

# **Factors Influencing Caregiver Decision Making to Change the Communication Method of their Child with Hearing Loss**

Nerina A. Scarinci<sup>1,2</sup>, Monica J. Gehrke<sup>1</sup>, Teresa Y.C. Ching<sup>2,3</sup>, Vivienne Marnane<sup>2,3</sup>, & Laura Button<sup>2,3</sup>

<sup>1</sup>School of Health & Rehabilitation Sciences, The University of Queensland, St Lucia, Australia

<sup>2</sup>The HEARing Cooperative Research Centre, Melbourne, Australia

<sup>3</sup>National Acoustic Laboratories, Australia

## **Address for Correspondence:**

Dr Nerina Scarinci  
School of Health & Rehabilitation Sciences,  
The University of Queensland  
St Lucia, Queensland, 4072  
n.scarinci@uq.edu.au

**Funding source:** The authors acknowledge the financial support of the HEARing CRC, established under the Cooperative Research Centers (CRC) Programme. The CRC Programme supports industry led end-user driven research collaborations to address the major challenges facing Australia

## **Abbreviations:**

LOCHI – Longitudinal Outcomes of Children with Hearing Impairment

**Abstract Word Count:** 156

**Body Word Count:** 7699

### **Abstract**

The communication journey of a child with hearing loss is often a complex, interwoven process in which the child's use of language or method of communication may change numerous times. As there has been limited research exploring the caregiver decision making process behind making such changes, this qualitative descriptive study aimed to explore the factors which influence the caregiver decision making process to change the communication method of their child with hearing loss. Individual semi-structured in-depth interviews were conducted with seven caregivers of children with hearing loss in Australia. Thematic analysis revealed five key themes which influenced caregiver decisions regarding changes to their child's method of communication, including: (1) family characteristics; (2) family access to information; (3) family strengths; (4) family beliefs; and (5) family-centered practice. The overall finding that the family unit is at the core of decision-making has important clinical implications regarding early intervention professionals' provision of family-centered services when working with the families of children with hearing loss.

**Keywords:** children, hearing loss, communication method, language, choice, decision-making, family-centered care, qualitative.

## **Factors Influencing Caregiver Decision Making to Change the Communication Method of their Child with Hearing Loss**

Caregivers of children with hearing loss are required to make several important decisions about their child's early intervention not only after the diagnosis of the hearing loss, but throughout their child's entire early intervention process. These decisions typically center around their child's use of hearing devices, including hearing aids or cochlear implants (Matthijs et al., 2012), and their child's method or mode of communication, specifically, the decision to implement oral language, sign language, or a combination of both oral and sign language (Decker, Vallotton, & Johnson, 2012). It is this decision regarding the child's method of communication which Marschark (2007) describes as one of the most important issues that families of children with hearing loss must address. Importantly however, the method or mode used by caregivers to communicate with their children can change, depending on a variety of factors, resulting in what Wheeler, Archbold, Hardie and Watson (2009) term a 'communication journey'. Early intervention professionals, including speech-language pathologists, audiologists, and teachers of the Deaf, play a significant role in supporting families to make decisions throughout each child's communication journey.

In early intervention the term "family" is used to describe any individual who plays a significant role in someone's life, who could be related in any way, such as a continuing biological, legal, or emotional relationship (Family Voices, 2008; Kilmer, Cook, & Palamaro Munsell, 2010). The involvement of family in early intervention is facilitated through family-centered care, a model of care which "involves the family through the continuum of care from the design and development of healthcare services to involvement in the provision of individualized healthcare for their family member" (McKean, Phillips, & Thompson, 2012, p. 236). In 1996, Allen and Petr analyzed definitions of family-centered practice across the professions of social work, health, and education, and proposed six key elements, including

family as the unit of attention, family choice, family strengths, family-professional relationship, family needs, and individualized services. More recently, Epley, Summers, and Turnbull (2010) examined whether these elements of family-centered care had changed in the literature, and found similar definitions to Allen and Petr (1996), proposing only that given “family needs” and “individualized services” overlapped considerably, five elements adequately described family-centered practice: family as the unit of attention, family choice, family strengths, family-professional relationships, and individualized family services. Early intervention professionals must consider each of these elements when providing family-centered services. In relation to children with hearing loss, family-centered practice involves early intervention professionals being flexible and holistic and recognizing each family’s strengths, whilst supporting the child’s development by engaging the family in services, and promoting family well-being, communicative interactions within the family, and the family’s self-efficacy (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). Research has shown that the provision of family-centered practice results in increased caregiver satisfaction, as caregivers value being involved in their child’s assessment, goal setting, and intervention (Crais, Roy, & Free, 2006).

Specifically in relation to hearing loss, Moeller et al. (2013) identified ten evidence-based principles to guide the implementation of family-centered intervention when working with children with hearing loss and their families. Of particular relevance to the support that families need when making decisions about their child’s method of communication are the principles: Family/Provider Partnerships and Informed Choice and Decision-Making (Moeller et al., 2013). The principle of “Family/Provider Partnerships” emphasizes the importance of early intervention professionals implementing flexible and individualized processes that respond to the changing needs, preferences and learning styles of families. This means that at various points throughout a child’s communication journey, it is important

that early intervention professionals continually assess and evaluate a family's needs and preferences, including how each family wants to communicate with their child. In order to maximize performance and learning outcomes, this information should be provided to families via a means that suits their learning style (Cassidy, 2004). The family-centered principle "Informed Choice and Decision-Making" requires that early intervention professionals recognize the ongoing nature of decision-making and acknowledge that such a decision about a child's method of communication is not a one-off, absolute decision, but rather a series of continual choices that parents make to either persist with an existing method of communication, or to introduce another method.

In recognition of the importance of understanding the process behind caregiver decision-making for children with hearing loss, there is a body of literature which has explored factors that influence caregiver decision-making in the period following the initial diagnosis of hearing loss (Chang, 2017; Crowe, Fordham, McLeod, & Ching, 2014; Crowe, McLeod, McKinnon, & Ching, 2014; Decker et al., 2012; Eleweke & Rodda, 2000; Li, Bain, & Steinberg, 2003; Li, Bain, & Steinberg, 2004; Scarinci, Erbas, Moore, Ching, & Marnane, 2017). To understand the reasoning behind caregiver decisions to *change* a child's method of communication, it is important to first understand the initial decision-making process. Some of the most frequently discussed influences when initially choosing a child's method of communication for both hearing parents and parents who are Deaf have included the individual characteristics of the child (Crowe, Fordham, et al., 2014; Li et al., 2003; Li et al., 2004), the influence of professionals, including the information they provide (Eleweke & Rodda, 2000; Scarinci et al., 2017), and their attitudes toward hearing loss and interventions (Eleweke & Rodda, 2000; Young, 2002), as well as caregivers' knowledge and beliefs (Chang, 2017; Decker et al., 2012; Li et al., 2003).

In several studies, the individual characteristics of each child have been reported to influence hearing and deaf caregivers' decision-making in the initial period following diagnosis, including the age of the child at diagnosis and the subsequent amount of time available for hearing caregivers to make decisions (Scarinci et al., 2017; Young & Tattersall, 2007), the extent of a child's hearing loss (Li et al., 2003, 2004), the success of amplification devices (Crowe, Fordham, et al., 2014; Crowe, McLeod, et al., 2014), and the age that the child received the hearing devices (Watson, Archbold, & Nikolopoulos, 2006). In addition, as most caregivers of children with hearing loss do not have hearing loss themselves, caregivers' initial choice of communication method is largely influenced by the information accessed after the diagnosis of hearing loss (Christiansen & Leigh, 2004; Eleweke & Rodda, 2000; Scarinci et al., 2017; Young, 2002). As most hearing and Deaf caregivers receive advice on choosing their child's method of communication from early intervention professionals (Chang, 2017; Crowe, McLeod, et al., 2014; Scarinci et al., 2017), the nature and scope of the information is influenced by the attitudes and views of the professionals themselves (Eleweke & Rodda, 2000; Young, 2002). However, both hearing and Deaf caregivers also receive information from a range of other sources, including family and friends, as well as caregivers' own independent research, online sources, and experiences with other children and adults with hearing loss (Chang, 2017; Christiansen & Leigh, 2004; Crowe, Fordham, et al., 2014; Porter & Edirippulige, 2007; Scarinci et al., 2017).

Although there is limited research describing the experiences of parents from culturally and linguistically diverse backgrounds, the language of the parents themselves, including whether one or both of the parents are Deaf, or speak a language other than English, are other family factors which may influence the initial decisions of caregivers (Chang, 2017; Guiberson, 2013; Hyde, Punch & Komesaroff, 2010). For example, in two different qualitative interview studies exploring the cochlear implant decision-making

process, both Chang (2017) and Hyde et al. (2010) found that parent participants who were Deaf reflected on the influence of the Deaf community and their own group identity and associated values and beliefs on the decision-making process to get a cochlear implant for their child. In another study exploring the influence of bilingualism on decision-making processes for children with hearing loss, Guiberson (2013) described the impact of close family members on the decision making process for Spanish parents of children with hearing loss, and the role of health professionals, including the reported limited access to information about the range of options for their child. This study also showed that it was not the child's degree of hearing loss, age, or cochlear implant status that was associated with the child's mode of communication and bilingual status, but rather, the bilingual status of the parents, their beliefs about bilingualism, and the encouragement they received to raise their child as bilingual (Guiberson, 2013). While it is important to understand these factors that influence the initial decisions of caregivers, in order to be able to provide the optimal level of support, early intervention professionals must also understand the factors that influence caregiver decisions to change their child's method of communication.

