

Canadian Families' Decisions of Communication Options* for Children Who are Deaf or Hard of Hearing: An Initial Exploration

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Abstract

Communication is an essential aspect of human interaction and helps connect us to the people around us. The majority of children who are deaf or hard of hearing are born to hearing parents who are likely unfamiliar with hearing loss. These parents are then asked to make critical decisions about communication options for their children. It can be a challenging process, but one that needs to be done quickly to capture the critical language development period. Little research has explored the factors associated with parents' decisions about communication options for their children who are deaf or hard of hearing and no studies have been done specifically with Canadian parents. This exploratory survey design study examined the factors which influence Canadian parents' decisions relative to communication options for their children who are deaf or hard of hearing. Results indicate that parents' personal judgement and a desire for their child to be able to communicate with their family and be happy in their own unique lives were driving forces behind the decisions that were made. Confirming research conducted in other countries, Canadian parents use a combination of their own judgement, professionals' opinions, the needs of their child, and internal values to make communication option decisions. Implications of these results are discussed as they pertain to parent-professional partnerships and family-centered services.

Keywords: Canada, Families, Communication, Deaf, Survey

Acronyms: ASL = American Sign Language; CIHTF = Canadian Infant Hearing Task Force DHH = deaf or hard of hearing; EHDI = Early Hearing Detection and Intervention; IDEIA = Individuals with Disabilities Education Improvement Act; LSQ = la Langue des Signes Quebecoise

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"Well, the doctor told us we shouldn't sign and to send him to the program in (city). Back then parents just did what the professionals thought best and we didn't question it." Parent statement regarding her deaf son born in 1980 (Pedersen, personal communication, December 14, 2019).

When a child is born with hearing loss, the need to provide early and appropriate intervention to avoid language deprivation and its consequences is urgent (Cole & Flexer, 2020; Yoshinaga-Itano et al., 1998). It is vital for families to make communication decisions as soon as possible because "effective communication supports cognitive development as well as social development, including the ability to develop positive relationships with others" (Decker et al., 2012, p. 326). The decisions families must make regarding communication options for their children

who are deaf or hard of hearing (DHH) will significantly impact their children and ultimately who and how others will communicate with them (Kluwin & Gaustad, 1991).

However, these important and urgent decisions can be difficult. More than 90% of children who are DHH are born to parents with typical hearing; the family may have very little or no previous experience with hearing loss. Moreover, strong emotions and differences of opinion related to the use of spoken languages and signed language, despite the lack of empirical evidence proving a superior method (Gardiner-Walsh & Lenihan, 2019), are longstanding and add to the complexity of communication decisions for parents. Upon diagnosis, the family will usually meet with a professional who will explain the procedures and options available to the family. Professionals are defined as social workers, intake service counselors, medical personnel (e.g., audiologist and ear nose and throat physician), and educational personnel (e.g., teacher of the deaf and speech language pathologist; Crowe et al., 2014b). Eleweke and Rodda (2000) found that:

*The term communication options is used in this article in place of communication mode/modality and is inclusive of listening, spoken languages, and signed languages.

The parents were strongly influenced by the information they received, especially in the period immediately after the hearing loss was diagnosed. This was because the information given to the parents might be either balanced (with detailed information provided on all available options) or not balanced (with only limited information provided, and with the expectations that the parents would follow it without consideration of other options. (p. 377)

Clearly parents rely on information shared with them by professionals; however, these professionals may not share information in an unbiased manner and may not be fully aware of all the options available, especially if a team approach is not in place (Eleweke et al., 2008; Crowe et al., 2014a). It is critical that professionals in both medical and educational fields understand the importance of factors that influence families' decision making to support these family decisions and to better deliver family-centered support services.

Communication Options in DHH Education History

In the most basic of terms, communication options for people who are DHH can be separated into oral/spoken languages (used by the hearing population in that area) and visual/signed/manual languages. These origins are traced back to France and Spain for signed languages and Germany and Great Britain for oral languages. From its inception, the field has been shaped by polarizing views about these two approaches to communication. The first school for the deaf in North America began in 1817 in Connecticut and used sign language. By 1867, schools for the deaf that employed oral methods were established. Tensions between *manualists* like Edward Miner Gallaudet and *oralists* like Alexander Graham Bell continued to build. A landmark event known as the Milan Conference took place in 1880 in Milan, Italy during which sign language was outlawed in the education of the deaf. Consequently, during the first half of the 20th century, it was most common for children who were DHH to be educated primarily using oral methods—with varying degrees of success. In the United States, passing of PL 94-142 in 1975 and its reauthorizations, most recently the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004, began a shift in segregated education for children with disabilities, including those who were DHH. A key tenant of IDEIA is free, appropriate public education in the least restrictive environment. Subsequent federal guidance on IDEIA for children who are DHH does not specify a communication modality that is most appropriate nor least restrictive and, despite the strong opinions in the field, research has not proven a superior method (Gardiner-Walsh & Lenihan, 2019). Although this is most likely due to the numerous individual variables that contribute to communication success for each child, this ambiguity can result in additional stress for parents and families about how and what to choose.

Variations in Communication Options

If communication options are conceptualized as a continuum, with oral methods at one end and signed methods at the other, there would be a number of sub-methods and variations that can be used in combination and are ever evolving. In general, current terminology describes the main communication options beginning with listening and spoken language (LSL) and ending with American Sign Language/Bi-Lingual Bicultural. Some common terms can be summarized as follows¹ (Anderson, 2011; Hands & Voices, 2020):

Auditory Verbal

Listening and Spoken language is generally how babies without hearing loss learn language.

Auditory Oral

Language can be spoken and heard. It can also be visual. When we watch someone talking we are getting some clues about what they are saying, even if it is noisy and we can't hear them well. This is called lipreading or speechreading. But not all speech sounds can be seen on the face so speechreading doesn't allow a child to fully catch language. Listening, talking, speechreading, using facial expressions, and gestures are all considered auditory oral communication approaches.

