hearing screening and habilitation, parent-

clinician relationships, emotional and informational support, decision-making, and parent-to-parent support. There was no predominant qualitative methodology used across the studies that explored the experiences of parents. The range included content analyses, reflexive thematic analysis, phenomenology designs, and constant comparative method (CCM).

Emotional Response to Diagnosis and Management

Parents have reported a wide range of emotions following diagnosis. This included being shocked, upset, overwhelmed, guilty, stressed, confused, uncertain, fearful, depressed, angry, and in denial (Geal-Dor & Adelman, 2018; Gilbey, 2010; Gilliver et al., 2013; Hardonk et al., 2011; Jackson et al., 2008; Russ et al., 2004; Scarinci et al., 2017; Scarinci, Erbasi, et al., 2018; Schulian & Lind, 2020; Young & Tattersall, 2007). It is interesting that parents recruited in these studies had a bias towards higher education than in their respected populations. In Jerusalem, Geal-Dor and Adelman (2018) noted that parents with high education tended to report lower levels of positive emotions compared to less educated parents. Sarimski et al. (2013) also noted that higher parental education is related to lower competence scores. Lower competence scores were related to increased parental stress. Though the findings of Geal-Dor and Adleman (2018), and Sarimski et al. (2013) cannot be generalised, due to the nature of qualtitaive studies, it may be interesting to note that the bias towards higher education could have an impact on the degree of negativity in parental responses.

There is also whether the emotions experienced by parents are linked to newborn screening or the diagnosis itself. From a study from nine parents of eight DHH children diagnosed throughout childhood that used CCM, Jackson et al. (2008) reported that increased parental stress levels was associated with diagnosis, information gathering, and worries about the child's future. Fitzpatrick et al. (2007) also used CCM to analyse 17 interviews from 21 parents of DHH children that were 5 years old or younger. They noted that there were differences between the experiences of parents of unscreened (and later-

identified) DHH children compared to parents of DHH children identified through screening programmes in Canada. Parents of unscreened DHH children described less feelings of shock and loss compared to parents of screened DHH infants. Parents of unscreened DHH children identified that they had a different mindset; diagnosis was to determine how bad the hearing is, rather than whether a hearing impairment was present (Fitzpatrick et al., 2007). In an Australian Infant Hearing Screening Programme of at risk infants at 7-9 months, parents had a less intense emotional response if they expected a hearing impairment (Russ et al., 2004).

Parents of screened DHH children and unscreened DHH children had a similar idea of what the respective opposite parents might have experienced. Both groups expressed similar perspectives on grief specific to screening or a late diagnosis. Parents of unscreened children discussed that they experienced regret from being unaware their child was DHH. That any initial shock from an early diagnosis would have outweighed the regret that they now experience (Fitzpatrick et al., 2007). Thematic content-analyses of parents within newborn hearing screening programmes, described that grief was a 'trade-off', as parents would have gone through a grieving process anyway. Some remarked that if the child was later diagnosed, there may have been 'retrospective' guilt for having missed it earlier (Gilliver et al., 2013; Young & Tattersall, 2007). This showed that parents of screened and unscreened children had similar ideas related to the emotions they might experience with either screening or no screening.

A small minority disagreed with the emotions towards newborn hearing screening. A couple of parents in England and Canada wished they had discovered their child was DHH later, so that they could have enjoyed the neonatal period with their child (Fitzpatrick et al., 2007; Young & Tattersall, 2007). This demonstrated that parents of DHH infants identified through screening process had a range of intense emotions, which may have appeared similar to the profile of emotions to parents of later identified children. However, it is clear

that the method of identification created differences in the emotional reaction of parents who underwent screening and those who did not.

Following the screening result or diagnosis of the DHH infants, parents expressed decreased feelings of parent-infant bonding, an impact on the spontaneity of parent-infant bonding, and strained communication with their infant (Schulian & Lind, 2020; Vukkadala et al., 2019). However, Vukkadala et al. (2019) reported that parents eventually learnt the best way to communicate with their child, subsequently leading to deeper feelings of connectedness.

Parents also reported that working with audiological aids were daunting, stressful, and frustrating to learn (Fitzpatrick et al., 2007; Gilliver et al., 2013; Jean et al., 2018; McCracken et al., 2008; Russ et al., 2004; Scarinci, Erbasi, et al., 2018). As discussed earlier, parental stress was related to daily hassles (Pipp-Siegel et al., 2002). Common difficulties for parents were related to device usage, keeping aids on, and ensuring they are functioning correctly. Gilliver et al. (2013) reported that these concerns were tied to the potential failure and subsequent negative impact if the intervention demands were not meet. On top of that, Canadian parents of children with unilateral or mild bilateral hearing impairments felt they were of lower priority, and perceived that they had received less support with amplification compared to those with more severe presentations (Fitzpatrick et al., 2016). Parents wanted more ongoing informational support and reassurance about their child's communication development, and it took time to fully understand the impact on the child (Fitzpatrick et al., 2016).

Additional Disabilities or Medical Concerns

The perspective and emotions of parents around the impact of DHH diagnosis of children with additional disabilities or medical concerns, differs to those without additional disabilities. Often additional disabilities or medical concerns were prioritised over audiological concerns or made it difficult to obtain audiometric data (Gilliver et al., 2013; Russ et al., 2004; Uus et al., 2012). In an exploratory qualitative study with a constructivist

epistemology, Uus et al. (2012) reported that all 25 parents of children with ANSD in their study had experienced extreme negative emotions from their child's medical conditions prior to the identification of ANSD. For some parents, ANSD was another issue on top of other established medical concerns, thus parents felt overwhelmed. For other parents, the additional health concerns put ANSD into a smaller perspective (Uus et al., 2012).

Many parents of children with ANSD and additional disabilities were simply grateful their child was alive, and expected that ANSD would be easily remedied. It was only later that parents felt worry, guilt, and sadness for neglecting the potential implications of ANSD (Uus et al., 2012). This is similar to Gilliver et al. (2013), who reported that parents of DHH children with co-existing health concerns noted an initial lack of perceived impact from being DHH, and had an overestimation of rehabilitation options and abilities. This may be reflected in health professionals' attitudes. In focus groups in the United States of America, paediatricians noted that hearing impairments in children were considered to be of lower importance compared to other health conditions that paediatricians deal with in daily practice (Moeller et al., 2006).

'Normalisation' of the DHH Child

The focus on child language and developmental outcomes are of particular importance to parents, and it could generate its own stresses. In many of studies, parents were acutely aware of the relationship between language development and early intervention, particularly around the possibility of 'normalisation' of DHH children. Some parents generated a 'time-table of acceptable intervention' (Erbasi et al., 2018; Fitzpatrick et al., 2008; Fitzpatrick et al., 2007; Gilliver et al., 2013; Matthijs et al., 2011; Young & Tattersall, 2007). It is interesting to consider if this originated from parents or from reassurances provided by health professionals. A Belgium study that involved both an interpretive phenomenological analysis and discourse analysis, showed that health professionals believed that the conceptualisation of a 'normal' child arose from parents' concerns of normal development, integration into society, and whether mainstream

schooling was possible (Matthijs et al., 2011). In England and Australia, parents were ultimately reassured during diagnosis by the benefits of appropriate language development arising from early identification (Gilliver et al., 2013; Young & Tattersall, 2007). On top of that, parents wanting their children to be 'normal' or like other children (including either hearing or DHH) affected the decisions made regarding communication modes and hearing devices utilised (Crowe et al., 2014). Crowe et al.'s methods described using reflexive thematic analysis, but it is important to consider that they did not specify an ontological or epistemological position, and included coding reliability strategies in their reflexive thematic analysis. Coding reliability strategies are typically used in other types of thematic analyses (Braun & Clarke, 2019). Programmes have discussed 'normal' child language development as a benefit of newborn screening programmes.

Internationally, parents felt ownership regarding their child's language development. In Michigan, parents of children that used either HAs, CIs or no aids, reported that they received information regarding the vital role parents played in developing language-skills in children (Decker & Vallotton, 2016). It was noted in Eastern Australia and from parents involved in the LOCHI study, that parents felt responsible for their child's language outcomes. Many changed their life-style and made financial sacrifices to facilitate language development, and felt personal guilt for failing their child if delays in language occurred (Erbasi et al., 2018; Punch & Hyde, 2010). As Gilliver et al. (2013) noted, the perception that early intervention would result in normal language development could cause unnecessary guilt or pressure when the intervention did not provide the desired outcomes. When children progressed in language development, Malaysian parents regained confidence in their aural habilitation and in the child's future ability to live independently (Jean et al., 2018). The perceptions of parents during newborn screening and diagnosis, could have a lasting impact on how parents engage with further services.

Regardless if the concept of normalisation and the perceived 'time-table of acceptable intervention' was driven by the parents or providers, it changes the perceived benefits from

newborn hearing screening. Some parents in narrative-based, semi-structured interviews that were analysed with thematic content analysis in England, perceived that clinicians' lack of action decreased the positive effect of learning about the hearing impairment early (McCracken et al., 2008; Young & Tattersall, 2007). A minority of parents in Canada found newborn hearing screening as frustrating and not beneficial, as their children could not effectively hear until after they were 12 months old anyway (due to timing of CI implantation and issues with HAs). They wished their child had not been identified until later (Fitzpatrick et al., 2007).

Though the concept of 'normalisation' is a huge contributor to the stresses parents faced, discussing 'normal' could have a positive effect as well. In another CCM study, parents of children who were unilaterally DHH reported that going through a process of "negotiating a new normal" (p. 3) helped parents overcome the guilt and perceived loss from not having the 'expected typical child' (Hussain et al., 2020). Vukkadala et al. (2019) reported that parents must 'seek a new equilibrium' as they overcame new challenges with a DHH child. Families' quality of life would be determined by the ability to achieve normalcy in their lives, and parents' emotional well-being related to their parenting experiences (Vukkadala et al., 2019). This demonstrated the difference in perspectives and emotional responses between 'normalisation' of the DHH child and creating a 'new normal.' The story generated between clinicians and parents greatly impacted how parents perceived newborn screening, diagnosis, and ongoing management.

Parent-Clinician Relationship

Parental perspectives were affected by the delivery of test results. This did not depend only on the content of the results provided, but on the clinician's personality, character, and the manner in which the results were given (Davids & de Jager, 2018; Fitzpatrick et al., 2008; Geal-Dor & Adelman, 2018; Hardonk et al., 2011; Mazlan et al., 2014; Russ et al., 2004; Young & Tattersall, 2005). In Malaysia, 66.7% of parents comments to open-ended questions on the Parent Satisfaction Questionnaire with Neonatal Hearing

Screening Programme (PSQ-NHSPs), were related to the clinician. Many parents expressed dissatisfaction with communication between them and the clinician (Mazlan et al., 2014). Analysis from the PSQ-NHSPS in Iran, showed that parental satisfaction was also linked to clinician's behaviour (Shojael et al., 2013). The clinician's behaviour, personality, character, and manner of delivering services had an important role in their perception of services.

There is also a similarity in the types of responses parents received across programmes in different countries. Using thematic content analysis with a phenomenological approach in Belgium, parents recalled the results from screening were an unusual response and/or the result was from malfunctioning equipment. Parents were confused from the unclear result, and most parents reported that there was no mention of a possible hearing impairment (Hardonk et al., 2011). A similar approach to delivering results was used in England, and while most parents were reassured by this, some parents were annoyed that clinicians did not acknowledge the possibility of deafness (Young & Tattersall, 2005). In the North of Israel, it was common for repeated tests and appointments with little to no information to be given. Parents perceived this as a lack of responsibility in the diagnosing clinician (Gilbey, 2010). This demonstrated that although there are similarities in the delivery of results during screening and diagnosing in different countries, parents had different responses to these messages in different countries.