Several studies have explored the factors that influence caregivers to change their child's method of communication after receiving cochlear implants (Hyde & Punch, 2011; Watson et al., 2006; Watson, Hardie, Archbold, & Wheeler, 2008; Wheeler et al., 2009). Unsurprisingly, a child's chosen method of communication is largely influenced by the child's hearing abilities, which can change, particularly when a child has a cochlear implant (Wheeler et al., 2009). In a study by Watson et al. (2008), 142 caregivers completed a questionnaire asking them to respond to statements about whether their child's method of communication had changed, and why, following cochlear implantation. The questionnaires elicited both qualitative and quantitative data from caregivers. In the vast majority of cases, cochlear implantation resulted in a shift away from sign towards oral communication. The

results of Watson et al. (2008) indicated that changes to oral communication occurred because of the child's increased audition, and also because of the child's communication preferences. The most effective method of communication, and one that would be of the most use in the future, were factors that were also found to influence caregivers' decisions. A limitation of Watson et al. (2008) was that caregivers rated their child's level of communicative or linguistic ability on a five point scale, and no further detail was provided. Additionally, caregiver responses explaining why they changed communication method were not in response to open-ended questions, but in response to a finite number of closed-response statements.

To address these limitations, twelve families who participated in the Watson et al. (2008) study were selected to participate in a subsequent qualitative study (Wheeler et al., 2009). In this study, caregivers were interviewed and provided with the opportunity to discuss in more detail, and in their own words, their child's language level and communication method pre- and post- cochlear implantation, and how the caregivers made these decisions. Caregivers' interview responses were then compared to their individual questionnaire results. In addition, Wheeler et al. (2009) separately interviewed children with hearing loss and teachers of the Deaf to obtain their views on how the child communicated, what the child's communication preferences were, and what the views of the teachers of the Deaf were on cochlear implantation and communication choice. Through more detailed exploration of individual families, Wheeler et al. (2009) confirmed the findings of the earlier study that caregivers generally choose to increase use of oral communication following cochlear implantation (Watson et al., 2008). While Wheeler et al. (2009) found that cochlear implantation resulted in hearing caregivers focusing more on oral communication, the change was largely reported to be gradual and child-led. While Wheeler et al. (2009) provided an in-depth look at factors influencing caregivers' decisions to change their child's method of



communication, the study only included the families of profoundly Deaf children who had received cochlear implants, and thus more exploration of factors pertaining to a broader population of children with hearing loss is required, including children who use hearing aids.

The existing body of literature on factors that influence caregiver decision-making regarding the communication method of their children with hearing loss is limited for several reasons. While there is a growing body of literature providing insight into the factors that influence caregiver decisions in the initial period following the diagnosis of a child with hearing loss, the factors that influence caregivers' later decisions to *change* communication method have largely not been investigated. The research that has explored changes to communication method has focused on changes following cochlear implantation.

Investigation in this area needs to extend beyond children who have received a cochlear implant to encompass children with varying degrees of hearing loss and who use other forms of hearing technology such as hearing aids. For early intervention professionals to be able to continually provide the best possible family-centered services to the caregivers of children with hearing loss, there needs to be an increased understanding of why caregivers change communication method throughout their child's communication journey. Thus, the current study aimed to explore factors which influence caregivers to change the communication method of their child with hearing loss.

## **Methods**

### ***Research Approach***

A qualitative descriptive design was utilized in this study to address the aim to explore factors which influence caregivers to change the communication method of their child with hearing loss. Qualitative description is an interpretive methodology which uses a naturalistic approach for obtaining a comprehensive summary of events using the everyday terms of participants and thus produces findings closer to the data provided by participants

(Sandelowski, 2000, 2010). In the context of the current study, the use of qualitative description allowed for the naturalistic exploration of caregivers experiences in changing the communication method of their child with hearing loss, an approach which was especially amenable to obtaining a straight descriptive summary of this experience in a way best fit the voices of participants (Sandelowski, 2000, 2010).

The participants interviewed in this study were the caregivers of children who participated in the Longitudinal Outcomes of Children with Hearing Loss (LOCHI) study (Ching, Leigh, & Dillon, 2013). The LOCHI study is a prospective population-based cohort study exploring the outcomes of Australian children with permanent hearing loss. The LOCHI study includes 451 children from New South Wales, Victoria, and Queensland who were recruited between 2005 and 2007. To be eligible for participation in the LOCHI study, children had to be born between 2002 and 2007 and have received audiological intervention at Australian Hearing Centers by three years of age. Australian Hearing is Australia's leading hearing specialist, and largest provider of Government funded hearing services in the nation (Australian Hearing, 2014).

### ***Sampling***

A total of 40 families participating in the LOCHI study participated in a qualitative sub-study. These families were recruited based on the following inclusion criteria: child had a nonverbal cognitive ability score of  $\geq 85$ , and no additional disabilities. All eligible LOCHI families were sent a letter of invitation, information sheet, and expression of interest form with a reply paid envelope. Those families who returned the expression of interest form were contacted by researchers to provide further details about the study and obtain consent. Purposeful sampling of these 40 consenting LOCHI participants was used to recruit families for the purposes of the current study. Purposeful sampling is frequently used in qualitative research as it aims to identify and select cases which are of specific relevance to the topic of

interest (Palinkas et al., 2015). A specific design of purposive sampling, which Palinkas et al. (2015) labels “Criterion-i Sampling”, was used in this study. This particular type of purposeful sampling aims to identify and select cases that meet a predetermined criterion of importance (Palinkas et al., 2015).. Of the 40 LOCHI families participating in the qualitative sub-study, seven caregivers met the specific criterion of importance for the current study, with their child with hearing loss changing their method of communication at least once since the diagnosis of hearing loss.

### ***Participants***

The seven caregivers in the current study consisted of five mothers and two fathers, with one father identifying himself as a single parent. Of the seven families, six lived in Victoria, and one in New South Wales. All seven caregivers were hearing and caregivers and their children came from an English-speaking background. A variety of services were accessed by families, including medical, audiological, and speech pathology services. The caregivers reported having accessed a variety of hearing intervention services, including center-based, home-based, and school-based services for their children. Various early intervention programs (e.g. bilingual services and oral approaches) were accessed by families, using a variety of communication methods and/or languages, including Auslan, finger spelling, lip reading, and oral communication. For a summary of participant demographic information, see Table 1.

[Insert Table 1 about here]

### ***Procedure***

The current study was approved by the Behavioral and Social Sciences Ethical Review Committee of [The University] and the Human Research Committee of [Organization]. Participant consent was obtained before commencing data collection. Individual in-depth, semi-structured interviews were conducted with caregivers to explore the

perceptions and experiences of caregivers of children with hearing loss. In-depth interviews enable researchers to achieve the same level of knowledge and understanding as the participants, and to articulate a multitude of views and perspectives of a topic (Johnson, 2001). A series of interview questions were utilized to interview caregivers on their experiences with early intervention for their child with hearing loss, and on the interactions between themselves, their child with hearing loss and their family. To ensure thoroughness and consistency across interviews, a guide of interview questions was developed and used by the interviewers. This interview guide consisted of open ended questions relating to the families' communication journey and factors which influenced parental decision making and involvement in early intervention. Each interview was based on the interview guide, with adaptations to the wording and ordering of questions based on the flow and nature of information provided by each participant. The interviews were conducted by two speech pathologists with experience in qualitative interviewing. Some of the families were known to the interviewers due to their role in conducting speech and language assessments for the LOCHI study, thus families were reassured that any comments made during the interviews would not affect their relationship with the LOCHI study or involvement with other early intervention services. Further, the use of a common topic guide ensured that this level of familiarity did not influence the conduct of the interviews. The interviews occurred predominately in the families' homes, with some completed in a place of convenience to the families, such as the child's school. Audio-recording was used in all seven interviews, with interviews ranging in length from 54 to 75 minutes ( $M = 60.43$  min).

### *Analysis*

The interview recordings were transcribed verbatim by a professional transcription service. The transcripts were then de-identified and thematic analysis was used to analyze caregivers' responses to interview questions. An inductive approach to data analysis was

adopted, meaning that coding was completed in a data-driven manner, without the use of a pre-existing theoretical approach or coding framework (Braun & Clarke, 2006). Thematic analysis followed Braun and Clarke's (2006) guidelines, with analysis consisting of six distinct phases. Firstly, the second author familiarized herself with each of the seven interview transcripts. An initial set of codes was then created from a second viewing of the transcripts. The quoted responses of caregivers were re-read and re-coded as appropriate. The codes were then reviewed by the first author, with amendments made until consensus was reached. The codes were then collated into potential themes and sub-themes by the first two authors who continued to analyze the themes and sub-themes until the meaning, content, and boundaries of each were apparent. Clear definitions and names of each theme were established, as well as the overall picture created by the themes. Lastly, a report of the analysis was produced, with the most suitable examples of data having been chosen and analyzed with regard to the research question. Braun and Clarke's (2006) six phases of thematic analysis were applied flexibly, with movement back and forth between phases occurring during the process.