Cued Speech

It is also possible to make spoken language into a visual form through Cued Speech, which provides hand shapes for the speech sound combinations.

Simultaneous Communication

This involves people signing words or concepts at the same time as they are talking. It may also be called SimCom or Manually Coded English (MCE).

Total Communication

This refers to a philosophy of educating children with hearing loss that incorporates all means of communication: formal signs, natural gestures, fingerspelling, body language, listening, lipreading, and speech.

American Sign Language (ASL)

ASL is a true language. It has a sign for every language concept. Because it is a different language than English, the order of the concepts is not the same as English word order, so you can't talk and use ASL at the same time. In Canada there are two recognized spoken languages, English and French, and two recognized sign languages which are American Sign Language (ASL) and la Langue des Signes Quebecoise (LSQ; Canadian Association of the Deaf [CAD], 2015).

Early Hearing Detection and Intervention (EHDI)

The field of education of children who are DHH has experienced unprecedented change during the last two

¹Many helpful infographics are available and provide more detailed descriptions of the aspects of these various terms (e.g., <https://sound-advice.ie/wp-content/uploads/2014/07/sound-advice-comm-options-infographic.pdf>).

decades. This is primarily due to technological advances of universal newborn hearing screening and sophisticated digital hearing aids and implantable devices such as cochlear implants (Strickland et al., 2011). Seminal research in the field (Yoshinaga-Itano et al., 1998) found that the language and communication outcomes of children who are DHH that received EHDI services by six months of age were far superior to those of children receiving services later in childhood; these gains held true across a number of variables including socio-economic status, degree of hearing loss, and presence of additional disabilities. Consequently, current best practice in EHDI world-wide dictates a 1-3-6 rule meaning screening should occur within one month of birth, a diagnosis confirmed by 3 months of age, and intervention implemented by 6 months of age (National Center for Hearing Assessment and Management, 2020). In Canada, through a joint effort of Speech-Language & Audiology Canada and the Canadian Academy of Audiology, a group of national experts formed the Canadian Infant Hearing Task Force (CIHTF) to monitor and oversee EHDI efforts. Consistent with the International Consensus Statement on Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing (Moeller et al., 2013), the CIHTF cites five core goals for Canadian EHDI programs:

1. Universal hearing screening of all newborns
2. Identification of babies with permanent hearing loss
3. Intervention services which include support for technology and communication development
4. Family support
5. Monitoring and evaluation of the program

The smaller national population of Canada spread out over a much larger geographical land mass poses unique challenges to achieving the goals of EHDI. The CIHTF issued a Canadian EHDI report card in 2019 and ranked achievement as *insufficient* overall. Individual provinces and territories varied in their ranking with only six of the 13 receiving a score of *sufficient* (Canadian Infant Hearing Task Force, 2019). This is relevant to the current study's topic as there is evidence to suggest parental decision-making on communication choices for their children who are DHH may be influenced by the availability of services where they live (Sibon-Macarro et al., 2014).

Family-Centered Practices and Decision-Making

Family support is a key component in early intervention for children with disabilities (Turnbull et al., 2015). Families must receive unbiased information, guidance, and be empowered to become both confident and competent to realize the benefits of early identification of hearing loss (Benedict et al., 2015; Friedman Narr & Kemmery, 2015; Moeller et al., 2013; Sass-Lehrer, 2004; Stredler Brown, 2005). When parents receive the diagnosis that their child is DHH, they are faced with a number of complex decisions about technology, services, and communication choices. Traditionally, parents of young children who were DHH were presented with a list of communication options and instructed to select one; because of the lack of evidence

on a *best* choice, parents could logically be confused! Some recent views of communication options for very young children embrace an eclectic approach and employ a discovery process to take time to determine which choice(s) best fit the child and their family and are likely to result in optimal language skills by school entry (Hall & Dills, 2020; Mitchiner et al., 2012). The Canadian Association of the Deaf recommends that parents choose a communication option that best suits the needs of the individual child. Then, whatever option(s) is chosen, the families work with qualified professionals who will support the family and child to develop those skills (CAD, 2015).

Although best-practice dictates a parent-professional equal partnership, this may not always be the case. Eleweke and Rodda (2000) noted that "the philosophies, practices, preferences, and attitudes of different educational authorities and professionals in the provision of services to individuals with hearing losses could influence the parents' decisions concerning communication approach" (p. 379). Some evidence indicates professionals' input to parents was often conflicting. Crowe et al. (2014a) noted that parents found the decision-making process stressful and that it was further complicated by differing views of professionals with strong opinions that seemed to be guided by their own philosophies. Clearly, there is a continued need for professionals to understand parental decision-making in order to be self-aware of their biases and provide truly family-centered supports in the EHDI process.

Previous Research on Parental Decisions on Communication Options

Early research examining this topic conducted by Kluwin and Gaustad (1991) found that "the mother appears to be the primary decision-maker for the family's mode of communication. Influenced by her own educational sophistication, she will base her decision on the child's degree of impairment and the nature of available services" (p. 33). More recently, the idea that family culture plays a role in communication decision making is also present in the research. Borum (2012) recommends that professionals working with families who have children who are DHH need to be more understanding of cultural perspective and ideas when providing resources and supports to families. Guiberson (2013) and Matthijs et al. (2017) also support these findings by indicating that family involvement, family beliefs and values, and culture are important factors and influences in the decision-making process for families who may be bi- or multi-lingual. In such cases, adding another language such as ASL may be more natural than for monolingual families.

A recent systematic literature review on the topic of parental decision making and children who are DHH (Porter et al., 2018), found only 37 peer reviewed studies. The two most common focus areas related to parental decision making were implantable devices and communication modality. Porter et al.'s (2018) data revealed only nine of the 37 studies pertained to communication modality and none of them took place with Canadian parents. Table 1 summarizes the characteristics of these nine studies.

The timeline of these studies is consistent with important advances in the field mentioned earlier, including newborn hearing screening and advances in hearing technology. Prior to these events, the average age of identification of profound hearing loss in children was 12 months, and 18–24 months for milder degrees of hearing loss (Norman & Heffernan, 2017). Often communication option decisions were dictated by the degree of hearing loss, medical models of hearing loss, and limitations of hearing technology.