It is not only the content of information, but the delivery of information that had an emotional impact on parents. In Israel, parents reported more anger and shock when the delivery of the diagnosis was blunt (Gilbey, 2010). Other studies have reported a lack of empathy and a call for increased emotional support from the diagnosing clinicians (Hardonk et al., 2011; Jackson et al., 2010; Park & Yoon, 2018; Scarinci, Erbasi, et al., 2018). In Korea, families felt helplessness when faced with the demands from the process. The helplessness was made worse by doctors' insensitive attitudes towards families (Park & Yoon, 2018). The manner in how the diagnosis is conveyed not only affected the immediate emotional response, but also affected how the parents accepted and adapted to the diagnosis, as well as

the parents' long-term coping (Davids & de Jager, 2018; Geal-Dor & Adelman, 2018). Due to the intense emotional response at diagnosis, some parents recommended a counsellor to be present (Davids & de Jager, 2018; Scarinci et al., 2017; Scarinci, Erbasi, et al., 2018).

The interactions between clinicians and parents were not limited to diagnosis. In Canada, parents of children with mild hearing impairments noted it was bothersome when clinicians were dismissive of their child as it was 'only' mild (Fitzpatrick et al., 2016). In the United Kingdom, parents of children with unilateral hearing impairment felt judged that their child was not "deaf enough" (p. 5) (Hussain et al., 2020). In contrast, Australian parents' needs were meet when clinicians were available for parents to debrief about previous clinical encounters, to discuss their fears or doubts, showed patience with the parents' acceptance journey, and provided emotional, social, and financial support (Muñoz et al., 2019; Nickbakht et al., 2019; Schulian & Lind, 2020). Parents appreciated the ability to build relationships with professionals over time (Roberts et al., 2015). Families required clinicians to be a "go-to person" (p. 677) and to walk through the journey with them (Nickbakht et al., 2019). Across the United States of America, the top four sources of support were ranked in order from clinicians, then other parents of DHH children, family support organisations, and lastly grandparents/extended family (Jackson, 2011). This highlighted the important role of clinicians in providing quality support across both informational and social-emotional domains.

Informational Support

Both families and clinicians identified that informational support was the primary need between diagnosis and early intervention enrolment (Fitzpatrick et al., 2008; Nickbakht et al., 2019). Parents have remarked that early intervention is similar to navigating a maze (Scarinci et al., 2017; Vukkadala et al., 2019). On top of this, parents perceived an urgency to make a decision, which may have limited the ability to make an informed choice (Roberts et al., 2015; Scarinci et al., 2017; Scarinci, Erbasi, et al., 2018). As demonstrated in different parts of the United States of America, parents were not always

aware of different services available to them (Findlen et al., 2019; Vukkadala et al., 2019). Parents' ability to receive appropriate services was affected by their knowledge of services and resources available (Fitzpatrick et al., 2008). Comprehensive, unbiased information was key for parents to make informed decisions (Decker & Vallotton, 2016; Jackson, 2011; Jackson et al., 2010; Moeller et al., 2013).

Individualised Information

Nickbakht et al. (2019) noted in their inductive reflexive thematic analysis of semi-structured interviews in Australia, that information must be individualised to address families' specific needs, and in an appropriate quantity that is simple to understand. The experiences of parents regarding information supplied depended on how well a family's informational needs were meet. Many studies reported parents requesting additional information, particularly surrounding families' needs, and the prognosis of the child's language and communication development (Decker & Vallotton, 2016; Findlen et al., 2019; Fitzpatrick et al., 2008; Gilliver et al., 2013; Roberts et al., 2015), regardless of the severity of hearing impairment (Fitzpatrick et al., 2008). When services and providers did not meet parents' needs, it was often from poor clinician understanding of the families' unique requirements (Roberts et al., 2015).

Other parents noted that it was only when they reported a specific problem that information was forthcoming. When information was provided, most of the information was theoretical, instead of practical information parents could use (McCracken et al., 2008). Parents also valued different information compared to audiologists. Among both Hebrew and Arabic speakers in Israel, parents valued information about the parents' role more than audiologists did. Conversely, audiologists ranked information regarding hearing impairments as more important than parents did (Geal-Dor & Adelman, 2018). Families with a DHH child with additional disabilities noted that their information and peer support was similar to that of DHH children without additional disabilities, however, both professionals and families agree the timing of interventions is different due to other

priorities the family has at the same time (Nickbakht et al., 2019). This shows that informational content that parents want versus information that parents receive can substantially differ.

Clinician Knowledge

A breakdown of effective communication between clinicians and parents occurred when limited information was provided. This lead to parents' perception that clinicians lacked sufficient knowledge, followed by parental dissatisfaction of services, misinformation, confusion, and frustration (Gilbey, 2010; Hussain et al., 2020; Jackson et al., 2010; Russ et al., 2004; Scarinci, Erbasi, et al., 2018; Zaitoun & Nuseir, 2020). Across the United States of America, primary care physicians (PCPs) played an important role in providing information and access to various services compared to other countries. Only 14% of PCPs reported training in medical school that prepared them for DHH children. Many PCPs demonstrated gaps of knowledge in audiological causes, appropriate referrals, and the potential impact on developmental outcomes (Moeller et al., 2006). Limited or insufficient knowledge has been demonstrated in other areas of audiology. Many Australian parents were told that early sign language usage would interfere with speech acquisition, despite this stance not being unanimously supported (Crowe et al., 2014). PCPs in the United States of America were more confident in addressing unilateral and mild bilateral sensorineural hearing impairments in terms of management and language outcomes, compared to other severities or types. Despite audiologists and researchers agreeing there are more uncertainties regarding language outcomes from various management strategies with unilateral and mild bilateral sensorineural hearing impairments (Moeller et al., 2006).

Biased Information

Families have reported they required clinicians to assist in evaluating and explaining information parents acquired (Jean et al., 2018; Nickbakht et al., 2019). Clinicians should be aware of the power they have in influencing parent's decisions. In Massachusetts, 40% of parents reported some degree of bias in the information presented about early intervention

and modes of communication (MacNeil et al., 2007). Many other studies have noticed a bias towards spoken languages with various providers, of which, many tended to align with a medical model of deafness (Decker & Vallotton, 2016; Decker et al., 2012; Matthijs et al., 2011; Roberts et al., 2015; Scarinci et al., 2017; Zaidman-Zait et al., 2018). Of concern, is that parents may not recognise the inherent bias towards a particular audiological aid or mode of communication. Decker et al. (2012) suggested that parents internalised information received from providers, and accepted it as their own beliefs. Ergo, some biases may not be recognised by parents. Parents also reported that their decision to use or not use a particular hearing device or communication mode was strongly guided by their clinician's views or policies of the provider (Crowe et al., 2014; Scarinci et al., 2017). Therefore, both overt and covert biases could easily influence parents' decisions.

When biases were overt, parents considered clinician's as rude and arrogant. Parents disliked clinicians that had a biased agenda (e.g. against signing), and felt it dismissed parents' feelings (Roberts et al., 2015). When parents had to fight to get desired information and access to services, the conflict between parents and clinicians created an 'us against the system' mentality. Parents felt judged, not supported in their decisions, and did not feel that clinicians considered them as equals in making decisions regarding their child's care (Decker & Vallotton, 2016; Hussain et al., 2020; Jackson et al., 2008; Nickbakht et al., 2021). In Belgium, parents felt guilty if they questioned or failed to follow the clinicians' advice (Matthijs et al., 2011). In contrast, supportive relationships with clinicians encouraged parents to be more involved in intervention, and have more frequent and open communication with clinicians (Zaidman-Zait et al., 2018).

There are other concerns from providers that aligned with the medical model of DHH. Parents of DHH children who interacted with centres that aligned with medical models were more likely to describe their role as passive, and reported their interactions with providers as unhelpful (Hussain et al., 2020). It is possible that parents interacting with these models did not have their emotional and personal needs meet (Scarinci, Erbasi, et

al., 2018). Of additional concern, is that parents of children who only used spoken language tended to receive information from fewer sources compared to parents who incorporated signing (Decker et al., 2012). This demonstrates that a variety of issues accompany insufficient informational support provided to parents, than simply a lack of or a bias in information provided.

Impact of Teachers of the Deaf, and Social Support Workers

Parents involved in the LOCHI study were more satisfied with personal and emotional support received from their teachers and habilitationists, and more dissatisfied with their diagnosing audiologist and child's general practitioner (Scarinci, Erbasi, et al., 2018). Every country has slightly different support roles, but these services are extremely valued by parents. The descriptions of these roles corresponded to the role of an AoDC in NZ. In the United Kingdom, parents recognised teachers of the deaf as valuable sources of information, and increased parents' awareness of different options. Teachers of the deaf liaised with the family and their child's school about the child's hearing needs, as well as advocated during audiology services (Hussain et al., 2020; McCracken et al., 2008). Parents in Canada had a high degree of satisfaction in social support workers, for the provision of initial support, information, and resources regarding all intervention options (Fitzpatrick et al., 2016). Belgium parents valued social workers, psychologists, and administrative support. Administrative support involved assistance with legal matters and paperwork (Hardonk et al., 2011). Parents did not have a preference of where information came from, but wanted their perceived needs meet with support specific to their child (McCracken et al., 2008). Parents tended to take the initiative to seek and integrate information across multiple sources. They valued their own research, experiences, observations of older DHH children, and preferences (Chang, 2017; Crowe et al., 2014; Muñoz et al., 2019; Roberts et al., 2015). This demonstrated that many formal support services exist around newborn screening and early intervention aside from only clinicians that were directly involved in diagnosing, audiological aid management, and monitoring language development.

Parent-to-Parent Support Networks

Parent-to-parent support and parent social networks were extremely valued by most parents (Geal-Dor & Adelman, 2018; Jackson, 2011; Jackson et al., 2008; Nickbakht et al., 2019; Roberts et al., 2015). Parent support networks or gatherings with DHH families provided emotional support, often more so than psychological providers within health care systems (Fitzpatrick et al., 2008; McCracken et al., 2008; Roberts et al., 2015). While friends and family tended to be supportive of DHH children, parents found they did not understand what it was like to raise a DHH child (Jean et al., 2018; Roberts et al., 2015), but other DHH families did.

Parents tended to seek parent-to-parent support networks (online or in person) to aid with practical advice or troubleshooting (Chang, 2017), which meet a wide range of practical information and support needs (Fitzpatrick et al., 2016; Nickbakht et al., 2019; Roberts et al., 2015). Parent support networks provided parents with a sense of what to expect with raising their child, as well as created opportunities for social comparison of their children (Fitzpatrick et al., 2016; Hussain et al., 2020). Parents commented that when DHH children saw peers with similar communication needs, it supported healthy development (Fitzpatrick et al., 2008). Parents relied on other parents' opinions and experiences for information, which impacted their decision-making (Chang, 2017), and parents that had gone through UNHSEIP found it rewarding and comforting to share that information (McCracken et al., 2008).

Decision-Making

Parents were required to make sense of the information provided, come to terms with their child's hearing impairment, and make decisions about their child's management simultaneously (Schulian & Lind, 2020). There were a range of factors that affected parents' decision regarding audiological aid and mode of communication. As discussed above, there is a variety of information from different sources that influenced decisions parents make regarding services and modes of communication.

Decisions regarding audiological aids and modes of communication was related to the availability of adequate (local) resources, parents' perception of the ability to reach fluency in a particular language, and the child's likelihood for audition or the ability to sign (e.g. motor impairments) (Crowe et al., 2014). However, decisions were largely focused around the impact on the child's future education, literacy, employment, social relationships, and providing options for children to make their own decisions in the future (Crowe et al., 2014; Roberts et al., 2015).