### ***Rigor***

Data analysis findings were reviewed at several points during the analysis process by the first two authors, with regular meetings held during which the codes, themes and sub-themes were discussed, reorganized, and redefined until consensus was reached.

### **Results**

Analysis of the qualitative interviews revealed that over time, a multitude of factors influence the caregiver decision making process regarding changes to the communication method of their child with hearing loss. An overarching theme of "The family unit is at the core of decision-making" was found to be common across the five themes identified, which individually and cumulatively provide insight into the reasoning behind caregiver decisions

to alter their child's communication method. The five themes influencing caregiver decisions regarding changes to a child's method of communication were: (1) family characteristics; (2) family access to information; (3) family strengths; (4) family beliefs; and (5) family-centered practice. Each of these themes and their corresponding sub-themes are discussed below, with example participant quotes provided in Tables 2-5.

The overarching theme of the family unit being at the core of decision-making was found to be an important link across the five themes. An abundance of caregiver descriptions of their family characteristics, the information available to them, and their strengths and beliefs made it apparent that the family unit was at the core of decision-making regarding changes to a child's method of communication. Additionally, caregivers described how the delivery of services that aligned with family-centered practice impacted on their lives, and subsequently on their decisions regarding their child's method of communication and subsequent engagement with services. Reference to the family unit being at the center of decision-making occurred regardless of the nature and severity of the child's hearing loss, the type of device used by the child, the family demographic, the type of communication approach utilized by the family, and the educational background of caregivers.

***Theme 1: Family Characteristics Influence Decisions Regarding Changes to a Child's Method of Communication***

During the interviews, caregivers provided extensive descriptions of their family unit and discussed how these characteristics influenced their decision making during their child's communication journey. Five subthemes were identified as being influential to changes to their child's method of communication: (1) characteristics of the child with hearing loss; (2) the child's relationship with hearing and communication interventions; (3) caregiver characteristics; (4) characteristics of the siblings of children with hearing loss; and (5) characteristics of the family unit and lifestyle. These subthemes are listed in Table 2, along

with example participant quotes. Interviewees frequently spoke about the characteristics of their child with hearing loss, including how the age of their child at the time of diagnosis and the nature of their child's hearing loss influenced decisions regarding changes to their child's method of communication. One caregiver, for example, stated that because their child was almost three at the time of diagnosis, *"We didn't get much support. Most of the support was for younger children"* (P7).

[Insert Table 2 about here]

Interviewees also discussed their child's relationship with hearing and communication interventions, and how this influenced decisions about changes to the method of communication used by the family. The child's relationship with hearing and communication interventions encompassed several areas, including the child's attitude to signing, the introduction of hearing devices, the child's need for more than one method of communication, and the child being in tune with their own communicative needs. When discussing how their child has use for more than one method of communication, one caregiver stated *"...she backs herself up with it...when she's talking, the pronunciation of the word is not a hundred percent clear yet – so she does the sign in the background...So she just reassures herself"* (P6).

Caregivers also discussed characteristics of themselves, the child's siblings, and the family unit as a whole, providing insight into how characteristics such as caregiver emotions influenced the choices they made on the child's communication journey. When discussing caregiver emotions, one interviewee said *"I was really focused and just kept doing everything that was sort of thrown at us or offered to us. We'd just take on and try everything"* (P2).

***Theme 2: Family Access to Information Influences Decisions Regarding Changes to a Child's Method of Communication***

Caregivers frequently referenced the information that they gained throughout their child's communication journey, and how this influenced their decision-making. Three subthemes were identified which reflected different sources of information which influenced decisions regarding changes to their child's method of communication: (1) caregiver sources; (2) professional sources; and (3) other sources. These subthemes can be found in Table 3 with example participant quotes. Participants provided several examples of how and where they sourced information for themselves, including existing information they used to make decisions, or additional information they researched themselves. Information received from professionals, including information regarding referrals to other services, was a topic that caregivers frequently mentioned. Explicit links were made between information received from professionals and decisions regarding changes to a child's method of communication. For example, one participant stated *"We were told by [organization], um, as soon as she was implanted not to sign. So, when she was planted at two, that was it. No more sign. Prior to that we were just using [sign]"* (P5). Some caregivers spoke highly of the information they received from professionals, while others felt dissatisfied. For example, one participant said:

*I was told by one of the groups that worked with her [Child with hearing loss], I'd say [Agency] ...that the only hope for [Child] was to go to [School] which is a special school and that there was no way she could be mainstreamed. That's what I was told... to be told that when your child's, what, three and a half, four, was pretty, um – yeah, it was pretty sad (P5).*

[Insert Table 3 about here]

Participants also provided several examples of information they accessed through other sources, such as social media or contact with an individual with a hearing loss or a caregiver of a child with a hearing loss. One interviewee stated, *"I tried to find people that have had 'em [cochlear implants], what they think of them"* (P6).



### ***Theme 3: Family Strengths Influence Decisions Regarding Changes to a Child's Method of Communication***

Discussion with caregivers revealed that family strengths influence ongoing decisions regarding changes to a child's method of communication. This theme has four sub-themes: (1) caregiver involvement in early intervention; (2) caregiver strengths; (3) the capability of the family; and (4) family supports available. These subthemes can be found in Table 4 along with example participant quotes.

[Insert Table 4 about here]

One family strength that influenced decisions regarding a child's method of communication was caregiver involvement in the early intervention process. For example, the dedication of caregivers to their children with hearing loss and the sacrifices they were willing to make was discussed by several participants. One caregiver stated, *"I quit my job and wanted to help her as much as I could and learn as much as I could"* (P7).

Through in-depth discussion with participants, a range of caregiver strengths were revealed, including being flexible and changing goals, relying on their own instinct, and advocating for their children. Caregivers often relied on their own instincts when making decisions about changing their child's method of communication, for example: *"There was just something at [Agency] that clicked with me...No other reason"* (P3). Strong links were also made between the capabilities of a family and the family's decisions regarding their child's method of communication, including caregiver competency with their child's devices and caregivers being attuned to and responding appropriately to their child's communication needs. Caregivers also spoke of the ease or difficulty in which they learnt to sign, and how this subsequently impacted on the family's use of sign language during their child's communication journey.

Throughout the interviews, participants discussed several supports and how this influenced decision-making regarding changes to their child's method of communication. Mentioned supports included support from family and friends, support from others in similar situations, and support from adult acquaintances with hearing loss. Links were made between these supports and a child's communication method. For example, one participant (P2) spoke of having a brother who was *“really hands on”* with the child with hearing loss and willing to learn some basic sign language to be able to communicate with his nephew.

***Theme 4: Family Beliefs Influence Decisions Regarding Changes to a Child's Method of Communication***

Participants provided a multitude of examples of how the beliefs of their family impacted on decisions regarding changes to their child's method of communication. This theme has four subthemes: (1) family beliefs on hearing loss and intervention; (2) family beliefs on language, literacy and social skill acquisition; (3) caregivers wanting a “normal” life for their child; and (4) caregivers taking on a “child-centered” perspective. These subthemes can be found in in Table 5 along with example participant quotes.

[Insert Table 5 about here]

During the interviews, participants discussed their beliefs on hearing loss and hearing interventions, specifically including their beliefs on sign language. Several caregivers indicated their support of the use of Auslan (Australian Sign Language). For instance, one caregiver stated, *“I think I would definitely use Auslan in the early days... until you can ascertain what level [of auditory input] they're getting and how well they can communicate that way, I just think that you just really have to use Auslan”* (P2). Conversely, some caregivers felt that sign language was not an option for them, with one caregiver noting *“We had no other choice...It was either that [cochlear implantation] or sign language... you know, people sit on the fence and say, ‘Oh, do I or don't I?’ There wasn't a choice. It was*

*easy*” (P5). Caregivers also discussed their beliefs on special education facilities and indicated that these beliefs influenced the decisions made along their child’s communication journey. For instance, one caregiver said, *“We were less keen to have a teacher of the Deaf because that was a term for a child who was Deaf and needed ... something special and, um, we didn't think she needed that”* (P7). The wide range of beliefs discussed by caregivers also included beliefs on language, literacy, and social skill acquisition. Caregivers’ desire for a “normal” life for their child was another family belief discussed by participants with one interviewee saying, *“Growing up and having that attitude that she's not different is really important”* (P7). During the interviews, caregivers also discussed taking on a “child-centered” perspective, including following their child’s lead, wanting the best for their child, and considering their child’s future. One interviewee suggested that they considered both what was best for their child, and following the child’s lead:

*[Agency] came to talk to us and said, "Look, we use both. Some children will go one way, some will go the other but it's – the child will decide what their best means of communication is. Most will end up using both to some extent.” And that just seems like giving [Child] – to us like we were giving [Child] a better chance that way* (P4).