Table 1
Studies of Parental Decisions of Communication Mode

Author	Country	Sample	Method
Borum (2012)	US	14 parents	Qualitative
Bruin and Nevøy (2014)	Norway	27 parents	Qualitative
Crowe et al. (2014a)	Australia	177 parents	Quantitative
Crowe et al. (2014b)	Australia	177 parents	Qualitative descriptive
Decker et al. (2012)	US	36 parents	Quantitative descriptive
Eleweke and Rodda (2000)	UK	2 families	Qualitative
Li et al. (2003)	US	83 parents	Quantitative
Matthijs et al. (2017)	Belgium	5 parents	Qualitative
Wheeler et al. (2009)	UK	12 parents	Qualitative

Note. UK = United Kingdom; US = United States of America.

The nine studies identified by Porter et al. (2018) have several common features relative to the findings on parental decisions of communication options. The exploratory study conducted by Eleweke and Rodda (2000) identified themes of the influence of information that was provided to parents and the attitudes of the professionals providing the information. They further found that parents' expectations about the child's hearing technology and the availability of resources were factors parents considered. The contribution of parental values was identified in several studies. Parental views about what they wanted the future to look like for their child who is DHH were associated with their choice of communication modality. Parents whose values most closely aligned with the medical model of hearing loss tended to select communication options that included spoken language, while parents who valued a socio-cultural model of hearing loss tended to support communication options that included sign language (Borum, 2012; Decker et al., 2012; Li et al., 2003). This association was also evident in relation to the child's hearing device. Parents who chose cochlear implants for their child also selected communication options that included spoken language and more often,

exclusively spoken language (Wheeler et al., 2009). The need for parents to receive unbiased information from a collaborative team was very evident (Decker et al. 2012; Eleweke & Rodda, 2000; Li et al., 2003; Matthijs et al., 2017).

The Current Study

Some research has been done regarding how families make communication decisions about their children who are DHH, but none of them have been conducted with Canadian parents; in fact, little research is available relative to families of children who are DHH in Canada. One qualitative study conducted by Fitzpatrick et al. (2008) explored the needs of Canadian parents after receiving their child's hearing loss diagnosis. Service coordination and lack of access to information was cited by parents as problematic aspects of early intervention. Fitzpatrick et al. (2008) called for further research into understanding the needs and actions of Canadian parents of children with hearing loss in a variety of settings and across variables to better support healthy family outcomes. Adding support to Fitzpatrick et al.'s (2008) call, the 2019 Report Card on Canadian EHDI Programs issued by the CIHTF graded Canada's status as insufficient. Beyond universal newborn screening and identification, the CIHTF lists support for communication development and family support as two of its five core goals (CIHTF, 2019). Further, the International Consensus Statement on Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing (Moeller et al., 2013) cites (a) informed choice and decision making and (b) parent-professional partnerships as two of its 10 principles. One thing is clear from the available literature—professionals must seek to thoroughly understand factors in parents' decision making for communication to offer truly family-centered services.

Parents of children who are DHH must make many critical decisions regarding communication for their child that parents of hearing children do not encounter. These critical decisions are complex, controversial, and need to be made in a timely manner for the child to receive maximum benefit of EHDI. Professionals are charged with providing evidence-based and non-biased information to empower parents to make educated decisions for their children who are DHH; however, scarce information is available regarding how Canadian parents make these decisions, what factors influence them, and what types and sources of information are most effective. The current study aims to explore various factors and influences that contribute to Canadian parents' decisions regarding communication with their child who is DHH. Using a survey design, the current study seeks to answer the research question, "What are the factors associated with the decision-making process of Canadian parents regarding communication option(s) for their children who are DHH?"

Method

Participants

The study sample was drawn from the population of Canadian parents of children who are DHH. Twenty-one parents who had a child who is DHH completed the survey. Ten of the families resided in Manitoba, two in

British Columbia, two in Saskatchewan, four in Alberta, two in Ontario, and one in Prince Edward Island. All of the participants reported that they were the child's mother. The majority of the participants indicated they were Caucasian ($n = 16$), while three were Indigenous, one Filipino, and one other. The participants' education backgrounds consisted of eight having a trade or college diploma, five holding a bachelor's degree, two with a master's degree, two had a Doctoral degree, two indicated some college, one had a high school diploma, and one had less than a high school diploma. The annual household incomes (Canadian dollars) reported by parents indicated three families earned more than 150K, nine families earned between 75 and 150K, five families earned between 35 and 75K and one family had an annual income of less than 35K. Three families did not report their annual income. Eleven families lived in an urban city with a large or medium population and seven families lived in a small population city of less than 35,000 people. Three families lived in a rural setting with less than 1,000 people in their town or village. All participants reported using English in the home. Additionally, three parents reported also using French, eight also using ASL, and one indicated that a different second language was also used.

Instrument

An electronic survey was created in Microsoft Forms® to collect participant responses. Content of the survey was replicated from previous instruments used by Decker et al. (2012) and Li et al. (2003), with the demographic section being enhanced per recommendations from Porter et al. (2018). The first section of the survey collected information related to the demographics of the child including hearing loss, age of diagnosis, current age, gender, personal technologies, and family demographics. The second part of the survey asked parents to identify the importance or significance that various factors and influences played on the decision they made in selecting communication options for their child. The final section contained Likert items regarding the degree to which parents perceive the importance of statements related to their child's future. Per Decker et al. (2012) and Crowe et al. (2014a, 2014b), these questions were designed to gather information regarding parental values and hopes for the future of their child, which may also influence their communication decisions. Finally, the survey had one open ended item allowing parents to comment on any aspect of the study topic if they wished. The survey instrument is contained in Appendix A.