Parents also made decisions from their own personal values, rather than from any new information provided by clinicians. Often parental decisions were related to a sense of belonging to or engaging with various communities of interest (Crowe et al., 2014; Young, 2002). In the LOCHI study, a large focus for deciding languages for their DHH child was influenced by the desire to belong to the majority community. This included parents of multilingual families focusing primarily on spoken English, or parents who decided to learn sign language to engage with the Deaf Community (Crowe et al., 2014). The viewpoint of the desired community affected parents' opinions and behaviours. There was pressure to conform, in order to gain a sense of belonging (Chang, 2017). Parents wanted their DHH child to be 'normal' or like other children, which related to the perceived ability to integrate successfully into society (Crowe et al., 2014; Gilliver et al., 2013; Matthijs et al., 2011; Roberts et al., 2015). Unfortunately, integration did not always occur. In the United States, hearing parents felt ostracised from Deaf communities for implanting their DHH child with a CI, but noted they did not belong to a hearing community either (Chang, 2017). Many parents were also worried whether their child would later disapprove of the decisions they made (Chang, 2017; Roberts et al., 2015).

Summary of Parents Experiences with Newborn Screening and Early Intervention

There are a wide range of experiences reported by parents and caregivers internationally, across a range of domains within newborn hearing screening and early

intervention. Parents experience a range of strong emotions in response to many stages throughout the process. Parents' experiences were linked to the emotional and informational support provided by both clinicians and parent-to-parent support networks, which strongly influenced parents' decision-making. Many of the findings of paediatric research exploring newborn screening and early intervention programmes refer directly to FCC (Moeller et al., 2013) or concepts that are incorporated within FCC frameworks (e.g. Decker & Vallotton, 2016; Findlen et al., 2019; Fitzpatrick et al., 2008; Fitzpatrick et al., 2007; Geal-Dor & Adelman, 2018; Harrison et al., 2016; Hussain et al., 2020; McCracken et al., 2008; Scarinci et al., 2017; Scarinci, Erbasi, et al., 2018; Schulian & Lind, 2020).

Study Rationale and Research Aims

Parents have an integral role in their DHH children's language and developmental outcomes. Their subjective experiences of newborn screening and early intervention programmes should be considered alongside objective evaluations (Findlen et al., 2019; Young & Tattersall, 2005). UNHSEIP is frequently monitored by local DHBs and at a national level, to ensure they are following best practise guidelines (National Screening Unit, 2015a). One major assessment resulted in significant changes to the protocols, after eight screeners across six DHBs deliberately falsified records (Young Futures, 2014). 113 families and 33 AoDCs also completed a survey as part of an evaluation of First Signs. This demonstrated the perceived role of First Signs, and suggested improvements to the service (Ministry of Education & Fitzgerald and Associates, 2019). Despite this, extensive searches of the internet and databases were unable to locate research explicitly detailing the experiences of parents with UNHSEIP and associated support services in NZ. A paediatric audiologist in NZ observed that every parent has a story about their journey through screening, diagnosis and habilitation with their DHH child. Many parents found it relieving to share their story, and not every parent has had the opportunity to do so (Peryman, 2017).

The aim of the study is to explore how NZ parents constructed their experiences of newborn hearing screening and early intervention, including any associated support systems

as defined by the parents. It is important to note that while FCC is incorporated in both research paediatric audiology literature and audiology practise, this study does not specifically set out to answer the perception of FCC in NZ. The premise of FCC within UNHSEIP framework in NZ supports the need to explore parents' experiences. Due to my experience as an audiology student working with FCC practices, as well as the surrounding FCC audiology literature, FCC will inevitably influence the design and analysis of the study.

Methods

The following chapter describes the methods used in this study. Data was gathered from an anonymous qualitative survey and semi-structured interview. Themes were generated inductively via reflexive thematic analysis (Braun & Clarke, 2006), with a social constructionist epistemology and relativist ontology. Social constructionism relates to multiple knowledges and beliefs (constructions) that are created and maintained through social interactions, and are bound in time and cultural context. Constructions sustain patterns of social activity, and thus have implications on the permissible activities of people within a society (Braun & Clarke, 2013; Burr, 2015; Chen et al., 2011). With a relativist ontology, the universe is meaningless outside of how society came to know it, thus these constructions are dependent on, and do not exist separately to the realities of the universe. This means there is not one 'true' reality, and that many constructs may exist simultaneously (Braun & Clarke, 2013; O'Grady, 2002).

Ethics

This study was approved via the University of Canterbury Te Whare Wānanga o Waitaha Human Ethics Committee on the 18th of June 2020, and amendments approved on the 26th of August 2020 and 7th October 2020 (appendix A). The study commenced after the 1st of September 2020.

Instrumentation

Questionnaire

The qualitative survey asked both demographic questions and open-ended questions. The open-ended questions were broad and general, to prompt parents to share their experiences and what they deemed as important information. The following steps were taken to design the questions. The survey design was influenced by Russ et al.'s study (2004) that involved an open-ended survey for parents' commentary of at-risk neonatal screening in Australia.

This survey focused on the families' journey, resources, decision-making, and family-centred care, influenced by similar themes discussed in previous research. The survey was discussed and refined by colleagues within the department and my supervisor. The final survey included five open-ended questions and five demographic questions. The open-ended questions are listed below:

1. Please give as full a description as you can about your/your family's/whānau journey through your child being screened, tested, diagnosed, and subsequent support for their hearing loss. This may include your emotional or thought processes during this time.
2. What resources or support did you/your family receive regarding the choice of diagnosis and support strategies (e.g. hearing aids, cochlear implants, sign language, Advisor on Deaf Children (AoDC), local parent groups etc.)? How did these impact the decisions you made for your child's care?
3. In your opinion, how were the needs of your child/family/whānau addressed during your child's first year of life?
4. In your opinion, are there ways in which the system of detecting, diagnosing, and supporting your child/family/whānau could be improved? This can include support or services received outside typical 'audiological', 'testing', 'hearing aid', 'cochlear implant', or 'hospital' services.
5. Are there any other comments you would like to make about services you/your child received?

Demographic questions included hearing instrumentation, languages spoken at home, parental/caregiver age when the child came into their care, location, and ethnicity, in order to determine if the sampled population reflected the population of NZ's DHH children population. Ethnicity questions provided the options of European, Māori, Pacific Peoples, Asian, and Middle Eastern, Latin American or African ethnicity (MELAA), reflecting that same ethnicity selection as the Deafness Notification Database in NZ. Similar to both the

Deafness Notification and the NZ Census, participants could identify as more than one ethnicity.

Location was the region of NZ a family lived for the majority of their child's first year of life. In 2010, only 56% of DHH children in NZ were still in the care of the notifying clinic 6 years after notification of the Deafness Database (Digby et al., 2019).

Information and consent statements were included in the survey (appendix B). The survey was anonymous.

Survey Distribution

Ministry of Education AoDC and Ko Taku Reo Early Intervention Centre staff forwarded brief information about the study and a survey link to potential participants. It is acknowledged that some parents may have been approached more than once. The survey was also advertised on Deaf Children New Zealand Tamariki Turi o Aotearoa's Facebook page. The survey did not record the service nor access point of the survey. The advertisements for the study are included in appendix C. On completion of the survey, participants were linked to an online form if they wished to enter a prize draw, request a copy of results, or express interest in participating in an interview. The separate link allowed responses to the survey to remain anonymous (appendix D). Personal information was promptly deleted after the intended purpose completed/no longer required.

Interview

Eight survey participants expressed interest in participating in a semi-structured interview, however, after contacting them, only two parents responded in a timely manner and participated. Each interview was up to one hour long, transcribed, and reviewed by the parent. Parents were provided the opportunity to edit their interview transcript. The information and consent forms for the interview are in appendix E. Guiding questions were generated from the survey responses from phase 1 of the data analysis.

The guiding questions probed into memorable experiences of parents from newborn screening to recent times, the effect of parent-clinician interactions on those experiences, incorporating their child's listening needs into their daily routine, any support (informal or from formal services) received during this time, and changes of their views or aspirations resulting from their child identified as DHH. Parents were provided the opportunity to discuss anything they deemed important that related to newborn screening, diagnosis, and intervention.

Participants

This project involved purposive sampling. At completion of the survey, participants were 18 years or older, and a parent/caregiver/had custody of a DHH child for an average of 2 or more days per week. The child's hearing impairment must have been identified within the last 5 years through NZ Newborn screening programme or associated hearing surveillance programme.

Qualtrics recorded 25 participants' responses. 10 responses were removed due to being incomplete. The remaining 15 survey responses and two interviews were analysed via reflexive thematic analysis. The 2 interviews respectively had the same story (and associated names within their stories) as their survey responses. From this, it was determined that survey participant 2 [q2] and interview participant 1 [i1] were the same person. The same goes for survey participant 11 [q11] and interview participant 2 [i2].

Data Analysis

Data was analysed via reflexive thematic analysis (Braun & Clarke, 2006). Reflexive thematic analysis is theoretically flexible and is intended to be used within a theoretical framework (e.g. social constructionism), following its values, rules, and assumptions. Therefore, within reflexive thematic analysis, a social constructionist framework aims to theorise possible socio-cultural contexts that enabled individual responses (Braun & Clarke, 2006).

Analysis involved six phases. Each phase did not necessarily progress linearly, rather I reflected on and between the codes/themes identified and the data corpus across the phases (Braun & Clarke, 2006, 2012). Theories were generated inductively. Both semantic and latent coding was used, but themes were created with a more latent approach. This involved focusing on assumptions and social contexts that underpinned the participants' responses, rather than descriptions of explicit content (Braun & Clarke, 2006). The six phases are listed below:

1. Familiarisation of the data, by actively reading and re-reading questionnaire responses, and created memos. This phase influenced the guiding questions for the interviews.
2. Systematically worked through the entire data set to create codes that identified ideas or concepts. As this study is inductive, every idea or concept identified was valuable at this stage.
3. Codes were collated and cut onto separate pieces of paper. Codes were grouped with other codes that shared common features, to generate candidate themes and overarching ideas.
4. Candidate themes were reviewed and refined at the level of the data extracts. This ensured formation of a coherent pattern, and validated the ability of the candidate themes to reflect the data set. Themes that did not reflect the data set, were re-worked, collapsed into other themes, or discarded for generation of more appropriate themes.
5. The themes were defined and refined to identify the 'essence' of each theme.
6. Themes were written up to narrate the data. Some quotations have had corrections to spelling and minor grammatical changes to make it more readable. personnel

Effort was made to ensure coding/themes did not reveal anyone's identity, including both participants and organisations (as agreed upon during the ethics process). To achieve

this, any information that had potential to identify a person or organisation was changed to a general non-identifying description (e.g. “child” or “service”) during data analysis. If this was impossible, the entire quote was not used. Any doctors, nurses, associated health professionals, advisors on Deaf children, speech language therapists, audiologists, support workers, or any associated service personnel is indiscriminately referred to as ‘clinician’.

Results

Participant Demographics

This was a heterogeneous sample, as shown in Table 1. Languages used at home included spoken English, sign language, Te Reo Māori, Hindi, and Tagalog. Interventions used by families included no aid or intervention used, HAs, CIs, remote microphone systems, and First Signs services. There was a mixed range of when the DHH child came into the parent's/caregiver's care.

Participants were recruited across NZ. Most DHH children lived the majority of their first year outside of Auckland, Christchurch, or Wellington, and a predominance from the Waikato or the Otago/Southland region. Though the families could have moved to other regions, there is likely a greater proportion of families that received rural/distance services compared to the NZ DHH population.