### ***Theme 5: Family-Centered Practice Influences Caregiver Decisions Regarding Changes to a Child’s Method of Communication***

Caregivers provided an abundance of examples of how family-centered practice influenced their decisions regarding changes to their child’s method of communication. This final theme consists of seven subthemes which were found to influence decisions regarding changes to a child’s method of communication. These subthemes, presented in Table 6, are: (1) ease of access to services and resources; (2) the nature of service delivery; (3) alignment of a service with a family’s goals; (4) services on offer to a family; (5) continuity of care; (6)

families feeling comfortable and supported in the care they receive from an intervention service; and (7) families' confidence in the services received from professionals.

[Insert Table 6 about here]

Caregivers detailed how ease of access to services and resources influenced their decisions to select a service, which impacted on changes to their child's method of communication. One such element was the offer of home visits from a service. For instance, one caregiver said *"At the time, it was probably the Auslan and the home visits. That was probably the two most things that drawn me to – yeah, that they'd come to you"* (P1).

There was also discussion of the nature of service delivery. This included discussion of the provision of individualized intervention, flexible services, and holistic, family-centered approaches to service. One participant said *"She [the teacher at the agency] was really flexible as well and understood that, you know, there's other – there's other pressures and other things in life and sometimes you just can't do everything"* (P5). Many caregivers spoke about the services they received from professionals in high regard, making positive reference to the family-centered nature of the service. Conversely, there were reports of dissatisfaction with services, due to caregiver perceptions that a family-centered approach was not being provided. One caregiver, when comparing two agencies, said *"[Agency 1] were very family orientated and holistic in their approach and offered a lot more services and support. Um, [Agency 2], big bad cross for the [Agency 2] in terms of how they expected children to um to be"* (P5).

The alignment of a service with a family's goals was another influential factor on decision-making. Caregivers discussed choosing a service because Auslan was offered or because a school offered a unit for children with hearing loss. One interviewee stated *"It was clear we had to move to another school and we – we decided in the end to come here. Ah, simply because of the unit [unit for children with hearing loss]"* (P4).

Participants also discussed the services that were offered to their family, such as the opportunity to be a part of groups at a service. One interviewee stated, *“We changed to [Agency] and started going to the two-year-old early intervention group”* (P2), indicating that the services on offer to a family influence the chosen service provider, and therefore the child’s method of communication. Within this subtheme was also discussion of the staff-to-student ratios at a service, with one interviewee noting, *“It was one on one, which was easier...there's not a lot of other people – around at the time. I suppose you had the undivided attention of – of the professionals...”* (P2). Participants also discussed continuity of care as an influential factor throughout their child’s communication journey, including mention of agencies overlapping or being affiliated with schools, not consistently seeing one early interventionist at a service, and collaborative teamwork and communication.

Interviewees frequently discussed the level of comfort and support they felt in the care they received from intervention services, and how this influenced the method of communication chosen for their child. They spoke of feeling comfortable or familiar with services, their child’s comfort/happiness in attending intervention, and feeling supported by early intervention professionals. Participants also spoke of their confidence in the services they received. One participant stated *“We, ah, were keen to go to every session. We didn't miss them. Um, so yeah, we found it very valuable”* (P7).

### **Discussion**

This study aimed to explore factors which influenced the caregiver decision making process to change the communication method of their child with hearing loss during their communication journey. By conducting an in-depth exploration of the experiences of seven families of children with hearing loss, participants shared a broad range of perspectives, with the overarching theme of “The family unit is at the core of decision-making” found to be common across the data. The findings of the current study echoed the five elements of

family-centered practice proposed by Epley et al. (2010), with several of these family-centered elements discussed by families in the current study, including family strengths, family choice, family-professional relationships, and individualized family services.

It is vital that early intervention professionals understand the family unit that they are working with in order to provide the best possible services to each family. Several interviewees spoke of the characteristics of their family and how these characteristics influenced their decision-making. Unsurprisingly, characteristics of the child with hearing loss were found to be an influential factor in caregiver decision-making about their child's method of communication, including the child's age at diagnosis, and the nature of the hearing loss. Li et al. (2003) found that the nature of a child's hearing loss was the factor with the largest impact on caregiver decision-making regarding their child's method of communication. Several caregivers in the present study also discussed their child's co-occurring conditions and how these impacted on their choices surrounding their child's method of communication. It has been previously noted in the literature that concerns and actions regarding a child's hearing loss take a "back seat" when a child has disabilities additional to hearing loss (Russ et al., 2004, p.356), and therefore it is not surprising that the participants in the current study discussed the influence of their child's global development in decision-making.

Importantly, however, caregiver discussion of the influence of child characteristics went beyond basic characteristics to include how the child's relationship with hearing and communication interventions influenced the family's chosen method of communication. The introduction of hearing devices, such as cochlear implants, was also found to influence caregivers' decisions regarding their child's communication method. Other researchers have highlighted the role that cochlear implants play in driving decisions to focus on oral language (Watson et al., 2006; Watson et al., 2008; & Wheeler et al., 2009), with Watson et al. (2008)

specifically finding that the majority of children change their communication method after receiving cochlear implantants, and that this change is mostly toward increased use of oral language.

Interestingly, several caregivers in the current study detailed how their child used two or more methods of communication at one point in time. Caregivers described how certain environments or situations influenced whether their child was more inclined to sign, such as around water, or across long distances. Others described how their child would use sign in conjunction with oral communication to maximize their communication skills. It therefore appears that caregivers do not always feel the need to restrict their child's communication method or use of language to just one option. Caregivers have previously reported that they value the use of sign language alongside oral language (Watson et al., 2008), which, alongside the findings of the current study, suggests that choices regarding a child's communication method or language should not be viewed as fixed or a lifelong commitment, by either caregivers or early intervention professionals.

In addition to discussing their child's characteristics and relationship with hearing and communication interventions, caregivers in the current study spoke about how they took a child-centered perspective when making decisions about their child's use of language or method of communication, including following their child's lead. Some caregivers reported embracing sign language more as their child got older because of their child's interest in learning to sign. Caregivers have previously reported that changes in their child's communication method were led by their child (Watson et al., 2008), which aligns with both the United Nations Convention on the Rights of Persons with Disabilities (Article 7, 3) (United Nations General Assembly, 2007) and the United Nations Convention on the Rights of the Child (Part I, Article 12, 1) (United Nations General Assembly, 1989). As both of these conventions stipulate that it is within the rights of every child to freely express their views on

the matters that relate to them, and have their views taken seriously, it is important that caregivers and professionals alike consider a child's preferences regarding the method of communication used.

The results of the current study also suggest that family strengths influence caregiver's decisions regarding their child's method of communication, which is consistent with the "family strengths" element of family-centered practice described by Epley et al. (2010, p. 273). Several strengths specific to caregivers were discussed, such as relying on instinct and advocating for their children, which have both previously been documented in the literature (Erbasi, Scarinci, Hickson, & Ching, 2016; Wheeler et al., 2009). The capabilities of families were also found to influence caregiver decision-making in the current study. Several family members were reported to have found it difficult to learn to sign, which is not a new finding (Hyde & Punch, 2011) and can be attributed in part to the limited opportunities available for practising with others (Napier, Leigh, & Nann, 2007). Regardless of what the family strength may be, Rouse (2012) stresses the importance of acknowledging a family's unique strengths to form a partnership with families and build on these strengths when providing family-centered practice. It is essential that family strengths are not only considered but incorporated by early intervention professionals into intervention plans (Allen & Petr, 1996).

The current study found that family beliefs on hearing loss and intervention also influence decisions regarding changes to a child's method of communication. This finding relates to the notion that family choice is a key aspect of family-centered practice, identified by both Epley et al. (2010) and Moeller et al. (2013). For example, caregiver beliefs on sign language and special education services influenced the choices made along the child's communication journey. Caregivers who believe that hearing loss needs to be corrected have been shown to prefer oral communication (Li et al., 2003), while caregivers who choose to



implement sign language have beliefs that align more so with a sociocultural approach to hearing loss (Decker et al., 2012), which focuses on Deaf culture (Reagan, 1995). Caregiver values and beliefs on language, literacy and social skill acquisition were also identified as influential factors. Caregivers explicitly identified that their concerns about their child's language development influenced their decisions to change intervention agencies and communication approaches, which reinforces the previously reported notion that caregivers always have their child's language development in mind (Erbasi et al., 2016). Caregivers in the current study also frequently discussed how their desire for their child to have a "normal" life influenced their decisions, which is a factor that Crowe, Fordham, et al. (2014) have previously reported.