Data Collection and Analysis

Canadian organizations that support families who have children with hearing loss were identified through internet searches of professional organizations and their affiliates including the Alexander Graham Bell Association, Canadian Hearing Services, the Hearing Foundation of Canada, the Canadian Hard of Hearing Association, provincial schools for the Deaf and Hard of Hearing, the Canadian Association of the Deaf, and Speech-Language and Audiology Canada. Following approval from the Institutional Review Board for Human Subjects (Protocol

2017), an invitation containing informed consent, a brief explanation of the study, and a link to the survey was posted to social media pages and/or emailed to Canadian organizations that serve children who are DHH and their families. A snowball procedure was used as the survey requested that the invitation be forwarded to that recipient's contacts, thus increasing the number of potential parents to participate in the study. The survey was available for a total of four weeks with a second round of postings and emails done after the first three weeks. Once the survey was closed, the raw data was exported from Microsoft Forms® into an Excel spreadsheet. Descriptive statistics in the form of percentages, tables and pie charts were used to represent the data and draw conclusions. Participant responses to the open-ended survey question were examined individually to determine if or how they aligned with each participant's quantitative responses as well as with the sample as a whole.

Results

DHH Children Demographics

Current Age and Age at Identification

Parents were asked both the current age of their child and the age at which their hearing loss was identified. Current ages of their child who was DHH indicate 16 were school age with seven children between six and 10 years old and six children between 11 and 18 years old. Three children were preschool age, between three and five years old, and one child was less than two years old. Four parents reported they had adult children who are DHH. The age at which their child's hearing loss was identified varied, with four children identified prior to six months old, seven children identified between six and 12 months, three between 13 and 24 months, three children between 25 and 36 months, and three children were identified between the ages of four and five years old. One child's hearing loss was identified at older than five years of age.

Hearing Loss Levels and Technology

Nineteen participants indicated that their child had a bilateral loss while two had unilateral losses. Standard audiological hearing loss level categories were offered as a forced choice question. The majority ($n = 13$) of children had profound losses. Two had severe, five had moderate-severe losses, and one had a moderate loss. Participants were asked about their child's assistive listening technology. Results indicated eight children used hearing aids, eight used cochlear implants, one had a bone anchored hearing aid, and three used an FM system. The remaining four parents indicated their children used another listening technology device but did not specify. Parents could select more than one choice, so it appears some children used more than one assistive listening device.

Early Intervention (EI)

Participants were asked to rate the quality of their EI services and nine thought their services were excellent and seven reported their services were adequate. Four parents believed their EI services were unsatisfactory. One parent indicated they did not receive EI services. The

majority ($n = 12$) of parents indicated that they were *not at all familiar* with hearing loss prior to their child being identified. Seven parents reported they were *a little familiar* and two parents were *very familiar* with hearing loss prior to their child's diagnosis.

Sources of Information

Parents were asked from what sources they sought information when they first learned that their child had hearing loss. Table 2 displays the percentage of parents seeking information from each source. The primary sources of information used by parents were medical professionals and audiologists/speech-pathologists. The next most often used sources of information by parents were the internet, books/magazines, and community agency professionals.

Factors Influencing Parents' Communication Decisions

Parents in the study reported that 13 of their children currently used listening and spoken language, six used ASL, and two used total communication. A list of potential influences which contributed to the decision made about their child's communication was presented to participants. They were asked to rate each factor on a four-point Likert scale from having *no influence* to having *a lot of influence*. Figure 1 illustrates the data on these items.

Of the 12 factors, the top four in descending order that parents ranked as having a lot of influence in their decision about communication mode were the parent's own judgement, the ability to communicate within the family's home community, the child's ability to communicate like the rest of the family, and their spouse's or child's other parent's opinion. In contrast, the factors rated as having no influence for most parents on their communication

Table 2
Parental Sources of Information

Information Source	N	Percentage
Medical professionals	17	81
Audiologist/speech pathologist	16	76
Community agency professionals	10	48
Books/magazines	9	43
The internet	9	43
People I know who are DHH	6	29
School/education program	4	19
Teachers/school personnel	4	19
Family members/close friends	3	14
Other parents I know	2	9
I don't know/don't remember	1	5
I didn't seek additional information	1	5

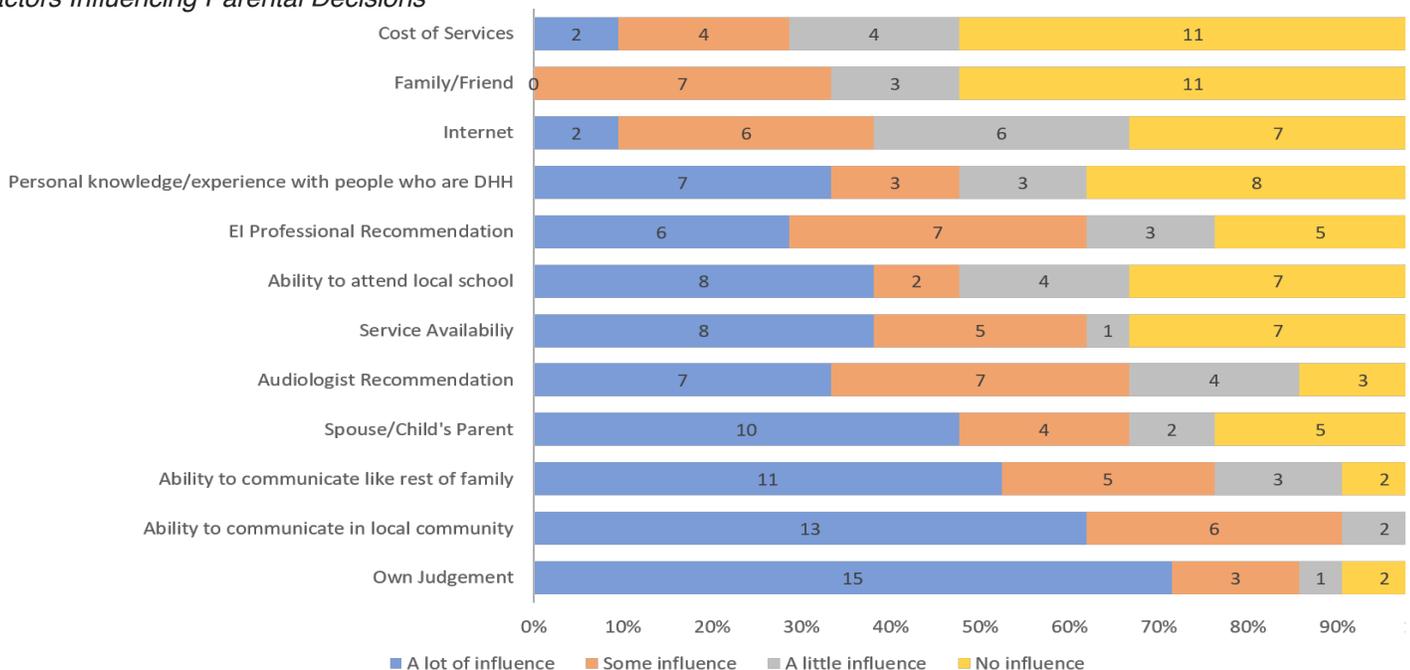
Note. DHH = deaf or hard of hearing.