Demographics Comparison

This study asked the parents' ethnicity rather than their DHH child ethnicity. There were more participants who identified as NZ/European than expected by the Deafness Notification database or the 2018 NZ Census (93.3% compared to 42% or 70.2% respectively). There was a similar proportion of participants who identified as Asian as expected (13.3% compared to 16% or 15.1%) (Digby et al., 2020; Stats NZ Tatauranga Aotearoa, 2020). There were less than expected participants who identified as Māori compared to the Deafness Notification Database, but more than expected compared to the 2018 census (26.6% compared to 32% and 16.5%), however, one parent noted that they answered NZ/European, but that her daughter is NZ European and Māori. If this was included, then there would be 32.2% Māori, making it similar to the DHH population. No participants identified themselves as Pacific peoples or MELAA. The small sample size makes the difference in the number of participants of different ethnicities more apparent, as well as less representative of the DHH population.

Table 1. *Participant Demographics*

Participant Demographics	Percentage (number)
Languages used at home	
Spoken English	93.3% (n = 14)
Sign Language	53.3% (n = 8)
Te Reo Māori	26.6% (n = 4)
Hindi	6.6% (n = 1)
Tagalog	6.6% (n = 1)
Devices Used	
Hearing aid/s	73.3% (n = 11)
Cochlear Implant/s	26.6% (n = 4)
Remote Microphone	20% (n = 3)
First Signs Services	60% (n = 9)
No aid or intervention	20% (n = 3)
Region of NZ	
Tai Tokerau/ Northland	6.6% (n = 1)
Auckland	6.6% (n = 1)
Waikato	33.3% (n = 5)
Tairāwhiti/Hawke's Bay	6.6% (n = 1)
Taranaki, Whanganui/Manawatū	6.6% (n = 1)
Wellington	6.6% (n = 1)
Otago/Southland	33.3% (n = 5)
Parental Ethnicity	
NZ/European	93.3% (n = 14)
Māori	26.6% (n = 4)
Asian	13.3% (n = 2)
Parental age when became caregiver of DHH child	
17 and under	6.6% (n = 1)
18-29	40% (n = 6)
30-39	40% (n = 6)
40-49	13.3% (n = 2)

Experiences Related to the Demands from Within the Process

Overarching Theme

Parents described newborn hearing screening and early intervention as a *process*. The process extended to managing audiological aids, navigation of services, learning or the use of NZSL, and how-to raise a DHH child. It also encompassed other services and organisations outside of UNHSEIP (e.g., services for NZ children, services for other disabilities or complex needs, day-care/kindergarten, etc). The process did not inherently have negative connotations, as it was referred to in positive, negative, and more neutral contexts. The process placed *demands* across many aspects of family life. This included attending services, balancing family obligations, including the care of other children, and availability of emotional support. These were often exacerbated by travel demands, and affected the whole family structure. Parenting a DHH child "just brought out a different level" [i1] compared to other children/siblings.

> They are HORRIBLE hearing aids. I just would like a better device for my child. I appreciate that he has the conductive hearing aids but they aren't user friendly for him or our family or for his ECE centre. [q1]
>
> The hearing aids we finally got are a big help it sort of calms him [*DHH child*] down but notices when his siblings come close to him he wants them out... It's been hard for his siblings trying to talk to him and he doesn't reply to them. And play with him and he don't really pay any attention to him. [q8]

Reciprocal to the concept of demands is the concept of *support*. These have been used to demonstrate two sides of the same coin. This led to the formation of the overarching theme, that parent's experiences were constructed by the perceptions of the demands on the family, but also on the mitigation (or potential mitigation) of the demands by the interactions with services, parent/DHH support networks, family, or friends (i.e., support). Three distinct themes have been generated, which relate to each other to form the

overarching theme; (1) "A very stressful journey, even with the right support it was hard"; (2) "Who is organising?", navigating the process; (3) Family-clinician interactions.

Theme 1: "A very stressful journey. Even with the right support it was hard." [q3]

The process was an "emotional rollercoaster." There was a grief process surrounding the initial diagnosis, but also various emotions experiences throughout the process. There were many explicit comments regarding the need for emotional support and counselling, however, emotional support was also demonstrated by practical support and the mitigation of the demands of the process. Parents' descriptions of support needs were mirrored across the various support structures, such as wider family members, friends, clinicians, services, and organisations.

Surrounding diagnosis and the initial period of the process parents were 'devastated' [i1], 'overwhelmed' [q2], and thought the process was 'more emotional than we could have ever thought' [q12]. Where for parents, "as one can imagine - these diagnoses were a lot to take in and we really were one day at a time." [q10]. This was particularly apparent in parents of DHH children with changing circumstances, including progressive hearing loss, complex needs, or complications from procedures. 'It just seemed like it kept piling on me" [q2]. Though the diagnosis was difficult, it was an "emotional rollercoaster" that persisted throughout the process, which included many positive experiences as well.

> Through all of this we went through all the emotions. Sad for our child blaming ourselves hurting because we can see our children in pain, angry when they had [procedure] they didn't need, happy when they were switched on, and ecstatic when they said their first word, and proud when they have said their first sentence and we look back over the last 5 years and wouldn't change a single thing. [q5]

The process was full of positive and negative times. Parents described both positive and negative emotions in response to events within the process. It was an extremely emotional time.

Parents wanted 'understanding' from clinicians and non-immediate family members/friends. For people 'to be aware that they will possibly be going through an extreme emotional rollercoaster" [i1]. Other parents described how they received or wanted emotional support from family members and friends, however, it often had an element of practical support that supported their emotional needs.

> Of course it was hard for [DHH + complex needs child] but my life changed a lot. I had to stop my work. Had to be full time mum. Can't go out a lot. And without family and friends, and husband working full time. I just became mad. I wanted a break so bad that I went to visit my family back in [*different country*] but [*DHH child*] was half of the time in hospital over there…but at least my parents were there for support which was really positive thing for me. I sometime wish if I had my parents with me things had been so different now. [q14]
>
> I kind of wish my side of my family, like my mum and that, had taken more of an interest. Like, my mum's, kind of supportive but she's not, emotionally supportive, she's kind of standoff, like if it suits her she's all in to help, but if it's not to her advantage she's, nowhere to be seen. Whereas, hubby's side, his mum and dad have been awesome. Umm, like I just have to say, 'Oh heck this has happened', and they'll be like 'Okay, let us talk to such and such and, see if we can get it that way.' [i1]

Parents discussed the need for emotional support in the same vein as needing practical ways of being supported. One parent found a procedure being "quite enjoyable" [q4] when someone else took on other family obligations at that time. Many parents wanted services to support their wider family (e.g., grandparents), so that their wider family could support them. Amongst this there was tension between parents that wanted the support from their wider family and friend system, but simultaneously did not want the demands that arose when they were inadequately supported. For one parent, it was easier to receive no support from family and friends, than it was to receive bad support. Parents wanted the support from family friends to decrease the demands placed by the process, and not to increase any

demands of the process. Emotional and practical support was discussed alongside each other.

Parents discussed similar ideas and attitudes towards emotional and practical support from services, including from parent/DHH support networks. Parents wanted counselling services specific to the grief and emotional toll from the process, but that also encompassed navigation of the process.

> We were never offered counselling which surprised me. [*Clinician*] pretty much filled that gap with her incredible support and dedication … I think a counsellor should be available to parents. Preferably a rehabilitation counsellor who is trained in understanding the grief process in relation to dealing with your child having a disability. We were pretty quick to grieve and move forward but I think we would have benefitted from someone to talk to occasionally who knew about CI's, the process etc. [q10]

Stress was also created or minimised with practical implementations from services. For example, one parent's anxiety was alleviated by shortening the delays at a service. The system played a major role in supporting parents with stress and emotional process, including the coordination of services.

> I want to say that everyone that has helped us along our journey has been amazing and although it was a pretty stressful time for us we also appreciated all the help that was offered [q5]
>
> So the process was good and fast and gave us time to process that our daughter is deaf. It was hard but the support from [*various services*] we knew she was getting the best help. And she still is today, [*clinician*] has been very helpful with many resources and advice to help us give our daughter the best opportunity's available. The support from [*various* services] has been amazing and made it such an easy process. [q12]

Parents that had support from services made it easier for them during the process, as services played an important role in creating, minimising, or supporting parents through the

process. Parents felt emotionally supported when they were also practically supported. Support needs from services and parent/DHH support networks mirrored the emotional and practical support needs received from wider family members and friends.

In summary, the process was an emotional rollercoaster. Even with the right support the process was difficult, and the 'wrong' support created more demands on the family. Parents' emotions were related to the ability of family, friends, and services to create or mitigate the demands placed on families. Emotional support was linked to understanding, counselling, and practical support from the wider family, friends, and services.

Theme 2: "Who is organising?" Navigating the Process.

Parents were required to navigate the process, with help from clinician coordination of services, or by parents' active involvement and information seeking. Most parents used active language, which reflected their active participation in navigating and advocating within the process. For example, parents recounted their story with, "We have chosen to attend…" [q1], or, 'I always forget to ask…' [i2]. This expressed ownership of their participation in the interaction. Even parents with more passive involvement, in both their language and role, still had a high degree of active language and involvement in their story. Parents were actively involved in navigating the process, however, their experiences related to how well the system had coordinated care within and between services, rather than the parents' ability to seek information and coordinate services.

The role of clinician coordination was reflected in both examples of good coordination and poor coordination of services. Parents discussed how clinicians 'helped guide' parents through the process. That clinicians were "great, any questions she was able to answer or put me in touch with the right person" [q7]. Clinicians were often going 'above and beyond' what was expected by the parents, to find resources, advocate on behalf of the parents at other services, or give tips about how-to raise DHH children. The process was thought of as 'streamlined' [q3], and 'extremely comprehensive, well-coordinated, and efficient.'[q15].

> We felt as though we weren't really ever left alone and not knowing what was …and not being able to attend everything we were invited to, we were still always thought of and invited. We were pretty happy with the services provided for us … We are overwhelmed with the support we have and the people who helped us along the way and I believe if these agencies etc were not I'm place we would have struggled a lot and not felt at ease. [q13]

Navigating the process was easier due to good coordination. Parents praised the services for their coordination, and recounted positive perceptions and experiences.

There were also services with "no coordination between them" [q4]. Parents found this frustrating. When services were not coordinated, it added more stresses onto parents. Parents either had to coordinate services and advocate for themselves, or they missed out on opportunities.

> There are some times when I just think 'what's going on?' one example is…[*removed to maintain anonymity*] …, but then I started to think well know 'they're from [*service*] they know what they're talking about' and then I thought, 'no stuff it' I'm going to say like, 'I'm sorry, I don't really know what you're talking about' …if I hadn't been up front and said, 'look, I don't know what you're talking about, I'm pretty sure this is not me,' I could a, I don't know…it was those sorts of things which really kind of umm, I don't know, you don't have the complete faith at times, and that's one example and probably the most dramatic example, but there are lots of little ones like that along the way where you're, where you are wondering who is organising. [i2]
>
> We are waiting since [*~7-9 months ago*] and till now no update. I am controlling my frustration since a long time. My son is getting older and he needs to learn and hear. But just because of the delay its hard. My [*different clinician*] helps me in contacting the [*clinicians*] but she also doesn't get any accurate answers. I'm glad other [*clinicians*] that I have are great. [q14]

These show how lack of coordination or delays in services were difficult. These parents show that it is not *all* services or clinicians, but those that do make poorer coordination of service added more stresses and demands on to parents. Clinicians that advocated on behalf of parents made the process a better experience, but as noted by q14, it would be a lot harder if parents were forced to do all the advocating and navigating.

Differences in parent's active involvement when services failed to coordinate care was highly demonstrated in the comparison of two parents in similar circumstances. The first parent spent time organising care and the latter relied solely on the system.