Moving beyond discussion of family beliefs, caregivers in the current study reported that their decisions were influenced by the information that they received from professionals. These caregiver reports are again encompassed by the family-centered element or principle of family choice (Epley et al., 2010; Moeller et al., 2013), and indicate that informed choice plays a large role in caregiver decisions regarding their child's method of communication throughout their child's communication journey. It is to be expected that caregiver decisions regarding changes to their child's communication method are influenced by the information that they receive from professionals (Decker et al., 2012, Li et al., 2003; Scarinci et al., 2017), which stresses how important it is for caregivers to have access to unbiased and accurate information in order to make informed decisions in the areas of service delivery and intervention (Allen & Petr, 1996; Eleweke & Rodda, 2000; Epley et al., 2010; Scarinci et al., 2017). While in the existing body of literature it is largely assumed that the method of communication used by a child at a particular point in time is taken as a constant (Watson et al., 2008), the results of the current study indicate that families require information at various

stages throughout their child's communication journey to continually make informed decisions regarding their child's method of communication.

In addition to accessing information through professionals, caregivers in the study reported sourcing their own information, including conducting their own research, on the internet and elsewhere. It has previously been reported that caregivers actively and independently research options for themselves regarding their child's communication (Erbasi et al., 2016), which is expected given that the internet results in greater public access to information as well as an increased desire to learn health care information (McCray, 2005). The appeal of using the internet to access health information is that it is less of a one-way process of receiving information, and more interactive (Cline & Haynes, 2001; Porter & Edirippulige, 2007). Caregivers in the current study also named social media as a source of information, including parent forums, which is unsurprising given that people use health-related social media to increase their knowledge and social support, and to exchange advice (Antheunis, Tates, & Nieboer, 2013). Social media is defined as internet-based applications that "allow the creation and exchange of user generated content" (Kaplan & Haenlein, 2010, p.61). Alternate sources of information were also identified by caregivers as being influential to their decision-making processes, including information from other caregivers of children with hearing loss, and information from hearing impaired adults. Meetings between caregivers and other adults and caregivers with experience with cochlear implants have previously been reported as common occurrences (Christiansen & Leigh, 2004).

Several families in the current study specifically discussed how comfortable and supported they felt in the care that they received from an intervention service, as well as their confidence in the services that they received, which falls within the "family-professional relationship" element of family-centered practice (Epley et al., 2010, p. 273). Many caregivers spoke about the services they received from professionals throughout their child's

communication journey in high regard. While parent satisfaction with early intervention professionals at the time of initial diagnosis has previously been reported (Scarinci et al., 2017), the results of the current study indicate that caregivers' appreciation for support and information continues beyond the initial period of diagnosis, throughout the child's communication journey. Some caregivers in the current study reported dissatisfaction with services, including not understanding the reasoning behind delivery of certain services and interventions, and disagreeing with the expectations that were placed on their children. These reports of dissatisfaction with the provision of services, in conjunction with previous reports of dissatisfaction (for example in Scarinci et al., 2017), indicate the need for early intervention professionals to be aware that family-centered services are desired by families. Family-centered services should consider the needs of each family, including the need for families to be involved in goal setting, which is considered a fundamental component of pediatric rehabilitation (Brewer, Pollock, & Wright, 2014).

The current study found that the nature of service delivery, including the provision of individualized, flexible and family-centered services, influences caregiver decision-making. This finding aligns with the "individualized family services" element of family-centered practice (Epley et al., 2010, p. 273), and the evidence-based principle "Family/Provider Partnerships" identified by Moeller et al. (2013), which stipulates that early intervention professionals should implement flexible and individualized processes that respond to the changing needs, preferences and learning styles of families. Therefore, the results of the current study, in conjunction with the literature, stress the importance of early intervention professionals providing individualized support for caregivers when making decisions about their child's communication along their journey.

Overall, the results suggest that it is not one single factor influencing caregiver decisions to change their child's method of communication, but rather, an interplay of factors

over time. As the needs of each family change throughout the child's communication journey, families require individualized support and information from professionals at various stages throughout the early intervention process. To achieve the best outcomes for families, decision-making must be viewed as an on-going process by professionals, so that the changing needs and preferences of families over time are met with individualized and family-centered services and support.

### ***Strengths, Limitations and Future Research***

A strength of the current study was its design, as asking families to reflect in qualitative in-depth interviews on their entire communication journey allowed for deeper insights into caregivers' decision-making processes across the span of several years. The resulting breadth of data obtained provides a valuable summary of the diverse and varied experiences of parents of children with hearing loss as they work through the process of decision-making. However, the information obtained from caregivers on the choices they made regarding their child's communication method could not necessarily be accurately matched to the child's age or stage of development. Furthermore, retrospective discussion of a child's communication journey could have potentially led to inaccurate recall of details by caregivers. Caregivers' memories of the events they experienced and decisions they made may have been influenced by the outcomes and success of their experiences and decisions, resulting in recollection bias. Therefore, future research expanding beyond retrospective data collection is required to obtain a more detailed understanding on the factors influencing caregiver decision-making at various stages of a child's growth and development. A larger scale prospective study exploring factors that influence caregiver decisions to change a child's method of communication would reduce the impact of recollection bias associated with retrospective studies. Additionally, the participants who volunteered to participate in the current study appear to be caregivers who are very involved in their child's early intervention. This could

be considered a strength as it allowed for a detailed account of factors that influence caregivers to change their child's method of communication. However, the findings of the current study may not be applicable to all caregivers and families. In addition, as all families in the current study were from English speaking backgrounds and were all hearing parents, and thus the influence of multilingualism and/or Deaf culture on caregiver decision-making could not be explored, future research including children from a wider variety of cultural backgrounds is required to obtain data that are more representative of the broader multicultural and multilingual society.

### ***Conclusion***

Caregiver decisions to change their child's method of communication throughout their child's communication journey were influenced by the characteristics, strengths and beliefs of each family, each family's access to information, and the provision of family-centered services. Although there is generally not one factor that parents identify as the reason behind a decision to change their child's method of communication, but rather an interplay of factors over time, one overarching theme was found. At the core of caregiver decisions to change their child's method of communication is the family unit. The findings of this study have implications for early intervention professionals in supporting families to make decisions throughout their child's entire communication journey, not just in the initial decision-making period following diagnosis of hearing loss. While the findings of this study offer a deeper understanding of the factors that influence caregivers to change the method of communication of their child with hearing loss, further research on the subject is warranted for early intervention professionals to provide supports that are, in the words of one caregiver, "nothing but the best" (P3).

## Declaration of Interest Statement

**Financial disclosure:** The authors have no financial relationships relevant to this article to disclose.

**Conflict of interest:** The authors have no conflicts of interest relevant to this article to disclose.

## References

- Allen, R. I., & Petr, C. G. (1996). Toward developing standards and measurements for family-centered practice in family support programs. In G. H. S. Singer, L. E. Powers, & A. L. Olson (Eds.), *Redefining family support* (pp. 57–84). Baltimore: Paul H. Brookes Publishing Co.
- Antheunis, M. L., Tates, K., & Nieboer, T. E. (2013). Patients' and health professionals' use of social media in health care: Motives, barriers and expectations. *Patient Education and Counselling*, *92*(3), 426-431. doi: 10.1016/j.pec.2013.06.020
- Australian Hearing. (2014). *What are the most common causes of hearing loss?* Retrieved from <https://www.hearing.com.au/causes-hearing-loss-australia/>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. doi:10.1191/1478088706qp063oa
- Brewer, K., Pollock, N., & Wright, F. V. (2014). Addressing the challenges of collaborative goal setting with children and their families. *Physical and Occupational Therapy in Pediatrics*, *34*(2), 138-152. doi:10.3109/01942638.2013.794187
- Cassidy, S. (2004). Learning styles: An overview of theories, models, and measures. *Educational Psychology*, *24*(4), 419-444. doi: 10.1080/0144341042000228834
- Chang, P. F. (2017). Breaking the sound barrier: Exploring parents' decision-making process of cochlear implants for their children. *Patient Education and Counselling*, *100*, 1544-1551.
- Ching, T. Y., Leigh, G., & Dillon, H. (2013). Introduction to the longitudinal outcomes of children with hearing loss (LOCHI) study: Background, design, sample characteristics. *International Journal of Audiology*, *52*(2), 4-9. doi:10.3109/14992027.2013.866342

- Christiansen, J. B., & Leigh, I. W. (2004). Children with cochlear implants: Changing parent and Deaf community perspectives. *Archives of Otolaryngology–Head & Neck Surgery, 130*(5), 673-677. doi:10.1001/archotol.130.5.673
- Cline, R. J., & Haynes, K. M. (2001). Consumer health information seeking on the internet: The state of the art. *Health Education Research, 16*(6), 671–92. doi: 10.1093/her/16.6.671
- Crais, E.R., Roy, V.P., & Free, K. (2006). Parents' and professionals' perceptions of the implementation of family-centered practices in child assessments. *American Journal of Speech-Language Pathology, 15*, 365 – 377. doi: 10.1044/1058-0360(2006/034)
- Crowe, K., Fordham, L., McLeod, S., & Ching, T. Y. (2014). "Part of our world": Influences on caregiver decisions about communication choices for children with hearing loss. *Deafness Education International, 16*(2), 61-85. doi:10.1179/1557069X13Y.0000000026
- Crowe, K., McLeod, S., McKinnon, D. H., & Ching, T. Y. (2014). Speech, sign, or multilingualism for children with hearing loss: Quantitative insights into caregivers' decision-making. *Language, Speech, and Hearing Services in Schools, 45*(3), 234-247. doi:10.1044/2014\_LSHSS-12-0106
- Decker, K. B., Vallotton, C. D., & Johnson, H. A. (2012). Caregivers' communication decision for children with hearing loss: Sources of information and influence. *American Annals of the Deaf, 157*(4), 326-339. doi:10.1353/aad.2012.1631
- Eleweke, C. J., & Rodda, M. (2000). Factors contributing to caregivers' selection of a communication mode to use with their Deaf children. *American Annals of the Deaf, 145*(4), 375-383. doi:10.1353/aad.2012.0087