modality decision were the cost of the services, the recommendation of a family member or friend, and their personal knowledge or experience with hearing loss. Sixty-two percent of parents indicated information found on the internet as having little or no influence on their decision of communication modality choice.

Parental Values Related to Communication

Participants were asked to rank statements reflective of their values about their child's communication on a four-point Likert scale from *very important* to *not important*.

Figure 1
Factors Influencing Parental Decisions



Note. DHH = deaf or hard of hearing.

Figure 2 summarizes the parent responses to these value statements. One hundred percent of the parents indicated that it was very important to them that their child lived the life that was right for their child and were less concerned with their child having a *normal* life. Ninety five percent of parents indicated that the parent-child relationship was very important to them as was their child's ability to communicate as early as possible in their life. In a similar manner, 95% of the parents said it was more important for their child to have opportunities and experiences that met their child's unique needs than for their child to have the same opportunities and experiences as other children. Parents further indicated it was more important to them that their child fit in with their peers who were also DHH than with their hearing peers.

Parent Comments

At the end of the survey parents were given the opportunity to provide comment on any aspect of the decision-making process for the communication modality for their child who is DHH. Sixteen of the 21 participants provided additional comments. The number of comments did not allow for thematic analysis; they are analyzed descriptively below. The verbatim comments are contained in Appendix B. Four of the 16 comments pertained to challenges faced by rural families such as access to the Deaf community and quality intervention. For example, one parent said,

We didn't actually have a choice. We were told that the school system we were in only used SEE [Signed Exact English]. This choice has been a huge disservice to my child, I believe that if a child is learning SEE for reading and writing they should also be taught ASL so they can communicate with other DHH persons as well. As it stands today my child doesn't fit in in the hearing world of his peers nor the peers in the Deaf community.

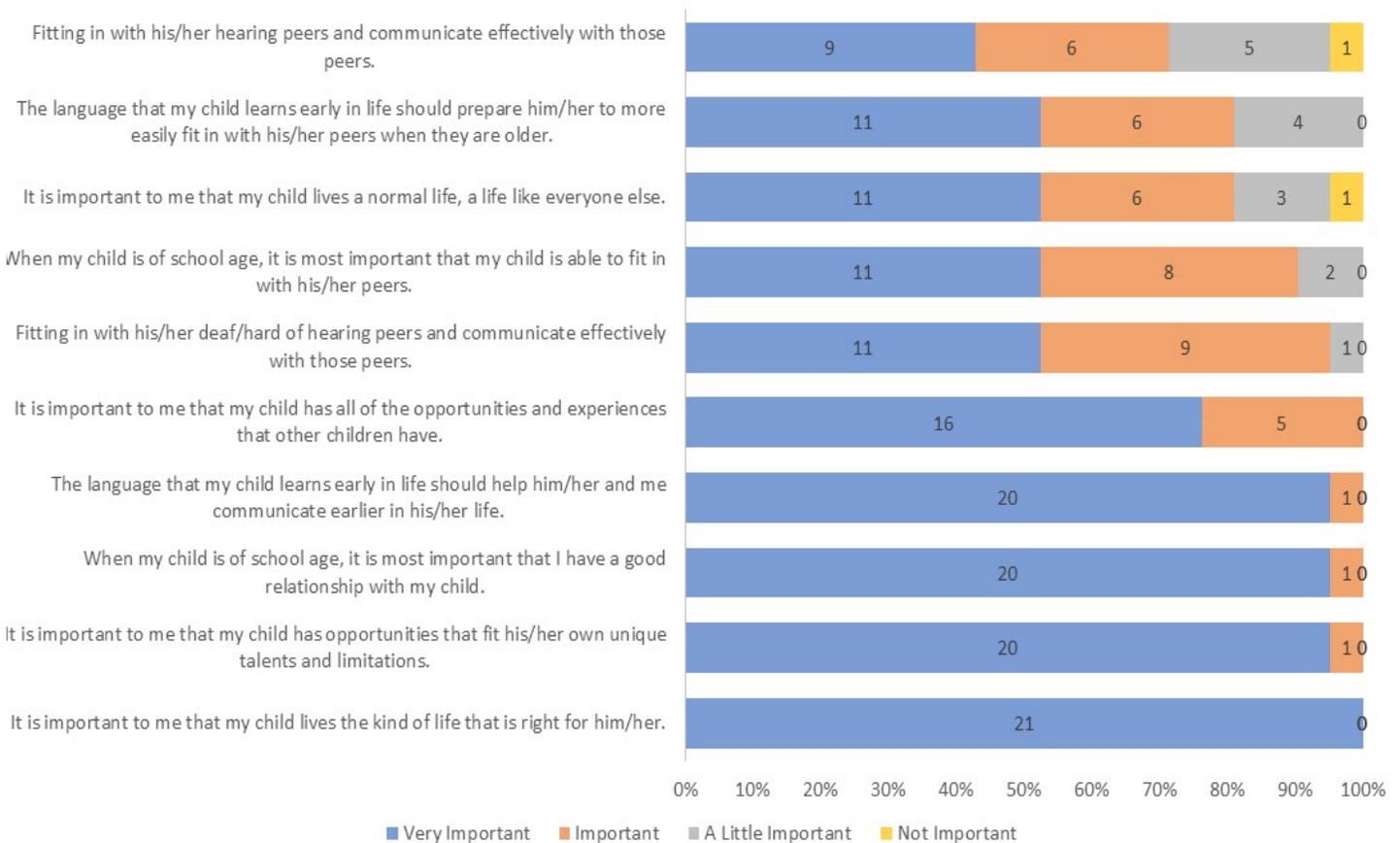
Another five comments expressed concerns and frustrations from parents on the real or perceived bias they felt from professionals. For example, one commented:

It was a very difficult decision for us and the fact that professionals were implying we had to choose one or the other made it harder and took us longer to decide. I wish we had support right from the start with choosing both ASL and spoken English via cochlear implant. With our second daughter we decided to use ASL right away which enabled us to communicate with her from the age of 6 months.

Discussion

Results of the current study were similar in many ways to the results found in previous studies from Decker et al. (2012) and Crowe et al. (2014a). Firstly, Canadian parents'

Figure 2
Parental values



Note. DHH = deaf or hard of hearing.

top sources of information after their child's diagnosis came from medical, speech-language and hearing, and other professionals. Parents in this study also sought information from the internet and books, but to a lesser degree than in previous studies by Decker et al. (2012) and Crowe et al. (2014a). Canadian parents received information primarily from medical and speech-language and hearing professionals; however, this did not appear to be the primary influence on parental decision making. Yet, parents did note that professional bias was still present in their experiences as one parent remarked, "Non-bias in both (or all) directions should be emphasized in communication choices."

Parents may certainly weigh advice from professionals and incorporate it into their decisions, parents in this study indicated their own judgement and their values relative to communication for their child appeared to be most influential. This does indicate a shift from earlier studies (Kluwin & Gaustad, 1991; Eleweke & Rodda, 2000), in which parents tended to follow professional recommendations. This may mean that the professionals involved in supporting families with DHH children have evolved and adopted more family-centered approaches. In the context of this study, separating the direct influence from a source of information from the indirect influence that source may have on parent's decisions is not possible to determine. It is possible that parents may have perceived that a decision was based on their own judgement, but information obtained from other sources may have influenced this judgment. Similar results were found by Decker et al. (2012) who also suggested that parents may internalize the opinions of professionals, which underlines the importance of providing unbiased information to families. Additionally, parent's judgments may also be reflective of intuition, or a feeling that the selected communication modality is a good fit for their child and family. Further exploration of the role of intuition and parent self-efficacy regarding communication options could add to the knowledge base about parent decision making.

The sample size used in this study did not allow for analysis of the relationship of parental values directly to the specific communication modality chosen as done in previous studies (Decker et al., 2012; Crowe et al., 2014a). However, insight into Canadian parents' values about communication for their children who are DHH was gained. Parents primarily valued their relationship with their child and ensuring that the individual and unique needs of their child were met rather than their child being normal. Further, parents in this study placed a greater value on their child fitting in with their peers who are DHH than peers with typical hearing. This may be reflective of greater appreciation of diversity and acceptance of hearing loss as a difference rather than a disability. This possibility is also strengthened by the fact that 29% of parents in this study indicated that people who are DHH were sources of information they sought regarding communication options for their children. EHDI efforts have recently focused on bringing the voice of individuals who are DHH to the EHDI discussion and ensuring that perspectives of these vital stakeholders are available to parents of children who are DHH (Benedict et al., 2015). This aspect of parental decision-making warrants further examination.

Finally, although parents in the current study did not identify access to services as a top influencing factor, 25% of the comments made by parents did pertain to frustrations with poor or unavailable access to support their communication choice. The field should continue to address innovative methods for increasing access to a range of services for families that include children who are DHH, particularly for families in rural areas as recommended by Sibon-Macarro et al., 2014.

Limitations and Future Directions

The current study was exploratory as there were no previous studies found to have been conducted with Canadian parents. Although generalization is limited due to the small sample size, these results can form the basis for future study using a larger sample. In Canada there is not federal legislation mandating universal newborn hearing screening nor EHDI services; consequently, the experiences of parents receiving a diagnosis of hearing loss may vary widely from province to province and from residence to residence. Canada's large geographic area also poses challenges to service delivery, particularly in rural and remote locations. A larger sample size could allow for a more rigorous statistical analysis of the relationship of parental values to the particular communication option(s) they chose for their child. Additionally, more in-depth mixed-methods research designs such as those conducted by Crowe et al. (2014a, 2014b) could yield a deeper understanding of parental decision making and recommendations for support directly from parents. Also, future studies on this topic should give extra effort to recruiting diverse participants to ensure results are representative of the multicultural nature of Canadian families. Kluwin and Gaustad (1991) found that mothers were the primary decision maker in families with children who are DHH. All parents in the current study were their child's mother; yet, almost half of them indicated their spouse or child's father's opinion was very important in their decision. Although not specifically explored in previous research relative to this topic, the literature on families of children who are DHH is still heavily weighted to mothers' perspectives. Given the increasingly active roles that contemporary fathers have in their child's life, further work needs to be done to gather perceptions of fathers regarding their involvement in the decision-making process (Pedersen & Olthoff, 2019). Finally, although one parent commented that parent-to-parent support was important to her family, the influence of parent-to-parent support was not specifically addressed in the current study. A growing body of evidence indicates that parental support from other parents who have similar experiences is a powerful tool for families with children who are DHH (Friedman Narr & Kemmerly, 2015; JCIH, 2013; Moeller et al., 2013; Ward et al., 2019). Future studies should include this component.