> …but that did take a lot of time my time ringing them up and making sure that all [*the various services]* all knew what they were doing at the same time because if I hadn't of rung them, they wouldn't've done all the things that they were meant to do all at the same time, so that just kind of comes back to how I'm pretty happy to ring up and ask, make sure people are doing what they need to be doing, but if you hadn't been in probably would have missed an opportunity … [i2]
>
> My son then had to have [*procedure].* At the time I thought why didn't they just do [*different* procedure] the same time! Would have saved me about 12 hours of driving and a lot of angst! [q3]

Uncoordinated care created more stresses and demands on parents' time, regardless of parents' ability or choice to advocate for better services. It impacted parental perceptions of the process, and in these cases, it created poorer experiences.

Navigating the process is not only about navigating the system of formal services, but also in information seeking. Information parents sought related to missing information or resources available to parents. One parent stated there is information out there if parents are 'interested' and 'inquisitive' [i2] enough to ask for it, suggesting that parents need to take ownership in the navigation of the process and gain access to resources. Parents often sought information variety of topics, including 'tips and tricks' [i1] on how-to raise a DHH child. Sources of information included various services, other parents of DHH children,

DHH adults, internet searching, parent support groups, television shows/programmes, and from letter correspondences to between clinicians.

> Children should receive a set of Aqua+ to go with their CI's... It seems daft to me that I have to go find funding for an essential piece of equipment for our child to access water - in NZ! I failed to find funding. I am the fundraising guru - and I couldn't find anyone who would fund an Aqua+. So we pay for them ourselves. I would have thought there would be funding for this. [q3]
>
> I found all the medical stuff great, only area could be improved would be socially, would have been great to meet regularly with other families with deaf kids, to get support and ideas. I unfortunately was notorious for questioning people in the supermarket etc if I saw they had a kid with a hearing aid or cochlear implant. [q7]

These passages show that parents frequently sought more information, and actively searched ways to navigate the process. This was in their own individual ways and often outside of formal services or organisations. The comparison between passages regarding the efficient and streamlined process compared to parents' active involvement, questions whether parental active involvement is partially derived from necessity or gaps within services. That active parental involvement, advocation, and information seeking were required to successfully navigate the process.

The experience of the process related to the coordination and advocation provided by clinicians. Most parents had good coordination and perceptions of services and the process. When the system failed to effectively coordinate services, it created huge demands and stresses on parents, as parents had to be more actively involved to navigate the process. However, even if the parents increased their involvement or did not, a lack of coordination still created additional demands and stresses on parents. This meant that clinician coordination created parental perceptions in navigating the process.

Theme 3: Family-Clinician Interactions

The process is made up of a series of interactions between families and clinicians/services over time. The interactions between families and clinicians constructed the parental perceptions of the process. However, it is not necessarily parent-clinician interaction, as parents put their children's experiences in the centre of their stories. Other parents put aside their feelings about interactions and ensured their child had good experiences, so that the family got the most out of appointments. Thus, it is the family-clinician interactions that were more important and influenced parents' experiences of the process.

Family-clinician interactions created the experiences of parents, rather than any event, procedure, or complication during services. For example, when a parent asked different clinicians the same question, "sometimes it's been received well and sometimes it really hasn't" [i2]. Examples of standard clinical situations were 'traumatising' due to the interaction with clinicians. What may be considered difficult circumstances or complications were recounted positively, and one parent described the clinicians in an interaction as 'lovely'. Below, a mother described a simple procedure that had the potential to have a difficult parent-clinician interaction.

> They required her to be sleeping when they did [*procedure*], which made the process pretty difficult given that your appointment is for a fixed time (and not just at a time when baby is sleeping!) However, the staff were wonderful and made things as comfortable as they could and did not put any pressure on us. [q6]

Clinician's behaviour mitigated or maximised stress in difficult situations. Parents also appreciated when interactions 'catered to our individual needs' [q10]. The interaction between the family and clinicians impacted how parents perceived the services and how they constructed their experiences of the process.

Experiences had a long-lasting impact on the families. Particularly negative experiences. Parents put their child's experiences at the centre of their perceptions of the

services. This means that it is not only the parent-clinician interactions that were important, but the family-clinician interaction. Family-clinician interactions had a long-term influence on future interactions.

> I was approached at a later date … My son refused to let anyone talk about his hearing for about 6 months after this completely inappropriate and unprofessional meeting. [q3]

Another parent described her experiences in both her questionnaire and interview:

> I am hoping that the previous [*clinician*] does not get to do to any other child what he did to ours, as it is extremely traumatising and we are left dealing with the after effects and I am still left feeling like I have failed my son in every way imaginable. [q2]
>
> Umm, well in all honesty I wish we hadn't had the negative one [*experience*]. Because that I think that put us way back even beyond where any gains had been made, because I think it's taken [*new clinicians*], now, probably four times longer just to get any outcome from [*DHH child*] from it. [i1]

Parents placed their child's experience in the centre of their perception of the situation. These experiences had a profound effect on future engagement with services. Those children did not interact with services in the same manner. Some parents decided to discontinue certain services due to family-clinician interactions. These interactions had a long-lasting impact on future interactions.

Despite the long-lasting impacts of poor interactions, good clinician interactions helped to remedy poor experiences, or filled gaps within other services.

> The negatives were definitely outweighed by the positives. For every person who was negative - there was a [*clinician name*] and an [*clinician name*]. The [*clinicians*] we had for all [*service*] visits were incredibly good at their jobs. They ensured we were

> all ok as a family. Reduced the stress of being in a foreign environment and ensured the wellbeing of us and our son [q3]

Families reported that there were more positive interactions than negative ones. Good clinician interactions helped families to move on or to re-engage with the process. Another parent described of other parents that moved to a new location to have specific clinicians. Parents valued the family-clinician interactions, rather than any service or organisation of itself.

There were fewer specific examples of good interactions than negative interactions. It may have been easier to remember specific negative experiences than positive ones. Parents named and discussed clinicians themselves as important actors throughout the process. Many parents also had a special thank you or "shout out" to specific clinicians (both within and outside of formal UNHSEIP) who supported their families.

> [*Clinician*] was fantastic, I can't say enough good things about her" [q7]
>
> A special mention to [*clinician*] as she is amazing" [q11]
>
> [*Service*] and [*different service*] were AMAZING to deal with! No problems at all! It was super support and services" [q10]

Though parents did not have specific interactions recounted, they captured the ongoing (positive) family-clinician interactions. Positive experiences of the process were also related to the family-clinician interactions.

The construction of parents' experiences were built by the series of interactions between families and clinicians. Parents put their child's experiences at the centre of their own story, suggesting family-clinician rather than parent-clinician interactions were important. These interactions had significant long-lasting impacts on families' engagement and choice of future services. Experiences were positive or negative, but it related to the clinician's behaviour and overall interactions, rather than the events during services.

Summary

The process referred to all aspects of newborn hearing screening and early intervention, including the interaction and navigation of services, technology, NZSL, and raising a DHH child. Parents' emotional needs were meet through understanding and counselling needs, but also by practical support. Practical support mitigated the demands of the process. The type and experiences of support were mirrored across family, friends, services, and parent/DHH support networks. Despite the support needs mirrored across the different service, family, or friend systems, experiences around navigating the process was related to the degree of clinician coordination. This was regardless of any parents' active involvement in navigation or information seeking. Parents experiences were also constructed through the series of family-clinician interactions. Family-clinician interactions had a long-lasting impact on the engagement and interactions with future services. Each theme involved different areas in the construction of parental experiences of the process, but they also related to the overarching theme; how family, friends, parent/DHH support networks, and services maximised or mitigated demands during the process. The following chapter considers these findings with relevance to previous literature, as well as identifying clinical implications and study considerations.

Discussion

This study set out to explore how parents constructed their experiences of UNHSEIP, including any associated service as determined by the parents. Parents' experiences of UNHSEIP and in extension to raising a DHH child, was referred to as the process. The process placed demands on parents, and the construction of parents' experiences related to how those demands were created or mitigated during the process. These centred around the emotional responses/stressful journey regarding the process and support systems, the degree of clinicians' involvement in navigating the process, and the family-clinician interactions.

Parents' experiences in relation to demands has been the premise for many stress-related studies. Parents' evaluations of events and ability to cope in their environments were related the stress experienced (Abidin, 1992; Lazarus & Folkman, 1984). Across the many facets of stress-related research in parents of DHH children, the commonality is the demands placed on parents. This included the amount and intensity of daily hassles (Jean et al., 2018; Pipp-Siegel et al., 2002; Sarimski et al., 2013; Zaidman-Zait, 2008), or the effect of child language delays or behavioural problems (Dirks et al., 2016; Hintermair, 2006; Lederberg & Golbach, 2002; Pipp-Siegel et al., 2002; Quittner et al., 2010; Sarant & Garrad, 2014; Sarimski et al., 2013). However, it is important to note that most stress-related studies have a more essentialist component, particularly surrounding the concept 'individual' resources. This differs to the ontological and epistemological position in this study. In reference to these studies, I have focused on the factors that created demands, rather than any individual resources parents may or may not have possessed.

The overarching theme in this study described how the process created many demands on parents and the entire family. This is similar to Davids and de Jager (2018) and Jackson et al. (2010), in that the process had a pervasive nature in all aspects of family life. Support was seen as the reciprocal to demands, as events/contextual-stresses created demands and support mitigated them. The three themes intersected to show how the

demands were created or mitigated. Other studies have discussed how experiences of stress were related to the relationship between contextual stressors and the mediation by various stress-reducing factors (Deater-Deckard, 1998; Jean et al., 2018; Quittner et al., 2010).

Parents noted that "It was a very stressful journey. Even with the right support it was hard." [q3]. UNHSEIP is also a major life event for many hearing parents, which creates demands on parents (Deater-Deckard, 1998; Lazarus & Folkman, 1984). This period was also surrounded by initial grief and a range of emotions, which has been described in previous literature (Geal-Dor & Adelman, 2018; Gilbey, 2010; Gilliver et al., 2013; Hardonk et al., 2011; Jackson et al., 2008; Scarinci et al., 2017; Scarinci, Erbasi, et al., 2018; Schulian & Lind, 2020; Young & Tattersall, 2007). As noted, the process was an "emotional rollercoaster", and similar emotional journeys have been reported as well (Fitzpatrick et al., 2007; Gilliver et al., 2013; Jean et al., 2018; McCracken et al., 2008; Russ et al., 2004; Scarinci, Erbasi, et al., 2018). Ongoing daily hassles were also irritating, frustrating, annoying and stressful (Crnic & Greenberg, 1990), which are similar to parental reports in this study.

Stress is one aspect of the journey. While literature often discussed stress as an aspect of coping, parents in this study also used 'stress' as an emotion. Hintermair (2000) used the term "emotional strain" (p. 505) for parental stress, which demonstrates an interplay between emotions and stress. In Malaysian parents of DHH children, managing parental stress was related to mothers' sense of well-being from the role and identity of a parent, which was challenged by conflicting emotions, such as ambivalence, grief, guilt, and confusion (Jean et al., 2018). Schulian and Lind (2020) noted that there is an implicit need for clinicians to respond to the parent's emotions and an explicit attendance to family wellbeing.

More interestingly, in spite of parents asking for emotional support or counselling, emotional support was often referred to in the same vein as practical supports or solutions. Prevention or intervention should decrease workload and strengthen social networks as a

means of reducing parenting stress (Östberg & Hagekull, 2000). In fact, Hintermair (2006) discussed the need for a "resource-orientated" (p. 496) approach towards counselling and support strategies. The concept is to increase access to social resources for parents to cope with raising a DHH child. This could involve practical help, advice on raising DHH child, and counselling on early intervention process (Hintermair, 2004). Similar to responses in this study, parents asked for counselling due to the grief process and emotional responses, but wanted counselling services with specific knowledge surrounding the process.