- Epley, P., Summers, J. A., & Turnbull, A. (2010) Characteristics and trends in family-centered conceptualizations. *Journal of Family Social Work, 13*(3), 269-285. doi: 10.1080/10522150903514017
- Erbasi, E., Scarinci, N., Hickson, L., & Ching, T. Y. (2016). Parental involvement in the care and intervention of children with hearing loss. *International Journal of Audiology, 1*-12. doi:10.1080/14992027.2016.1220679
- Family Voices. (2008). *Family-centered care self-assessment tool: Provider tool*. Retrieved from: [http://www.familyvoices.org/admin/miscdocs/files/fcca\\_ProviderTool.pdf](http://www.familyvoices.org/admin/miscdocs/files/fcca_ProviderTool.pdf)
- Guiberson, M. (2013). Survey of Spanish parents of children who are deaf or hard of hearing: Decision-making factors associated with communication modality and bilingualism. *American Journal of Audiology, 22*, 105-119.
- Hyde, M., & Punch, R. (2011). The modes of communication used by children with cochlear implants and role of sign in their lives. *American Annals of the Deaf, 155*(5), 535-549. doi:10.1353/aad.2011.0006
- Hyde, M., Punch, R., & Komesaroff, L. (2010). Coming to a decision about cochlear implantation: Parents making choices for their deaf children. *Journal of Deaf Studies and Deaf Education, 15*(2), 162-178.
- Johnson, J. M. (2001). *Handbook of interview research* [SAGE Publications version]. doi:10.4135/9781412973588
- Kaplan, A. M., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of Social Media. *Business Horizons, 53*(1), 59-68. doi: 10.1016/j.bushor.2009.09.003
- Kilmer, R. P., Cook, J. R., & Palamaro Munsell, E. (2010). Moving from principles to practice: Recommended policy changes to promote family-centered care. *American Journal of Community Psychology, 46*, 332–341. doi:10.1007/s10464-010-9350-9

- Li, Y., Bain, L., & Steinberg, A. G. (2003). Parental decision-making and the choice of communication modality for the child who is Deaf. *Archives of Pediatrics and Adolescent Medicine*, *157*(2), 162-168. doi:10.1001/archpedi.157.2.162
- Li, Y., Bain, L., & Steinberg, A. G. (2004). Parental decision-making in considering cochlear implant technology for a deaf child. *International Journal of Pediatric Otorhinolaryngology*, *68*, 1027-1038.
- Marschark, M. (2007). *Raising and educating a Deaf child*. New York: Oxford University Press.
- Matthijs, L., Loots, G., Mouvet, K., Van Herreweghe, M., Hardonk, S., Van Hove, G., . . . Leigh, G. (2012). First information caregivers receive after UNHS detection of their baby's hearing loss. *Journal of Deaf Studies and Deaf Education*, *17*, 387-401. doi: 10.1093/Deafed/ens020
- McCray, A.T. (2005). Promoting health literacy. *Journal of the American Medical Informatics Association*, *12*(2), 152-163. doi: 10.1197/jamia.m1687
- McKean, K., Phillips, B., & Thompson, A. (2012). A family-centered model of care in pediatric speech-language pathology. *International Journal of Speech-Language Pathology*, *14*(3), 235-246. doi: 10.3109/17549507.2011.604792
- Moeller, M. P., Carr, G., Seaver, L., Stredler-Brown, A., & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are Deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education*, *18*(4), 429-445. doi:10.1093/Deafed/ent034
- Napier, J., Leigh, G., & Nann, S. (2007). Teaching sign language to hearing parents of deaf children: An action research process. *Deafness and Education International*, *9*(2), 83-100. doi:10.1002/dei.214

- Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, 42(5), 533-544. doi: 10.1007/s10488-013-0528-y
- Porter, A. & Edirippulige, S. (2007). Parents of deaf children seeking hearing loss-related information on the internet: The Australian experience. *Journal of Deaf Studies and Deaf Education*, 12(4), 518-529.
- Reagan, T. (1995). A sociocultural understanding of Deafness: American Sign Language and the culture of Deaf people. *International Journal of Intercultural Relations*, 19(2), 239-251. doi:10.1016/0147-1767(95)00007-x
- Rouse, L. (2012). Family-centered practice: Empowerment, self-efficacy, and challenges for practitioners in early childhood education and care. *Contemporary Issues in Early Childhood*, 13(1), 17-26. doi: 10.2304/ciec.2012.13.1.17
- Russ, S. A., Kuo, A. A., Poulakis, Z., Barker, M., Rickards, F., Saunders, K., . . . Oberklaid, F. (2004). Qualitative analysis of caregivers' experience with early detection of hearing loss. *Archives of Disease in Childhood*, 89(4), 353-353. doi:10.1136/adc.2002.024125
- Sandelowski, M. (2000). Focus on research methods - whatever happened to qualitative description? *Research in Nursing and Health*, 23(4), 334-340. doi: 1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g
- Scarinci, N., Erbas, E., Moore, E., Ching, T. Y., & Marnane, V. (2017). The parents' perspective of the early diagnostic period of their child with hearing loss: Information and support. *International Journal of Audiology*, 1-12. doi: 10.1080/14992027.2017.1301683

- United Nations General Assembly. (1989). *Convention on the Rights of the Child*, 20 November 1989, United Nations, Treaty Series, vol. 1577. Retrieved from <http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1007&context=child>
- United Nations General Assembly. (2007). *Convention on the Rights of Persons with Disabilities: Resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Watson, L. M., Archbold, S. M., & Nikolopoulos, T. P. (2006). Children's communication mode five years after cochlear implantation: Changes over time according to age at implant. *Cochlear Implants International*, 7(2), 77-91. doi:10.1002/cii.301
- Watson, L. M., Hardie, T., Archbold, S. M., & Wheeler, A. (2008). Caregivers' views on changing communication after cochlear implantation. *Journal of Deaf Studies and Deaf Education*, 13(1), 104-116. doi:10.1093/Deafed/enm036
- Wheeler, A., Archbold, S. M., Hardie, T., & Watson, L. M. (2009). Children with cochlear implants: The communication journey. *Cochlear Implants International*, 10(1), 41-62. doi:10.1002/cii.370
- Young, A. (2002). Factors affecting communication choice in the first year of life – assessing and understanding an on going experience. *Deafness & Education International*, 4(1), 2-11. doi:10.1002/dei.113
- Young, A., Carr, G., Hunt, R., McCracken, W., Tattersall, H., Seewald, R., & Bamford, J. (2008). Informed choice and Deaf children and families. *Proceedings of Sound Foundation*, 4, 107-117. doi: 10.1093/deafed/enj041

Young, A., & Tattersall, H. (2007). Universal newborn hearing screening and early identification of Deafness: Caregivers' responses to knowing early and their expectations of child communication development. *Journal of Deaf Studies and Deaf Education, 12*(2), 209-220. doi:10.1093/Deafed/enl033

Table 1

*Participant Demographics*

Interviewee	Age of Child at Interview (Years; Months)	Child's Grade	Child's Gender	English Speaking Background	Degree of Hearing Loss at 5yr Interval (4FA Better Ear)	Type of Hearing Loss	Age at Diagnosis	Hearing Devices	Age of Child at Device Fitting	Method(s) of Communication Used by Family	Maternal Education	Paternal Education	State of Residency
1 Mother	6;9	1	Male	Yes	Mild	Bilateral	0;2	Hearing aids	0;3	Mostly oral. Some sign.	13-18yrs	Unknown	Victoria
2 Mother	6;6	1	Male	Yes	Profound (CI)	Bilateral	0;1	Hearing aids Right cochlear implant Left cochlear implant	0;1 1;3 3;0	Used sign early on. Now mostly oral. Some sign when devices not in use.	13-18yrs	7-12 yrs	Victoria
3 Mother	8;7	2	Female	Yes	Severe	Bilateral	0;5	Hearing aids	0;6	Attempted sign but chose oral.	7-12 yrs	7-12 yrs	Victoria
4 Father	7;0	1	Male	Yes	Mild	Bilateral	0;4	Hearing aids	0;9	Mostly oral. Some sign.	University	University	Victoria
5 Mother	11;6	6	Female	Yes	Severe	Bilateral	1;0	Hearing aids Right cochlear implant Left cochlear implant	1;1 1;9 4;0	Mostly oral. Some sign and lip reading.	University	University	New South Wales