Conclusion

The ultimate goal that all parents expressed was for their child to be happy and successful in whatever path they choose in life. Parents wanted to select a communication option(s) that was right for their child. The current study supports the importance of professionals who offer unbiased

and up-to-date information to the families they serve. Professionals working in their specific areas also need to be aware of the geographical area that they are serving and know what sources of support and resources are available to parents so that they can direct parents on where to go and also be open to changing their decision as time goes on. The national parent-support organization for families with children who are DHH is Hands and Voices, whose motto is “What works for your child is what makes the choice right.”™ Co-founder LeeAnn Seaver (2004) gives professionals this advice for supporting families through the communication modality decision-making process:

When we have shifted from appropriately sharing the benefit of our experience and knowledge into intentionally manipulating a family, we’ve crossed the line into bias. Ultimately, we’ll experience greater trust in the relationship with the family when we approach them with an open mind. Encouraging their independent thought serves the greater good: increased sensitivity and awareness of this child-driven process, deeper investment and ownership of their choices, and more effective advocacy for their child. (p. 4)

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Appendix A
Survey Items

1. Which province/territory do you live in? (Forced-choice list)
2. Person completing this survey: a) child's mother; b) child's father
3. What is the population category where you live? (Forced-choice list)
4. How do you describe the primary ethnicity of your family? (Forced-choice list including *other* and *prefer not to answer*)
5. What is your family's annual income? (Forced-choice list including *prefer not to answer*)
6. What languages are used in the home? a) spoken English; b) spoken French; c) American Sign Language (ASL), d) Langue des signes du Québec (LSQ)
7. What is the highest level of schooling in your household? (Forced-choice list)
8. What is the current age of your child who is deaf or hard of hearing (DHH)? (Forced-choice list)
9. At what age was your child's hearing loss diagnosed? (Forced-choice list)
10. My child's hearing loss is: a) unilateral (in one ear only); b) bilateral (both ears)
11. My child's hearing loss can be described as: a) Slight/Mild (15-40 dB); b) Moderate (41-55 dB); c) Moderately-Severe (56-70 dB); d) Severe (71-90 dB); e) Profound (90+ dB)
12. What is your child's primary communication mode? a) Listening & Spoken Language; b) American Sign Language (ASL); c) Langue des signes du Québec (LSQ); d) Total Communication (mix of talking, signing, lipreading etc.); e) Cued Speech; f) Other
13. What assistive listening technology does your child use? Check all that apply. a) hearing aids; b) cochlear implants; c) bone anchored device; d) FM/Remote microphone; e) other
14. Prior to becoming the parent of a child who is deaf or hard of hearing, my familiarity with hearing loss was: a) very familiar; b) somewhat familiar; c) a little familiar; d) not at all familiar
15. The early intervention services our family receives/d to support my child with hearing loss are/were: a) excellent; b) adequate; c) unsatisfactory; d) we did not receive early intervention services
16. When I first learned my child had a hearing loss, I sought information from (Check all that apply): a) Medical professionals; b) Community agency professionals or personnel; c) Family members/close friends; d) Other parents I know; e) Teachers/school personnel; f) A school/educational program for the Deaf; g) Audiologist/speech pathologist; h) People I know who are DHH or have a child who is DHH; i) The internet; j) Books or magazines; k) I didn't seek additional information; l) I don't know/don't remember
17. The following factors influenced my decision about my child's communication mode (Likert Scale: *a lot of influence, some influence, a little influence, no influence*): a) Recommendation of an audiologist; b) Recommendation of a family member or friend; c) Internet resources/information; d) My spouse's/my child's other parent's opinion; e) My own judgement; f) Cost of the therapy/services; g) Availability of support close to home; h) Recommendation of an early intervention professional; i) Ability to communicate like the rest of the family; j) Ability to communicate within our home community; k) Personal knowledge and experience with people who are Deaf/Hard of Hearing; l) Ability to attend our local school
18. Please rate how important each of the following statements are for you (Likert Scale: *very important, important, a little important, not important*): a) When my child is of school age, it is most important that my child be able to fit in with his/her peers; b) When my child is of school age, it is most important that I have a good relationship with my child; c) It is important to me that my child lives a normal life, a life like everyone else; d) It is important to me that my child lives the kind of life that is right for him/her; e) It is important to me that my child has all of the opportunities and experiences that other children have; f) It is important to me that my child has opportunities that fit his/her own unique talents and limitations; g) The language that my child learns early in life should prepare him/her to more easily fit in with his/her peers when they are older; h) The language that my child learns early in life should help him/her and me communicate earlier in his/her life; i) When my child is of school age, it will be very important for him/her to fit in with his/her hearing peers and communicate effectively with those peers; j) When my child is of school age, it will be very important for him/her to fit in with his/her deaf or hard of hearing peers and communicate effectively with those peers.
19. Is there anything else you would like to say about the decision-making process of your family regarding communication choices for you child who is DHH? (Open comment box)