Parents wanted to be supported by family and friends, as long as it did not increase the demands placed on them. Vukkadala et al. (2019) showed that parents felt anxiety or negativity when they had to be a mediator for non-family members or the general public in educating about hearing impairments and its impact. Parents felt emotionally supported when they were also practically supported, related to the concept that demands can result in emotional strain/parent stress. Social support has been discussed to encompass practical support before (Dirks et al., 2016; Pipp-Siegel et al., 2002). Other studies in typically-developing children populations showed that social support had an effect on the perception of demands. Crnic and Greenberg (1990) noted in parents of typically-developing children that intimate support, friendships, and community support affected parental experiences of daily hassles. They suggested that parents need more practical support, such as child care and decreasing daily hassles, rather than just emotional support. In mothers randomly selected from the Swedish population, social support had a main effect on stress, and indirectly affected work-load or fussy-difficultness (demands on mothers) (Östberg & Hagekull, 2000). Perceived social support is key to decreasing stress when it mitigates demands and does not increase demands from the process.

Support needs were mirrored across support from wider family, friends, parent support groups or other parents of DHH children, clinicians, and services. Zaidman-Zait (2008) noted in Canadian parents of DHH children with CIs, that the choice of person to collaborate with depended on the problem. Parents sought out clinicians due to their

availability, knowledge and experiences, for emotional and informational support, and for an external point of view. They sought spouses as they already understood and shared any problems, and looked to other parents of DHH children due to their similar experiences, comparable solutions, and to discuss the options available. Though each parent had different motivation towards their approach to potential support personal, they were regularly approached with similar problems. This shows how support needs can be mirrored, but there are still nuances with the support received from each support system.

In contrast to parents' support needs mirrored across services, family, friends, and DHH support networks; parent's experiences relating to navigating the process were not mirrored across the services. A lack of coordination of services placed demands on families, regardless of the parents' ability or choice to actively navigate services themselves. The experiences linked only to how well clinicians coordinated services. This is likely due to the increase of demands on families, particularly as these demands are an ongoing demand (Crnic & Greenberg, 1990; Lazarus & Folkman, 1984). Unlike how family, friends, and parent support networks could mitigate or increase demands, service coordination is primarily mediated by clinicians. Between 2000 to 2014, Henderson et al. (2014) found 29 studies that referred to inadequate support in navigating services for DHH children. Navigation was overwhelming and emotionally taxing, as parents felt lost at what to do next (Larsen et al., 2012). Similar to this study, disjointed care resulted in frustrations (Fitzpatrick et al., 2008). More recent studies still demonstrated difficulties in navigating services and call for the importance of providing well-coordinated care (Findlen et al., 2019; Scarinci et al., 2017; Scarinci, Gehrke, et al., 2018). Clinician coordination of services is vital to ensure good experiences of the process.

While clinician coordination is vital to parents' perceptions in navigating the process, parents in this study had an active parental involvement and information seeking. Information was available if parents were 'interested' or 'inquisitive' enough to find it. Parents actively sought out new information from a variety of sources. This is similar to

McCracken et al. (2008) in that practical or useful information was only forthcoming when asked about. Parents required new information to not only navigate services, but to navigate the entire process. There still remains a question of whether active parental involvement was in part due to missing information/ poorly-coordinated care, or whether active involvement is a normal part of parent participation.

Parental involvement is an important component of FCC (Allen & Petr, 1996; Epley et al., 2010; Moeller et al., 2013). UNHSEIP in NZ was built and maintained around FCC principles. This may encourage parents in NZ to have more active involvement in facilitating their DHH child's care. Erbasi et al. (2018) described parents as "case managers" (p. 20) as they had to engage with-, and have knowledge of services and resources to achieve their wanted outcome. Other factors, such as increased perceived social support and increased self-efficacy (Brand et al., 2018; Zaidman-Zait et al., 2018) are associated with higher parental involvement. These align with the suggestions for clinicians to encourage parental involvement from the FCC principles (Moeller et al., 2013). Active parental involvement in this study may derive from a need to fill a missing gap or as a product of FCC in UNHSEIP in NZ. Regardless of the degree of active parental involvement, clinician coordination of care impacted the demands faced by families and their overall perceptions of navigating the process.

Parent's experiences were also influenced by the family-clinician interactions. This is similar to many studies overseas. The clinician's personality, character, behaviour and manner was more important than any results or events that took place at services (Davids & de Jager, 2018; Fitzpatrick et al., 2008; Geal-Dor & Adelman, 2018; Hardonk et al., 2011; Mazlan et al., 2014; Park & Yoon, 2018; Russ et al., 2004; Shojael et al., 2013; Young & Tattersall, 2005). Purposeful clinician interactions during appointments have the ability to change parents' perceptions. In habilitation sessions with CI children in Australia, clinicians made positive commentaries towards parents during child-related tasks to re-engage parents and ease any (potential) parental concerns or feelings during the task (Ekberg et al., 2018).

However, in the North of Israel, parents often had poor interactions when clinicians were silent and did not interact with the parents until clinicians present a summary (Gilbey, 2010). Interactions with clinicians changed parents' perceptions of the events or results from the process. It is important to consider the family-clinician interactions, rather than just the events that occur.

Parents also put the child at the centre of their experiences, making family-clinician interactions, rather than only parent-clinician interactions. The development of this theme was interesting, as the initial development of the theme related more towards parent-clinician interactions as the study's aim explored parents' experiences. The approach to the consideration of the whole family interaction is different from FCC models. FCC refers to family-directed therapies in opposition to the previous model of child-directed therapies (Epley et al., 2010; Foster et al., 1981; Moeller et al., 2013), as opposed to a perspective shift from the study intentions. Despite this, other studies have shown that parental experiences place importance on the whole family system. Parents felt supported and comfortable when there were good family-clinician relationships (Scarinci, Gehrke, et al., 2018). These emphasise that parents experiences relate to family-clinician relationship and interactions rather than the parent-clinician or child-clinician relationships.

Opposed to specific examples of good family-clinician interactions, many parents praised various clinicians and services over time. The series of interactions were important. Similar to Russ et al. (2004), parents with good experiences had positive personal descriptions surrounding the clinician's behaviour. In another Australian study, parents preferred clinicians that took time to build relationships with families (Roberts et al., 2015). Good relationships took time to build, and occurred over a series of good interactions between families and clinicians. This is important as good clinician interactions have been shown to have positive long-lasting impacts on family's interactions with services.

Similar to good interactions and developing good relationships, poor interactions also had a long-lasting impact on family future interactions. Some parents were traumatised

due to poor family-clinician interactions, which resulted in barriers in future interactions or the decision to not attend specific services. From studies in Australian at-risk hearing screening and subsequent early intervention services, there were numerous stories surrounding misunderstandings and poor communication between parents and clinicians. This also had a negative impact on DHH children's future care (Russ et al., 2004). It is important to recognise the long-term impact that both good and poor family-clinician interactions can have on families. Good interactions can remedy poor interactions, and build good family-clinician interactions. Most parents shared stories, praise, or expressed thanks from good family-clinician interactions and relationships.

Clinical Implications

Parents' experiences in this study, as well as the wider literature on stress-related studies, showed that experiences were related to the creation or mitigation of demands. Clinicians should aim to decrease the demands placed on parents. This includes through the provision of practical support, good coordination of services, and facilitating good family-clinician interactions. As support needs were mirrored across different support structures in families' lives, clinicians should encourage increased family support. Parents may require help in educating wider family members and friends surrounding DHH, so that family and friends can support families as opposed to increasing demands. For other additional support, clinicians should increase knowledge of or access to parent support networks (e.g. wider DHH community or other parents of DHH children). Many parents also raised the need for a counsellor to be present in the early stages of diagnosis, particularly surrounding the grief. They wanted a counsellor that was specific to DHH diagnosis, and someone who was familiar with navigating the process. Together, these should improve the mitigation of demands and decreasing emotional strain parents experience.

Research Considerations

The original purpose of this study was to explore the experiences of parents' experiences with universal newborn hearing screening and early interventions, including

associated support services, within the Southern regions of NZ. The intended ontological and epistemological assumptions were further clarified and developed throughout the study. This means that the initial probing questions within the questionnaire fit a more critical realist, descriptive/experiential study design, than a relativist social constructionist study. Though analysis still adequately looked at the construction of parents' experiences, it is important to note that the questions may not have been the best fit for the study design.

Modifications were also made due to the unknown projection of COVID-19 in NZ from around March 2019. This meant there was limited ability to use face-to-face in person interviewing as a method of data collection, and resulted in further consideration surrounding the research design. The primary considerations were availability for data collection, health and safety risks for meeting, participant willingness, and concerns regarding the short time frame of a master's level project. This led to the decision of qualitative surveys, with the potential for in-person interviewing at a later date.

Open-ended questions are best designed for interviews as opposed to surveys, as interviews provide the option to clarify responses. Surveys also require more thinking from participants than interviews, and also tend to have lower response rates (Pickard, 2007). However, qualitative surveys are not necessarily less than qualitative interviews, and can have advantages over interviews (Braun et al., 2020). Qualitative surveys allow participants to maintain their anonymity, which can be especially important when discussing sensitive topics (Braun et al., 2017). This may be appealing to parents who did not want to identify themselves or the clinicians involved, in case it later reflects poorly on either party. Online surveys can allow for greater geographical reach than traditional face-to-face interviews (Braun et al., 2020; Braun et al., 2017). This allowed for sampling across all of NZ, as opposed to those receiving services from only the Canterbury region.

The study has a small sample size, however in the context of qualitative studies, it is difficult to determine exactly what is classed as too small. There is a wide variation in the size and amount of credence placed on qualitative studies sample sizes by different

methodological designs. Those with more positivist approaches were more likely to value a large sample size compared to those of social constructionist or contextualist approaches (Boddy, 2016). Braun et al. (2020) noted that small samples tended to have between 20-49 survey responses, however, it is not the number of responses, but the richness of data within each response that matters. This is a small study, but it is difficult to determine if it is too small to contain sufficient research value. There was sufficient data to develop in-depth themes that related to each other by an overarching theme, as well as to explore the nuances within each theme. However, interviews were also performed to increase the richness of the data available. There were also other potential themes that could have been generated, however, further into data analysis, it became apparent that it was located within a small section of the data set. For example, the idea of experiential knowledge. That searching for information and the value of information derived from parents' own-, DHH adults'-, or parents of DHH children's experiences.

This study was only provided in English, which may have deterred those who with English as a second language or have limited literacy skills. There were no Pacific persons or MELAA participants. From reading the responses from parents it is also unlikely that there were any DHH parents within this sample. This means that their voices and experiences are less likely to be reflected in the data set and subsequent analysis. However, it is important to note that the deafness notification database only included children diagnosed with a permanent hearing impairment that is greater than average across 0.5, 1.0, 2.0, and 4.0 kHz that is equal or greater than 26 dB HL (Digby et al., 2020). This means that the 'true' NZ DHH child population may differ to that reported.

There were no demographic questions regarding hearing severity, type, the configuration, or laterality in this study, as it is only be reliant on parent reporting. This means there is no information regarding similarity to the DHH population. There were also likely more families that received rural services or had to travel to access services than present in the NZ paediatric DHH community. This means the extent of difficulties or

demands placed on families may differ from the demands of families who received local services, ultimately affecting the overall experiences and perceptions of demands in this study.

Future Research

This study shared insights into how parents' experiences were constructed, but it did not provide an evaluation of parents' experiences with these services. Given the lack of research or evaluations of UNHSEIP in NZ, it would be beneficial to evaluate parents' experiences in order to identify areas of improvements. This would also align with the FCC principles that outline the need to evaluate services and use evidence-based practise in NZ.

It would be interesting to do further research specifically focusing on the relationship between practical support and emotional needs. Though stress-related studies provided insights into this phenomenon, it would be interesting to explore further and determine ways to best support parents in NZ.

Conclusion

The aim of study was to explore the ways parents constructed their experiences of UNHSEIP, including any associated support services. Parents' experiences are an important consideration in NZ services, due to the emphasis on their role in family-directed services. This study also provided parents the opportunity to share their story regarding UNHSEIP, as many parents find it relieving to do so (Peryman, 2017).