Table 1 Continued

Interviewee	Age of Child at Interview (Years; Months)	Child's Grade	Child's Gender	English Speaking Background	Degree of Hearing Loss at 5yr Interval (4FA Better Ear)	Type of Hearing Loss	Age at Diagnosis	Hearing Devices	Age of Child at Device Fitting	Method(s) of Communication Used by Family	Maternal Education	Paternal Education	State of Residency
6 Father	9;2	3	Female	Yes	Profound (CI)	Bilateral	2;0	Attempted hearing aid in right ear Left cochlear implant	2;1 2;11	Signed and finger spelled only until commenced first year of primary school (prep). Started talking in prep. Uses both now, but sign is secondary to oral.	N/A	1-6 yrs	Victoria
7 Mother	9;3	3	Female	Yes	Mild	Bilateral	2;7	Hearing aids	2;9	Oral. From first year of primary school (prep), used finger spelling. Not officially learning sign.	University	University	Victoria

Table 2

*Theme 1: Family Characteristics Influence Decisions Regarding Changes to a Child's Method of Communication*

Sub-theme	Category	Example Participant Quote
Characteristics of the child with hearing loss influence decisions regarding the child's method of communication	Age of child at diagnosis	<i>So we decided because he was diagnosed – [child] was diagnosed so young, didn't really have any language, and at that point, um, we thought we'd go through [Agency] because they encouraged signing and Auslan (P1).</i>
	Nature of child's hearing loss	<i>So she goes up and down and she has days where, you know, her hearing's not so good and then an hour later it'll be back to its normal. So many big adjustments (P7).</i>
	Child's co-occurring conditions	<i>He was born, um, in trying circumstances. I mean, he had an Apgar of zero, he was in the neonatal intensive care for a month and so, um, we had plenty of questions like would he ever walk, would he ever speak and so on...And so that he had a hearing loss...it didn't seem like such a big deal compared to everything else we were dealing with (P4).</i>
	Personality of child	<i>He really is so confident... So it – that helps him so much. Like, when he gets taken out of the class with his aide, he doesn't care, like, he doesn't care that 'I might be different' or whatever, you know (P2).</i>
Child's relationship with hearing and communication interventions influences decisions regarding the child's method of communication	Child's attitude to signing	<i>I sign-language to her. And she turned – she actually turned around, she goes, "Excuse me, Dad, I'm not Deaf. I can hear you. You don't need to sign to me anymore" (P6).</i>
	Introduction of hearing devices	<i>Since he was implanted and when he was getting that useful hearing from his speech processor, he – you could see he loved it and he loved to verbally communicate so clearly we encouraged it and worked on it (P2)</i>
	Child's need for more than one method of communication	<i>He doesn't usually just sign. He'll usually sign and speak. Um, but sometime – he's worked out that sometimes he can just sign and that that's actually quite good, being able to communicate, say, across a long distance. So you can get him at the other end of the playground or something and sign, "Come here," or "Time to go home," and he'll probably shake his head and run away but he understood what you said (P4).</i>
	Child's acceptance of hearing devices and competency with devices	<i>He was fitted with hearing aids at about six weeks, but as – as he got a little bit older, it was very, very clear that they weren't working and he hated them. He just detested them. And, you'd put one on and by the time you got that one on, you know, you'd put that on, that one was off. He just really hated them (P2).</i>
	Child being in tune with their own communicative needs	<i>I was washing the dishes last week with my back to [Child] sitting at the bench conversing and he's like, "Mum, you know I can't hear you while you're washing those dishes." I'm like, "I'm so glad, you know, you're telling me that." And he – he's quite vocal about it. He's like, you know, "Don't do that. I can't hear while you're doing that." (P2).</i>



Table 2 Continued

Sub-theme	Category	Example Participant Quote
	Child's ability to cope with nature of intervention	<i>She was exhausted...it was probably all a bit too much, um, for her (P5).</i>
Caregiver characteristics influence decisions regarding the child's method of communication	Caregivers of children with hearing loss lead busy lives	<i>The first year was just – it was really, literally full time just buzzing around from one place to another (P2).</i>
	Caregiver emotions	<i>It was very easy to give up. Well, I – I had given up, you know (P2).</i>
	Caregiver's work circumstances	<i>We needed pretty much a full-time parent, whatever combination of us at home, to make all of us work. And so that's what we've done. Um, we're fortunate we both work in jobs where we can just do that (P4).</i>
Characteristics of the siblings of children with hearing loss influence decisions regarding the child's method of communication	Older sibling with hearing loss	<i>We decided at the start because of – [Sibling] went through [Agency a] – our eldest went through [Agency a] for her early intervention, um, so ... we thought we'd go through [Agency b] (P1).</i>
	Hearing siblings	<i>I did really want to have [Child] at a level of going to mainstream school and the reason being is I didn't want her to be any different to the other children... Having them together made her equal. She did – she was no different because she was Deaf. And I found if you moved her to another school or somewhere else it made her different... I wanted to keep going the same path as her twin sister (P3).</i>
Characteristics of family unit and lifestyle influences decisions regarding the child's method of communication		<i>I was a single parent at the time because I took custody of [Child] when she was three months old. Um, had to go thr – through all the decisions solely on my own with the implants and that sort of stuff (P6).</i>

Table 3

*Theme 2: Family Access to Information Influences Decisions Regarding Changes to a Child's Method of Communication*

Sub-theme	Category	Example Participant Quote
Caregiver sources of information influence decisions regarding the child's method of communication	Caregiver's prior knowledge of system	<i>With [Child], we knew, I suppose, how the system works or knew what we wanted and we decided we'd try [Agency] because of the signing (P1).</i>
	Caregivers own research	<i>Not just Google but also, ah, we early on dug up a lot of scientific papers, went through the medical literature trying to understand thing and we – because we've – we've got access to that literature and know how to read it... but we – a – a lot of information just on the web as well (P4).</i>
	Caregiver confusion of how system works due to lack of information	<i>With [Agency], you're either in the early intervention system or the, um, or the school based system. And that – that was actually very confusing as parents (P4).</i>
Professional sources of information influence decisions regarding the child's method of communication	Information from professionals	<i>[Audiologist] was amazing...And whatever we questioned or had queries about, if she couldn't help us on the spot, she would always, um, you know, investigate it further and email the stuff to you or – so, yeah – look, everything was covered, everything (P2).</i>
	Recommendations/referrals received from a service	<i>It was actually, er, one of the girls there [at hearing center], um, that sat down. Oh, it was probably after we got her hearing aids and said, "Look, this is going to be a long journey." She was actually really good and she started everything rolling. And she put me in touch with the [Agency] on the [Location] to start lessons or to get her, you know – to get all the applications in to start that (P5).</i>
Other sources of information influence decisions regarding the child's method of communication	Information from social media	<i>I joined [not-for-profit organization] and get most of my information from there, I would think from the parent forum which is now on Facebook as well (P7).</i>
	Information from other caregivers of children with hearing loss	<i>We hooked up with them [agency] and just started to, um, meet some people and just chat to them and just talk about their experiences and what, you know, where they were. And that was really, really helpful (P2).</i>
	Information from hearing impaired adults	<i>[Organization] gave me er – referred me to people who had cochlear implants to get feedback and to have a chat to (P5).</i>

Table 4

*Theme 3: Family Strengths Influence Decisions Regarding Changes to a Child's Method of Communication*

Sub-theme	Category	Example Participant Quote
Caregiver involvement in early intervention influences decisions regarding the child's method of communication	Caregiver dedication/sacrifice	<i>There's nothing we wouldn't have done, I suppose. There's nothing they asked us to do that I thought 'no, I wouldn't do that' or – no – always, um – nothing was every too much trouble (P1).</i>
	Caregiver's communication/educational/long-term goals for their children	<i>That was what I – [Agency] and I worked with, with my wish, was to try and get her up to the same as I possibly could to keep her in that particular mainstream school as the other girls (P3).</i>
Caregiver strengths impact on child's early intervention and influence decisions regarding the child's method of communication	Caregiver being flexible/changing goals	<i>If she didn't make progress well, obviously – your goals and that are changed all the time. It's as they go and as they make progress (P3).</i>
	Caregivers relying on own instinct	<i>I was fairly clear that he wasn't benefiting from the hearing aids so that's why I felt we needed to be able to communicate. So that's why I wanted to make sure that we were using Auslan because otherwise he would have had – no communication. Even though people were encouraging us to keep using them and – my instincts just told me it just wasn't working for him (P2).</i>
	Caregivers advocating for their children	<i>You've also got to be very proactive and obviously you're your child's greatest advocate so you have to go in and not aggressively but say, "Look, this is what she really needs. If you can – um, if you're – if you're able to do this it will make her learning so much better" (P5).</i>
Capability of family influences decisions regarding the child's method of communication	Caregiver competency with child's devices	<i>Not too bad at troubleshooting...we're both a – a bit more relaxed so if something goes wrong we've got – we know what sort of processes we have to do (P5).</i>
	Caregiver attuned to and responds appropriately to child's communication needs	<i>I guess we've adjusted. We speak loudly and clearly to get his attention where sometimes you're signing in a busy environment (P4).</i>
	Family's ability to use sign language	<i>With the sign, initially sign did cross my mind. I started to try and learn it but never really picked it up real good (P3).</i>