Appendix B

Parent Survey Comments

1. Right now he is with a great teacher who is knowledgeable of [deaf or hard of hearing] DHH and on how to work with my child.
2. Gave the best of both worlds with CIs [cochlear implants] and ASL [American Sign Language]. Then it's her choice when she's older, but she has all the tools, and perfect speech.
3. I think that my past personal experience was important. When I was in high school I was in the debate club and regularly travelled to our university to research in the libraries. One day a group of teens got on my bus; they were so animated! I watched, fascinated by their expressions, body language, and signing (I figured out that they were deaf and signing). I enrolled in a sign language class at the school for the deaf. Unfortunately, after the class ended it was summer break and I couldn't take another class nor find any deaf people to practice with; I forgot everything by fall and was too disheartened to start all over again. I think having an ESL background matters too. Having English as my second language has made me fascinated in learning languages. I had taken Mandarin and Japanese in university before I had my daughter. I encourage her to pursue other languages too. She is interested in learning other sign languages and written forms of German and Mandarin.
4. I answered cost of services had no influence but not sure if I should have selected a lot of influence! Services in (my province) are free so cost of services was not a barrier to our choices.
5. Families facing this need to receive unbiased, neutral information right from the outset. This is not a tragedy, but a difference. Parents need options available to them that are easily accessible, free, and flexible. Parent-to-parent support is invaluable, and should be provided and encouraged automatically starting from day one, and continuing on through the school years, far beyond early intervention. Parents shouldn't necessarily have to make choices; there shouldn't be a divide. Non-bias in both (or all) directions should be emphasized in communication choices. Opportunities for connecting the children to others like them and mentors like them (not only Deaf, but also hard of hearing) should be provided to every family. Opportunities for continuing your education about your child's hearing loss should be available as well. Hearing devices should be covered by our health care system. You shouldn't be non-eligible for the disability tax credit because you wear cochlear implants and "can hear". The decision we made around our communication choice for our child was not an easy one, and one which we continue to grapple with to this day, more than 10 years later. We are extremely proud of the hard work and outcomes that auditory oral language therapy has elicited for our child. We do recognize, however, that our child is and always will be deaf and hearing through a mechanical device using a damaged auditory system. This is something that we try never to forget and educate people in his life about. It is a gift, but it is far from perfect. We have seen now, as our child gets older, that he struggles with feelings of loneliness and isolation which we attribute to his feeling different in the "hearing world," though puberty probably has something to do with it too. This is hard to bridge, but we are working through it with him. Over the years we have continued to give our son opportunities to learn sign language, but up to now, the programs for signing have seemed restrictive since he is a new signer. This has been discouraging for him. It's like the opposite discrimination or bias occurs. I find this a tragedy. We use some basic sign and gestures at home when he is without implants. We participate in and have always participated in the hard of hearing community in our area so he maintains some ties to other oral deaf and hard of hearing kids. Upon identification, our audiologist did not persuade us to choose a listening and spoken language outcome, but she did almost immediately suggest that we should seek cochlear implantation for our child. The structure and proactive approach to auditory oral therapy was something that appealed to us right away. In retrospect, adding some visual aids would have benefited our son. We were also fortunate to be able to pay for additional private speech therapy and could afford my leaving work to be at home and work with our child all day every day on language learning and enrichment. It is probably the most important work I've done in my life, regardless of whether it was spoken or signed.
6. I think it is important to take into consideration how available support is in that person's area. We live in a Rural community with no other deaf or hoh [hard of hearing] individuals. As well as no one to teach us or our child ASL. . . I had to try to teach myself to the best of my abilities in order to teach him.
7. We don't have a Deaf community where we live. We wanted to give our daughter the best communication skills possible. We also want her to have independence. She is absolutely thriving.
8. Went through cochlear implant assessment and was not a fit. Decision accepted and continued with ASL.
9. The (province) deaf community is more than just a linguistic community. It is a social community which is extremely difficult to engage with when you are not deaf. They are kind and nice people but they are also insular. I found in teaching our son sign language as a child before he was verbal that the easiest tool was to use a phone app with signs - but these are not (PROVINCE) SIGNS and some signs he learned were ridiculed and I was pressured to use the (PROVINCE) sign resource - a duotang with illustrations. This simply does not cut it as a resource. I would have

been happy to continue longer with a bilingual approach with sign and spoken language but the community (despite kindness and great motivations I am sure) was not ultimately providing what we needed. My child soon preferred spoken language mostly out of a desire to be like his peers and not stand out, and as we were a verbal family at home, we allowed sign to essentially die out as a home language.

10. It was a very difficult decision for us and the fact that professionals were implying we had to choose one or the other made it harder and took us longer to decide. I wish we had support right from the start with choosing both ASL and spoken English via cochlear implant. With our second daughter we decided to use ASL right away which enabled us to communicate with her from the age of 6 months.
11. The only thing that matters is him being able to express himself and be happy.
12. We used ASL as well as cued speech initially to communicate. He is bilingual in both English and ASL. Due to distance away from families and medical issues with his grandparents we started English. Moved to ASL in school. Went to public school.
13. I was surprised and disappointed that the medical community still pushes oral communication above the use of ASL and spoken language. We try to use ASL at home and are in college programs to help support that. There was little support around the family learning ASL once we decided the oral communication was important to us too. Most ASL supports are in (large city) and make it difficult for us to attend.
14. The decision to pursue Cochlear Implants was greatly influenced by our ENT doctor's recommendations.
15. I have 2 children ages 9 and almost 11.
16. We didn't actually have a choice. We were told that the school system we were in only used SEE [Signed Exact English]. This choice has been a huge disservice to my child, I believe that if a child is learning SEE for reading and writing they should also be taught ASL so they can communicate with other DHH persons as well. As it stands today my child doesn't fit in in the hearing world of his peers nor [with] the peers in the Deaf community.



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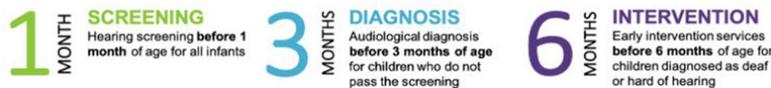
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- COMMISSION FOR THE DEAF
- PUBLICATIONS & REPORTS
- DATA
- ADDITIONAL RESOURCES

The Louisiana Early Hearing Detection and Intervention (LA EHDI) Program

Communication is Key

The Louisiana Early Hearing Detection and Intervention (LA EHDI) program supports coordinated systems of care that ensure families of babies and children who are deaf or hard-of-hearing (D/HH) receive appropriate and timely services. These services include hearing screening, diagnosis, early intervention (EI) and family to family support.

It is important to identify a baby's hearing level **as early as possible** so families can figure out the best way to communicate with them. Hearing screening is the first step in finding out if a child is deaf or hard of hearing. Louisiana law mandates that all babies be screened prior to hospital discharge. EHDI follows the **Joint Committee on Infant Hearing's Position Statement** and national benchmarks for hearing screening no later than 1 month of age, diagnosis no later than 3 months of age for infants who did not pass the screening, and enrollment in early intervention services no later than 6 months of age for those identified as D/HH. Enrollment in early intervention as soon as possible plays an important part in helping children who are deaf or hard of hearing reach their full potential.



<https://ldh.la.gov/index.cfm/page/768>

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