Parents described UNHSEIP, and all related phenomena including associated support outside of formal UNHSEIP, raising a DHH child, and managing/learning to use technology or NZSL, as a *process*. Parent's experiences were linked to how well the demands of the process were created or mitigated. This overarching theme was similar to Lazarus and Folkman (1984) ideas of stress, that went on to influence many stress-related studies (Abidin, 1992; Jean et al., 2018; Pipp-Siegel et al., 2002; Sarimski et al., 2013; Zaidman-Zait, 2008). More specifically, parents' experiences were related to the emotional and practical support that was mirrored across family, friends, clinicians, and service support systems; clinician coordination in decreasing the demand in navigating the process; and the series of family-clinician interactions, that had a long-lasting and cumulative effect to construct parents' experiences. Clinician's should be aware of the influence they have on creating or mitigating demands from the process.

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Appendices

Appendix A. Ethics Approval and Amendments

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2020/44

18 June 2020

Caelyn Jessica Eades
Psychology, Speech and Hearing
UNIVERSITY OF CANTERBURY

Dear Caelyn

The Human Ethics Committee advises that your research proposal "Exploring the Experiences of Parents/Caregivers with Newborn Hearing Screening and Subsequent Support Services" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 17th June 2020; **and the following:**

- *In Appendix 3, please make the audio recording a choice, rather than a requirement, i.e. change the text to: "If you consent to audio recording, the interview (online or in person) will be audio recorded…".*
- *Please remove the unnecessary second comma from the fourth bullet point of the Participant Information Page (Page 21 of your application).*

Best wishes for your project.

Yours sincerely

pp. R. Robinson

Professor Geoffrey Rodgers
Deputy Chair
University of Canterbury Human Ethics Committee

University of Canterbury Private Bag 4800, Christchurch 8140, New Zealand. www.canterbury.ac.nz

F E 8

HUMAN ETHICS COMMITTEE
Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2020/44 Amendment 1

26 August 2020

Caelyn Jessica Eades
Psychology, Speech and Hearing
UNIVERSITY OF CANTERBURY

Dear Caelyn

Thank you for your request for an amendment to your research proposal "Exploring the Experiences of Parents/Caregivers with Newborn Hearing Screening and Subsequent Support Services" as outlined in your emails dated 18th and 21st August 2020.

I am pleased to advise that this request has been considered and approved by the Human Ethics Committee, **subject to the following:**

- *Please ensure than any requirements from the Ministry of Education, such as their approval of the updated forms, are completed as necessary.*

Yours sincerely

R. Robinson

pp.

Professor Geoffrey Rodgers
Deputy Chair, Human Ethics Committee

HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2020/44 Amendment 2

7 October 2020

Caelyn Jessica Eades
Psychology, Speech and Hearing
UNIVERSITY OF CANTERBURY

Dear Caelyn

Thank you for your request for an amendment to your research proposal "Exploring the Experiences of Parents/Caregivers with Newborn Hearing Screening and Subsequent Support Services" as outlined in your email dated 6th October 2020.

I am pleased to advise that this request has been considered and approved by the Human Ethics Committee.

Yours sincerely

R. Robinson

pp.

Professor Geoffrey Rodgers
Deputy Chair, Human Ethics Committee

Ngāi Tahu Consultation and Engagement Group

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH, New Zealand

30 March 2019

Tēnā koe Caelyn

Re: Evaluating the Experiences of parents/caregivers of Deaf and Hard of Hearing Children following Universal Newborn Hearing Screening and Subsequent Early Interventions

This letter is on behalf of the Ngāi Tahu Consultation and Engagement Group (NTCEG). The NTCEG considered your proposal and acknowledge it is a worthwhile and interesting project and you are clear about how you ought to take participants' (cultural) needs into account if and when applicable.

Given the scope of your project, no issues have been identified and further consultation with Māori is not required.

Thank you for engaging with the Māori consultation process. This will strengthen your research proposal, support the University's Strategy for Māori Development, and increase the likelihood of success with external engagement. It will also increase the likelihood that the outcomes of your research will be of benefit to Māori communities. We wish you all the best with your current project and look forward to hearing about future research plans.

The Ngāi Tahu Consultation and Engagement Group would appreciate a summary of your findings on completion of the current project. Please feel free to contact me if you have any questions.

Ngā mihi
Maxine Bryant (on behalf of the NTCEG)

Director Research Services | Kaihautū
Research & Innovation | Te Rōpū Rangahau
University of Canterbury | Te Whare Wānanga o Waitaha
Phone +64 3 369 5791, Private Bag 4800, Christchurch | Ōtautahi
maxine.bryant@canterbury.ac.nz
http://www.research.canterbury.ac.nz

Appendix B. Survey Information, Consent, and Questions

Experiences of parents/caregivers with newborn hearing screening and subsequent support

Q1 Kia ora, my name is Caelyn Eades and I am currently a student at the University of Canterbury/Te Whare Wānanga o Waitaha, studying a Masters of Audiology degree. This research project aims to explore the experiences of parent's/caregiver's with newborn hearing screening and early support services.

This information has been forwarded to you because a child in your care receives support/early intervention services, and professionals within these services think you may be a good candidate. Please note, no information, including you or your child's identity, has been or will be shared with me by the services/professionals who forwarded this study to you.

What is involved in taking part?

Taking part involves filling out an anonymous, online questionnaire. It may take time to recall and answer the questions, so it is advisable to take breaks as needed. It may be easier to answer the questions on a computer or laptop, rather than a phone or tablet.

How long will it take?

It is estimated to take 20-30 minutes. It involves answering 5 questions about your experiences related to your child being identified with a hearing impairment, as well as support provided around that time and factors that influenced decisions you made regarding their care. Please be assured that there are no wrong answers. There are also generic demographic questions to determine if the respondents represent the diversity of the NZ population.

Who can participate?

Anyone over 18 years of age and is a parent/caregiver/guardian/have custody of a child diagnosed with a hearing impairment for an average of 2 or more days per week. The

child's hearing impairment must have been identified within the last 5 years through the NZ newborn screening programme or associated hearing surveillance programme (e.g. cleft lip/palate, Down's syndrome, other syndromes, familial risk of hearing loss etc).

If you choose to participate, you have the right to withdraw at any stage without penalty. To do so, simply close your browser window. All data entered up to this point will be deleted. Please be aware that once you submit your responses, it will not be possible to remove your data as the questionnaire responses are anonymous and we will not be able to identify you. Participation is voluntary. Your decision to participate or withdraw will not affect your relationship with anyone at the University of Canterbury/Te Whare Wānanga o Waitaha or any service providers involved in your child's care.

What happens to the information I provide?

All responses will be uploaded to password protected files in the UC server. Data will be backed up on University of Canterbury servers. To ensure confidentiality, participants will be identified using a code (e.g. participant 1). Access to data will be restricted to the primary researcher (Caelyn Eades) and supervisors (Dean Sutherland and Paul Peryman). All data will be destroyed after a period of five years, as per the University of Canterbury research data protocols.

A thesis is a public document and will be available through the University of Canterbury library in hard copy and through an online thesis repository, but you may be assured of the complete confidentiality of data gathered in this study; identities will not be made public. In addition, the findings may be written up and submitted for publication in a peer-reviewed scholarly journal or presented orally or via poster at a professional conference.

Any identifying information provided in your responses that could identify a person or organisation will be changed to a general non-identifying description (e.g. "Child" or "organisation") before data is analysed.

What is the prize draw?

After completing the questionnaire, you can choose to enter a random prize draw for one of five $50 gift vouchers. This will involve clicking a link which will take you to another questionnaire where you can enter your contact information. These details will be stored separately and will not be able to be linked with your questionnaire responses. Personal information provided for this, will not be used for any other purpose.

Can I have a copy of the results?

At the end of the questionnaire, you will automatically onto another questionnaire and indicate if you would like a copy of the results. These details will be stored separately and will not be linked to your questionnaire responses. I will email you a summary of the research at the conclusion (early 2021). Personal information provided for this, will not be used for any other purpose.

Are there other opportunities to be involved?

At the end of the questionnaire, you will be asked if you might be interested in being contacted about participating in an interview about your experiences of universal newborn screening programmes and early support services in NZ. If you decide to leave your contact details, these will be stored separately and will not be linked to your responses. If we contact you about taking part in an interview, we will first send you full information about the interview for you to consider.

Who is doing the research?

This project is being carried out as a requirement for the MAud (Masters of Audiology) degree by Caelyn Eades, under the supervision of Dean Sutherland and Paul Peryman. They will be pleased to discuss any concerns you may have about participation in this project.

Who can I contact regarding any questions or enquiries?

If you have any questions, please contact:

Caelyn Eades, caelyn.eades@pg.canterbury.ac.nz

Dean Sutherland, dean.sutherland@canterbury.ac.nz

Paul Peryman, paul.peryman@kotakureo.school.nz

If you feel distressed or affected by any of the questions presented in the study, please do not hesitate to contact your audiologist, advisor on deaf children (AoDC), doctor, counsellor, or community health service. Alternatively, you can contact a free anonymous counselling service-

-Lifeline: 0800 543 354

-Need to Talk? Free call or text 1737

-WHATSUP: 0800 942 8787 (1pm to 11pm)

This project has been reviewed and approved by the University of Canterbury/ Te Whare Wānanga o Waitaha Human Ethics Committee. Participants should address any complaints to the Deputy Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz). Reference code HEC 2020/44.

Ngā mihi

Caelyn Eades

Q2 In submitting this form:

-I agree to my responses being used for the purposes of exploring the experiences of parents/caregivers with newborn hearing screening and subsequent support services. The information will only be accessed by the researchers involved in this study.

-I understand that my data will be held securely and will not be distributed to third parties, though the results of this study will be published. Published results will not identify me, my child, any other person or organisation.

-I understand that once I submit my answers to the questionnaire, my data will not be able to be removed.

Q3 Are you 18 years of age or older, and are the parent/caregiver/guardian/have custody of a child diagnosed with a hearing impairment for an average of 2 or more days per week?

Q4 Was your child's hearing impairment identified within the last 5 years through NZ Newborn Screening Programme or through a hearing surveillance programme following birth (e.g. your child also has cleft lip or palate, Down's syndrome, other syndrome identified around time of birth, other risk factors)?

Q5 There are 5 questions regarding your experiences with hearing screening, testing, and early services, which will then be followed by some basic demographic questions. Please feel free to take a break and come back to the survey at any time.

Q6 Please give as full a description as you can about your/your family's/whānau's journey through your child being screened, tested, diagnosed, and subsequent support for their hearing loss. This may include your emotional or thought processes during this time.

Q7 What resources or support did you/your family receive regarding the choice of diagnosis and support strategies (e.g. hearing aids, cochlear implants, sign language, Advisor on Deaf Children (AoDC), local parent groups etc)? How did these impact the decisions you made for your child's care?

Q8 In your opinion, how were the needs of your child/family/whānau addressed during your child's first year of life?

Q9 In your opinion, are there ways in which the system of detecting, diagnosing, and supporting your child/family/whānau could be improved? This can include support or

services received outside of typical ‘audiological’, ‘testing’, ‘hearing aid’, ‘cochlear implant’, or ‘hospital’ services.

Q10 Are there any other comments you would like to make about services you/your child received?

Q11 The following questions are demographic questions. This information is to determine if the people participating in this survey represent the diversity of the NZ population.

Q12 Please select any hearing device or intervention your child has used in the past.

-No aid or intervention used (1)

-Hearing aid/s (2)

-Cochlear implant/s (3)

-Remote microphone/FM system (e.g. Roger Mic) (4)

-First Signs (if Sign language is only learnt due to child with a hearing impairment) (5)

Q13 Please select any/all languages used at home with your child?