Table 4 Continued

Sub-theme	Category	Example Participant Quote
Family supports available influence decisions regarding the child's method of communication	Support from family/friends	<i>My mother came a lot to appointments. Um, if I couldn't do an appointment for whatever reason... she would take them. Um, when we were doing signing, she'd ["my mother"] come and she learnt some a little bit, didn't come to all the sessions but was willing to, um, give it a go (P1).</i>
	Support networks consisting of similar people	<i>Being able to speak to people who have gone through the same thing is really helpful, and we did that in very early days. And it just – it's very reassuring in the early days when you think your whole world is caving in and you don't know which foot to put first and where to start, it's just very, very overwhelming (P2).</i>
	Adult family member/friend /acquaintance with hearing loss	<i>My grandmother who I was the carer of, she lived with me for 15 years before she passed away. Ah, she was, ah, profound Deaf... Um, she used to wear hearing aids and amazingly enough I used to take her to [company] for her appointments (P3).</i>

Table 5

*Theme 4: Family Beliefs Influence Decisions Regarding Changes to a Child's Method of Communication*

Sub-theme	Category	Example Participant Quote
Family beliefs on hearing loss and intervention influence decisions regarding the child's method of communication	Family beliefs on sign language	<i>She's sort of independently moving away from the sign-language. And hopefully – hopefully she's sort of growing out of it but she does use it still a lot. She and you'll see she backs herself up with it (P6).</i>
	Caregiver's beliefs on hearing loss/Deafness and intervention	<i>Both my husband and I have always called her Deaf. And that was part of our acceptance rather than a hearing loss, that she is Deaf and that's who she is. Um, we've always been encouraging to be proud of her – she wears jewelry on her hearing aids and um, we don't hide them. And we encourage her to be proud of them and that's who she is (P7).</i>
	Caregiver beliefs on special education services and facilities	<i>If I took [Child] to [School], they're a Deaf facility. So she walks in, she gets enrolled. "Oh, okay, you've got a cochlear implant. Okay, well, you're going to be Student Number 235 and you'll go to this department. And then from there you'll go to this department." Where they're like a number and they just pass them through the system (P6).</i>
Family beliefs on language, literacy and social skill acquisition influence decisions regarding the child's method of communication	Caregivers are conscious of their child's social interactions	<i>Because we wanted to send him to the local school, we thought we'll pull him out and send him to a local 4 year old kinder so it's just natural progression and he just feeds into the school and he'll make friends and – so on and so forth (P2).</i>
	Caregivers consider their child's language development	<i>I wasn't that happy about going to [Agency] but [Parent], my husband, he really wanted to go there and, um, yeah, look. I sort of went there under sufferance in some ways... I think [Parent] was just thinking we need to get his oral language happening (P2)..</i>

Table 5 Continued

Sub-theme	Category	Example Participant Quote
	Caregivers consider the relationship between sign, language and literacy	<i>And certainly I believe that once he got to [Agency] his spoken language made huge advances. And I put that down to the combination of – of sign and spoken English that they do there (P4).</i>
Caregivers wanting a “normal” life for their child influences decisions regarding the child’s method of communication		<i>I'd made up my mind that I'd have to do everything I can to give [Child] a – a normal life. And if it meant that she was profound Deaf, that the cochlear implant would be the best option out of everything (P3).</i>
Caregivers taking on a “child-centered” perspective influences decisions regarding the child’s method of communication	Caregivers follow the child’s lead	<i>Probably when [child] was in prep [first year of primary school], um, [child] started to want to learn sign language and we hadn't wanted to go that route but [child] started teaching herself the alphabet and, um, showed an interest in making up her own language. So we tried to embrace that a bit more (P7).</i>
	Wanting the best for child	<i>We would sometime be asked, “Well, what are your goals for [child]?” And we're actually thinking, well, we – we – you know, we just want him to – to – we just want whatever is the best for [child] in terms of progressive forward (P4).</i>
	Consideration of child’s future	<i>But she could have – have a fluent conversation with you in sign language...I'm thinking, well, that's great but I need more. I need her to talk and I need her to try and to sort of look at the – her future of where she's heading (P6).</i>

Table 6

*Theme 5: Family-Centered Practice Influences Caregiver Decisions Regarding Changes to a Child's Method of Communication*

Sub-theme	Category	Example Participant Quote
Ease of access to services and resources influences decisions regarding the child's method of communication	Ease of home visits/services	<i>I liked that – going through [Agency b] because it was also home visits whereas [Agency a] was center based, you'd have to go there two or three times a week, whereas [Agency b] would come to you once – I think it was initially once a fortnight – so that made it a lot easier, especially, yeah, even if I didn't have a young [Sibling 1b] at the time (P1).</i>
	Ease a factor in selecting communication method	<i>But it [verbal communication] was just easier. I think if she didn't respond back or speak back the way she does, I probably would have went more into the sign but I was getting response by verbal so I chose to stay the verbal (P3).</i>
The nature of service delivery influences decisions regarding the child's method of communication	Ease/convenience a factor in selecting kindergartens/ childcare	<i>The kin – local kinder we chose because it was down the hill then. Because at the time we chose it, it seemed to us that [child 4] was likely to eventually end up at the local primary school (P4).</i>
	Individualized intervention as a reason for selecting/changing services	<i>I liked it because it was individualized... it was a one on one with you and the teacher of the Deaf. Um, and I liked that (P3).</i>
	Flexible services	<i>I just felt they [agency] were very flexible to my needs and for me to fit it in. They were on my terms rather than the center's terms (P3).</i>
Alignment of a service with a family's goals influences decisions regarding the child's method of communication	Holistic family-centered approaches to service	<i>[Agency], um, who are more holistic in their approach and it's not just about the child, it's about the family as well (P5).</i>
	Choosing service because Auslan offered	<i>We decided okay, well let's, um, go with [Agency] who – mostly because – ma – well, one of – for a number of reasons. One of which was that they came to us but also because they were, er, bilingual. They were doing sign and spoken English and he would choose which or of those or what combination he – he needed to use (P4).</i>
	Choosing school because unit for children with hearing loss offered	<i>We did choose a school that had support, um, but we didn't really think she was going to need it. We just thought it would be good there as a backup if she loses her hearing (P7).</i>

Table 6 Continued

Sub-theme	Category	Example Participant Quote
Services on offer to a family influence decisions regarding the child's method of communication	Groups offered at a service	<i>They [agency] offer extra, you know, play dates and, you know, there's just more of an open – lots of different alternatives where you can – can do those things if you want to, if you're interested, if you have time, there's no pressure (P5).</i>
	The staff to student ratio at a service	<i>I think the good thing in the kinder groups was the ratio of teachers to children. So, that was obviously helpful. It was just basically giving them a bit of extra support, you know, or reducing the ratios... it was a group kinder but it was like 15 children to 3 adults. Whereas in our local kinder it's 25:2. So... So, obviously that helps, you know, um... (P2)</i>
Continuity of care influences decisions regarding the child's method of communication	Agency overlaps with or is affiliated with school	<i>We were really fortunate because she had been going to lessons within the school. So she was really familiar with it... the room that she had was in the room that she was starting school with the following year. She knew the teacher she was seeing the – the following year. So she was very comfortable going to school. And confident. And that to me was the most important thing (P5).</i>
	Not consistently seeing one early interventionist at a service	<i>I think I got lost – lost in the way between, um, I think it was the changeover of the different staff...initially it was all good but you saw the same person. And then you'd go back the – you know, three months later and you've got a different person (P3).</i>
	Collaborative teamwork/communication	<i>The [Agency] lady that looked after [child] also went to the center as well to visit a couple of times. So there was a really good inter – er, working relationship with everybody (P5).</i>
Families feeling comfortable and supported in the care they receive from an intervention service influence decisions regarding the child's method of communication	Caregivers feeling comfortable/familiar with services	<i>They're [agency] almost like family to be honest. Yeah, they're really, really good (P5).</i>
	Child's comfort/happiness in attending intervention	<i>And the kids were happy, so that was the main thing too, they were comfortable going between – either of them, they both enjoyed their – when they were there (P1).</i>
	Caregivers feeling supported by early intervention professionals	<i>So we were with early intervention down at [Suburb] and they were absolutely sensational. Um, they were probably the best support that I did have. Um, we got to know them, they got to know me. Um, and I thought they were really good for any family in this situation in support (P3).</i>



Table 6 Continued

Sub-theme	Category	Example Participant Quote
Families' confidence in the services received from professionals influences decisions regarding the child's method of communication		<i>Knowing the questions, knowing – they [the agency] just had the right answers... We used to go there every Wednesday and we'd spend two to three hours there in a really great environment. It was really, really good and I highly recommend it to anyone. The things they had [Child] doing and – and they picked up things straight away about her attention span and things she was doing and wasn't she doing (P3).</i>