Parents of Children with Hearing Loss: Meeting Parents’ Needs and Concerns Through the Early Intervention Process

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Parents of Children with Hearing Loss: Meeting Parents’ Needs and Concerns Through the Early Intervention Process

A Dissertation

Submitted to the Graduate Faculty of the University of New Orleans in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Special Education

by

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Dedication

To my family who gave up hours of their time and family events while I embarked on this
endeavor, especially my children, who initially sparked the curiosity that led me down this path.
And to my better half, Dennis, I promise I will never have to “work on my paper” again. Thank
you for always supporting me.
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Abstract

The crucial early years of child development are impacted by intrinsic factors, such as the introduction of a disability like as hearing loss, and by extrinsic factors such as their environment, family members, and parenting styles. The diagnosis of a disability in a child has the potential to create an increase in parenting demands and parental stress when family needs are unmet (JCIH, 2019; Poon & Zaidman-Zait, 2012). These high levels of stress can alter parent-child relationships and parenting styles (Hutchinson, Feder, Abar, & Winsler, 2016) which can negatively impact child development (Dirks & Reiffe, 2019; Sipal & Sayin, 2013). Early Intervention attempts to mitigate these potential impacts by providing parents with appropriate knowledge to support child development and by meeting parent identified needs. Parents of children with hearing loss face unique challenges which require an in depth look into their needs through the early years of development.

The purpose of this study is to develop a deeper understanding of needs of parents of children with hearing loss during the crucial early years of a child’s life, to understand how those needs are met through birth-to-three Early Intervention programs, and to determine if parent identified needs align with the recommended practices for Early Intervention for children with hearing loss stated by the Division for Early Childhood (DEC) and the Joint Committee of Infant Hearing (JCIH). This study used a quasi-structured web-based survey with both closed and open-ended questions. Three themes emerged from this study: needs for supports for the parent, support for communication, and support for the child. Although parents’ felt that their needs were met in general, more than 70% of participants identified one or more unmet need. Additionally, parent needs aligned with the recommended practices, but there was a divergence between the reasonings or justifications of those needs between parents and the professional organizations. This study can support programs in ensuring that their programs are designed to
meet the needs of specific families, further improving child outcomes through the birth-to-three Early Intervention process.

Keywords: Birth-to three early intervention, early intervention, disability, disabilities, hearing loss, deaf, deafness, parent, parent needs, recommended practice, child development
Chapter 1

Introduction

Early experiences, including interactions with parents and the environment, play an essential role in early child development, contributing to a child’s social-emotional, adaptive, physical, cognitive, and communicative growth. When these early experiences are enhanced and promoted, child development can be positively impacted, often resulting in academic achievement and life successes. Conversely, early experiences can be hindered by both biological factors, such as a disability, or environmental factors, such as poverty or parental emotional well-being. As primary caregivers and influencing factors on a child’s early years of life, parents and families play a crucial role in enhancing those early experiences and mitigating the potential negative impact of biological factors. In order to support families through this period of child growth, it is important to understand the values and viewpoints of the families in regards to Early Intervention and their identified needs as it relates to supporting their child’s growth.

When a child is diagnosed with a disability, families may experience changes in their understanding of how to support their child’s development and experience child-related difficulties such as behavioral challenges (Eisenhower, Baker, & Blacher, 2005; Tervo, 2012), navigating doctor appointments, financial strain (Kuhlthau, Hill, Yucel, & Perrin, 2005; Murphy, Carbone, & the Council on Children with Disabilities, 2011; Resch, Mireles, Grenwelge, Peterson, Zhang, 2010), and a sense of isolation (DiGiacomo, Green, Delaney, Patradoo-Ho, Davidson, & Abbott, 2017; Woodgate, Ateah, & Secco, 2008). In addition to some of these concerns, families with children with hearing loss, a subsection of the larger umbrella of disabilities, face unique challenges that impact the child, parent, and extended family. Issues such as diagnosis, financial concerns, difficult and frequent doctor appointments, limited school
options, and the child’s communication issues have all been identified as areas of parental concern when raising a child with hearing loss (Burger, Spahn, Richter, Eissele, Erwin, & Bengel, 2005; Dirks, Uilenburg & Rieffe, 2016; Dogan, 2010; Vohr, Jodoin-Krauzyk, Tucker, Johnson, Topol, Ahlgren, 2008b).