-Sign Language (1)

-Spoken English (2)

-Te Reo Māori (3)

-Other, please specify: (4)

Q14 Which area of NZ has your child lived most within their first year of life? Please refer to the map provided.

-Tai Tokerau/Northland (1)

-Auckland (2)

-Waikato (3)

-Waiariki/Bay of Plenty (4)

-Tairāwhiti/Hawke's Bay (5)

-Taranaki/Whanganui/Manawatū (6)

-Wellington (7)

-Nelson/Marlborough/West Coast (8)

-Canterbury/Chatham Islands (9)

-Otago/Southland (10)

Q15 Which age were you when your child was born/came into your care?

-17 and under (1)

-18-29 (2)

-30-39 (3)

-40-49 (4)

-50+ (5)

Q16 What ethnicity do you most identify with? You can select more than one option.

-NZ/European (1)

-Māori (2)

-Pacific Peoples (3)

-Asian (4)

-Middle Eastern, Latin American, or African ethnicity (MELAA) (5)

Q17 By continuing, you are submitting your responses to this survey. After this, we will not be able to retrieve or delete any information you have provided due to the anonymity of the survey.

Appendix C. Study Advertisements

Ko Taku Reo and AoDC Advertisement

Are you interested in sharing your experiences with your child's newborn hearing screening and subsequent support?

Kia Ora, my name is Caelyn Eades and I am a student studying for a Masters of Audiology Degree at the University of Canterbury/Te Whare Wānanga o Waitaha.

This has been forwarded to you, as a child in your care receives support/early intervention services, and professionals within these services think you may be a good candidate in the study. This research project aims to explore the experiences of parents/ caregivers of children identified with hearing impairment during and after the universal newborn hearing screening and subsequent early support. Please note, no information, including you or your child's identity, has been or will be shared with me by the services/professionals who forwarded the questionnaire to you.

This would involve participating in an online questionnaire (estimated 15-25 minutes) and sharing your story and experiences.

In completing the questionnaire there is a chance to win one of five $50 Westfield vouchers. After the questionnaire, you may indicate interest in participating in an online or face-to-face interview about your experiences.

Link to questionnaire: http://canterbury.qualtrics.com/jfe/form/SV_0Go3eCfYdI8CuPj

For further information or any questions, please contact –

Caelyn Eades (caelyn.eades@pg.canterbury.ac.nz), or

Paul Peryman (paul.peryman@kotakureo.school.nz), or

Dean Sutherland (dean.sutherland@canterbury.ac.nz)

This study has been approved by the University's Human Ethics Committee. Reference code HEC 2020/44.

Deaf Children NZ Tamariki Turi o Aotearoa Facebook page

Are you interested in sharing your experiences with your child's newborn hearing screening and subsequent support?

In completing the questionnaire there is a chance to win one of five $50 Westfield vouchers.

Kia Ora, my name is Caelyn Eades and I am a student at the University of Canterbury.

This study aims to explore the experiences of parents/caregivers of deaf and hard of hearing children identified with newborn hearing screening and subsequent support.

This would involve participating in an online questionnaire (estimated 15-25 minutes) and sharing your story and experiences.

After the questionnaire, you may indicate interest in participating in an online or face-to-face interview about your experiences.

Link to questionnaire: http://canterbury.qualtrics.com/jfe/form/SV_0Go3eCfYdI8CuPj

For further information or any questions, please contact –

Caelyn Eades (caelyn.eades@pg.canterbury.ac.nz), or

Paul Peryman (paul.peryman@kotakureo.school.nz), or

Dean Sutherland (dean.sutherland@canterbury.ac.nz)

This study has been approved by the University's Human Ethics Committee. Reference code HEC 2020/44.

Appendix D. Anonymous Survey Link

Thank you for Participating

Q1 Thank you for participating in the survey. This page is not linked to your previous answers.

If you have any questions or would like to contact the researchers:
Caelyn Eades (Caelyn.eades@pg.canterbury.ac.nz), Dean Sutherland (dean.sutherland@canterbury.ac.nz), or Paul Peryman (paul.peryman@kotakureo.school.nz)

If you feel distressed or affected by any of the questions presented in the study, please do not hesitate to contact your audiologist, advisor on deaf children (AoDC), doctor, counsellor, or community health service. Alternatively, you can contact a free anonymous counselling service-

-Lifeline: 0800 543 354

-Need to Talk? Free call or text 1737

-WHATSUP: 0800 942 8787 (1pm to 11pm)

This project has been reviewed and approved by the University of Canterbury/ Te Whare Wānanga o Waitaha Human Ethics Committee. Participants should address any complaints to the Deputy Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz). Reference code HEC 2020/44.

Q2 Please include your name and email or phone number if you would like a copy of the final results.

Q3 Please include your name and email or phone number if you would like the chance to win one of five $50 gift vouchers

Q4 Please include your name and email or phone number to indicate your interest in participating in an online or face-face interview regarding your experiences with newborn screening and early support services.

The interview will be up to an hour long and will be semi-structured, meaning that a selection of pre-determined questions will be asked, but has the flexibility to also discuss any points raised by you. Participation is voluntary. If you choose to participate, you have the right to withdraw at any stage without penalty.

A sign language interpreter (NZSL) will be provided for parents/caregivers who prefer to use NZ sign language to communicate.

Appendix E. Interview Information and Consent Forms

School of Psychology, Speech and Hearing
caelyn.eades@pg.canterbury.ac.nz
Date: 09/11/2020
HEC Ref: HEC 2020/44

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Study Title: Exploring the experiences of parents/caregivers with newborn hearing screening and subsequent support services

Information Sheet

Kia ora, my name is Caelyn Eades and I am currently a student at the University of Canterbury, NZ/Te Whare Wānanga o Waitaha, studying a Masters of Audiology Degree. This research project aims to explore the experiences of parents/caregiver's with newborn hearing screening and early support services.

You have been approached as you indicated your interest in being interviewed during a survey about newborn hearing screening, diagnosis, and early support services. With your permission, I would like to interview you about your experiences with universal newborn hearing screening and early interventions.

Please note, no information, including you or your child's identity, has been or will be shared with me by the services/professionals mentioned.

What is involved in taking part?

An online interview (through Zoom) or in person interview (at Van Asch DEC, Christchurch) can be arranged at a convenient time. The interview will be up to an hour long and will be semi-structured, meaning that a selection of pre-determined questions will be asked, but has the flexibility to also discuss any points raised by you. Paediatric audiologist, Paul Peryman, will be available for support during the interview via online interview or in person (if the interview occurs at Van Asch DEC). The interview (online or in person) will be audio recorded, in order to support the transcription of the interview. Once transcription has occurred, the audio recording will be deleted.

Light refreshments (tea, coffee, biscuits) will be provided if the interview occurs in person. There will also be the provision of breaks or options of stopping, rescheduling, or withdrawing from the interview.

A sign language interpreter (NZSL) will be provided for parents/caregivers who prefer to use NZ sign language to communicate. The sign language interpreter will sign a confidentiality agreement prior to commencement of the interview.

What happens after the interview?

Following the interview, a transcript of the interview will be created. This may involve third party transcription services, though I assure you that it will be treated with respect and confidentiality. The transcript will be returned to you, in which you have 10 days to return any amendments to the transcript. A $20 voucher will be provided after the interview for sharing your experiences.

Who can participate?

Anyone over 18 years of age and is a parent/caregiver/guardian/have custody of a deaf or hard of hearing for an average of 2 or more days per week. The child's hearing impairment must have been identified within the last 5 years through NZ newborn screening programme or associated surveillance programme (e.g. cleft lip/palate, Down's syndrome, other syndromes, familial risk of hearing loss etc.). This was the same criteria as the survey you completed and indicated interest to be interviewed in.

Participation is voluntary. If you choose to participate, you have the right to withdraw at any stage without penalty. You may ask for your raw data (audio file and transcript) to be returned to you or destroyed at any point. If you withdraw, I will remove all information relating to you. However, once the analysis of data commences (1st of December 2020), it will be increasingly difficult to remove the influence of your data on the results.

What happens to the information I provide?

All recordings will be recorded on a dedicated recording device and will be deleted once transcribed. Third party transcription services may be used in transcribing your data; however, confidentiality and privacy will be maintained. All transcriptions will be uploaded to password protected files in the UC server. Data will be backed up on University of Canterbury Servers. To ensure confidentiality, participants will be identified using a code (e.g. participant 1). Access to data will be restricted to the primary researcher (Caelyn Eades) and supervisors (Dean Sutherland and Paul Peryman). All data will be destroyed after a period of five years, as per the University of Canterbury research data protocols.

A thesis is a public document and will be available through the University of Canterbury library in hard copy and through an online thesis repository, but you may be assured of the complete confidentiality of data gathered in this study; identities will not be made public. In addition, the findings may be written up and submitted for publication in a peer-reviewed scholarly journal or presented orally or via poster at a professional conference.

Any information provided that could identify a person or organisation will be changed to a general non-identifying description (e.g. "child" or "organisation") before data is analysed.

What are the benefits?

This study has potential benefits for participants, other parents/caregivers of children who are deaf or hearing impaired, and the service providers who support them. For example, participants may find that sharing their stories and perspectives is a positive experience. The research outcomes could help service providers better understand the needs of NZ parents/caregivers, and improve the services that are available. The research may also identify gaps/areas that could be improved within the existing services and processes.

Can I have a copy of the results?

Please indicate to the researcher if you would like to receive a copy of the summary of results of the project on the consent form.

Who can I contact regarding any questions or enquiries?

If you have any questions, please contact:

Researcher: Caelyn Eades, Caelyn.eades@pg.canterbury.ac.nz

Supervisors: Dean Sutherland, dean.sutherland@canterbury.ac.nz

Paul Peryman, paul.peryman@kotakureo.school.nz

This project has been reviewed and approved by the University of Canterbury/ Te Whare Wānanga o Waitaha Human Ethics Committee. Participants should address any complaints to The Deputy Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz). Reference code HEC 2020/44

Please complete the attached consent form and return it electronically to caelyn.eades@pg.canterbury.ac.nz, or as a hard-copy to Paul Peryman or Caelyn Eades at an arranged interview time.

Ngā mihi

Caelyn Eades

School of Psychology, Speech and Hearing
caelyn.eades@pg.canterbury.ac.nz
Date: 09/11/2020
HEC Ref: HEC 2020/44

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Study Title: Exploring the experiences of parents/caregivers with newborn hearing screening and subsequent support services

Consent Form for Participants

- ☐ I have been given a full explanation of this project and have had the opportunity to ask questions regarding this research.
- ☐ I understand what is required of me in this study.
- ☐ I understand that my participation in the study is voluntary and I may withdraw permission at any time without penalty. Withdrawal of participation will also include the withdrawal and destruction of any information I have provided, and that with the commencement of data analysis (1st of December 2020), this may become more difficult.
- ☐ I consent to the interview being audio-recorded.
- ☐ I understand that data collected in this study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.
- ☐ I understand that a thesis is a public document and will be available through the University of Canterbury library in hard copy and through an online thesis repository.
- ☐ In addition, the findings may be written up and submitted for publication in a peer-reviewed scholarly journal or presented orally or via poster at a professional conference. Any information provided that could identify a

person or organisation will be changed to a general non-identifying description (e.g. "child" or "organisation") before data is analysed.

- ☐ I understand that I can contact the researcher, Caelyn Eades (caelyn.eades@pg.canterbury.ac.nz) or supervisors, Dean Sutherland (dean.sutherland@canterbury.ac.nz) and Paul Peryman (paul.peryman@kotakureo.school.nz) for further information.
- ☐ [optional] I would like to receive a summary of the results of this study. I can also contact the researcher at any time to further discuss the results of the study.

By signing below, I give consent to participate in this research project.

Name: _____ Date:_____