These experiences of parents of a child with hearing loss, especially hearing parents of children with hearing loss, can increase the burden placed on parents and the resources that are at their disposal. This imbalance leads to an increase in emotional distress (Lazarus, 1966) which can impact parents as well as the entire family (Darling, Senatore, & Strachan, 2011; Dyke, Mulroy, & Leonard, 2009; Hintermair & Sarimski, 2019). When not addressed, these unmet needs and resulting parental emotional distress can influence parenting styles and consequently can impact the child’s development (Giallo, Treyvaud, Cooklin, & Wade, 2013; Kersten-Alvarez, Hosman, Riksen-Walraven, van Doesum, Smeekens, & Hoefnagels, 2012). This is especially harmful to children with disabilities who begin life with developmental challenges to overcome. For children with hearing loss, the adverse parenting behaviors that result from unmet needs hinder development in areas that are most affected by the hearing loss such as the child’s communication, social-emotional, and adaptive skills (Blank, Frush Holt, Pisoni, & Kronenberger, 2020; Hwa-Froelich, Cook, & Flick, 2008; Sipal & Sayin, 2013).

Although families may face challenges, research has shown that families are able to find ways to overcome, cope and persevere through trials and hardships (Benson, 2010; Migerode, Maes, Buysse, Brondeel, 2012; Zaidman-Zait, Most, Tarrasch, Haddad-eid, & Brand, 2016). Professionals can support families and their perseverance by guiding them to positive outcomes for their child. One way to help guide a family through these hurdles is to ensure that the concerns and needs of the family, both the parents and children, are met (Dunst, Trivette, &
Hamby, 2006; Trivette, Dunst, & Hamby, 2010; Joussement, Mageau, Koestner, 2014). This understanding is intertwined into the foundation of Early Intervention and family-centered care which seeks to support the child as well as the family (Dempsey & Keen, 2008; King, King, Rosenbaum, & Goffin, 1999; Schaub, Ramseier, Neuhauser, Burkhardt, & Lanfranchi, 2019). The identification of the families’ concerns, priorities, and resources related to the growth and development of the child is primary in the delivery of family-centered care (Bruder, 2000; Dunst, Trivette, & Deal, 1994; Tomasello, Manning, & Dulmus, 2010).

**Early Intervention**

Early Intervention (EI) is a service delivery system for young children with disabilities from birth-to-three and their families. It seeks to increase a family’s quality of life by impacting the family in two different areas (1) by providing the family with knowledge of how to support their child throughout daily living and (2) by supporting parents’ identified needs, concerns, and priorities to create emotionally healthy caregivers and positive parenting (Guralnick, 2001; Guralnick, 2011).

Interventions are found to be more beneficial if they are incorporated into the family’s daily routines (Bernheimer & Weisner, 2007; DesJardin & Eisenberg, 2007). Additionally, parents who utilize Early Intervention services and supports demonstrate improved parenting behaviors which directly impact child development such as improved interactions during playtime with their child as well as improvement in communication (McConachie & Diggle, 2006; Oono, Honey, & McConachie, 2013). Rather than providing interventions strictly through one-on-one, direct therapy to the child, Early Intervention professionals are expected to focus on providing parents with the appropriate knowledge and skills to incorporate strategies and techniques into their interactions with their child. By inserting interventions and therapeutic
interactions into everyday activities, Early Intervention programs seek to not only enhance the parents’ capability, but also manage the amount of intervention that a child can receive throughout the day. However, to ensure the effectiveness of these interventions, Early Intervention programs work to support parents in their role as a model and teacher for their child. Trivette and Banerjee (2015) state that “family-centered intervention recommended practices build capacity of the parents to support their child’s learning at home and to get the resources and services that are important to promote their child’s growth and development” (p. 69).

The long-term impacts of interventions can be strengthened when the family unit is supported in their role as caregiver (Dunst, 2002; Mahoney & Wiggers, 2007). Early Intervention facilitates this by acknowledging the importance of the family, respecting the family as decision makers, supporting the family in their role of raising their child with a disability, and developing a plan to mitigate specific stressors which further supports the family in their role as caregiver (Division for Early Childhood, 2014; Guralnick, 2005). Additionally, research shows that families who participate in family-centered programs report feeling more confident in their abilities to care for their children, accessing support within the community, and advocating for their child (Bailey, Hebbeler, Spiker, Scarborough, Mallik, & Nelson, 2005; Hebbeler, Spiker, Bailey, Scarborough, Malik, Simeonsson & Nelson, 2007) which further supports the importance of family-centered Early Intervention.

Early Intervention also seeks to positively influence the long-term achievements of children who are at risk of development delays. The initial early childhood programs were geared towards children from economically disadvantaged backgrounds. A review of those programs, such as Head Start, showed that the enrolled children demonstrated gains in academic achievement, cognition, and social-emotional development (Schanzenbach & Bauer, 2021).
Furthermore, Early Intervention proved beneficial for children who experience risk factors such as chromosome linked disabilities; pre-, peri-, and post-natal trauma; physical challenges; cognitive delays; and other developmental delays. In addition, children with disabilities who are enrolled in family-centered Early Intervention programs have shown improvements in verbal skills, communication, social skills, and better psychological adjustment (Dawson, Rogers, Munson, Smith, Winter, Greenson, Donaldson, & Varley, 2010; McConachie et al., 2006; Oono et al., 2013).

Early Intervention supports children with disabilities, including hearing loss, and their families, and provides children and families with the potential for improved developmental outcomes. Early Intervention works to support the needs and concerns of the families by not only improving parents’ abilities to support their child’s development throughout their daily lives, but also improving the parents’ ability to navigate the increase in demands and additional stressors related to raising a child with a disability.

**Young Children Birth-to-Three with Disabilities and Their Families**

The diagnosis of a disability in a child shortly after birth has been shown to have a profound effect on parent well-being. Parenting a child with a disability has been shown to increase parental stress and depression which can negatively impact the child and the family dynamics (Ansari, Dhongade, Lad, Borade, Yg, Yadav, Mehetre, & Kulkarni, 2016; Dogan 2010; Hayes et al., 2012; Lee, 2013; Resch, Elliot, & Benz, 2012; Sipal & Sayin, 2013). To mitigate this potential, Early Intervention works directly with families to identify their areas of needs and assist in finding support for those areas.
Needs and Concerns of Parents of Children Birth-to-Three with Disabilities

The family unit plays an integral part in the Early Intervention process. Identifying parental and family need is a crucial cornerstone to appropriately supporting families of children with disabilities (Guralnick, 2001; Ziviani, Feeney, & Khan, 2011). Research has shown that parents of children with developmental disabilities identify disability-specific needs as stressors and disability-specific information as an essential need (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Pearson, Waite, & Oliver, 2018;). This includes information about short-term and long-term prognosis and information about how to help their child’s development. Additionally, the severity of a physical disability influences parent identified need (Palisano, Almarsi, Chiarello, Orlin, Bagley, & Maggs, 2010). Understanding the importance of disability specific information for families is integral to developing an Early Intervention program which fully supports parents and the child with disabilities.

Young Children Birth-to-Three with Hearing Loss and Their Families

It is clear that the diagnosis of hearing loss in an infant has a significant influence on parents. Similar to the diagnosis of a disability in a child, the diagnosis of hearing loss in a young child has an immediate influence on the parents, family, and the child (Burger et al., 2005; Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Haddad, Steuerwald, & Garland, 2019). Initially, the diagnosis of hearing loss directly impacts the child’s development. This effect, combined with the increase in demands on parents, leads to changes in parent well-being and further impacts the ability for parents to positively support their child’s development (Hwa-Froelich et al., 2008; Dirks & Rieffe, 2019). Hearing parents report a change in emotional well-being, including feelings of sadness, anger, and a sense of being overwhelmed when they receive a diagnosis of hearing loss for their child (Gilbey, 2010; Haddad, et al., 2019; Kurtzer-White &
Luterman, 2003). Most notably, the family must immediately make a series of decisions that they feel are best for their child and their family with limited understanding of the impact of the disability or of their decisions. Porter and Edirippulige (2007) noted:

“Parents whose children are diagnosed with a hearing loss in an infant screening program usually have little understanding of deafness in children or its management. They are required to weigh up information and possible outcomes regarding issues such as technology, communication options, education, and habilitation (DesGeorges, 2003; Kurtzer-White & Luterman, 2003) at a time when they are emotionally vulnerable.” (p. 518)

**Hearing Loss Definition**

Hearing loss is a multifaceted and varied condition. Defined as the partial or total inability to hear, nearly 48 million individuals nationwide are impacted (The Facts About Hearing Loss, 2021). An individual’s hearing loss is defined by the type of loss, the degree of loss, and the configuration of the loss (Vila & Lieu, 2015). Within that definition, hearing loss can occur in one ear or both ears, hearing loss can be progressive or sudden, the amount of loss can fluctuate or be stable, and loss across frequency can vary. Additionally, it can be identified as a conductive loss when sound cannot travel effectively from the outer ear to the inner ear; a sensorineural loss when sound cannot be processed within the inner ear or along the neural pathways to the brain; or a mixed loss when a combination of conductive factors and sensorineural factors are present. The countless number of possible combinations of type, degree, and configuration of hearing loss makes it difficult to determine prognosis which adds another layer of difficulty for Early Intervention professionals to address the needs of the family and child.
Hearing loss in children.

National statistics show that roughly two to three of every 1,000 babies born each year in the United States exhibit some form of hearing loss in one or both ears (Centers for Disease Control and Prevention, 2017). Of this number, more than 90% are born to hearing parents who have limited prior experience with deaf culture and community (American Speech-Language-Hearing Association, 2008; Mitchell & Karchmer, 2004). Changes to technology and the adoption of newborn screening practices have decreased the mean age when children are diagnosed with hearing loss, leading to a larger population of young children with identified hearing and related Early Intervention needs (Durieux-Smith, Fitzpatrick, & Whittingham, 2008, Harrison, Roush, & Wallace, 2003).

Needs and Concerns of Hearing Parents of Children Birth-to-three with Hearing Loss

Research of the identified needs and concerns of hearing parents of children birth-to-three with hearing loss identifies three broad categories: (1) needs and concerns related to the emotional impact on parent and family (Fitzpatrick et al., 2008; Haddad et al., 2019; Jackson, 2011; Jackson, Wegner, & Turnbull, 2010; Jackson, Traub, & Turnbull, 2008; Kurtzer-White & Luterman, 2003), (2) needs and concerns related to the specific disability related needs of their child and of parenting their child and (Burger et al., 2005; Vohr et al., 2008b; Yucel, Derim, & Celik, 2008) (3) needs and concerns related to supports for their child (Jackson et al., 2010; Yucel et al., 2008).

When a child is diagnosed with a hearing loss, parents and families face immediate changes to their stress, coping, family planning, and long-term expectations (Fitzpatrick et al., 2008). Jackson and others (2008) identified initial areas of parental need related to the diagnosis of hearing loss including initial reaction, decision making, impact on family interaction, leisure
time, and worries about their child’s future which impact the parents’ emotional well-being. This onslaught of information leads to parents reporting feelings of a general emotional impact, including feelings of being overwhelmed (Fitzpatrick et al., 2008; Jackson et al., 2008; Kurtzer-White & Luterman, 2003). Research has demonstrated that parents have also expressed a desire for supports to relieve stress, supports for relationships with other family members, and supports for parents to enjoy activities outside of caring for their child’s disability (Jackson et al., 2010). Beyond the initial emotional impact of raising a child with hearing loss and the increase on parental demands, hearing parents of children with hearing loss also report feeling pressure and judgement from others for their decisions, especially in the areas of amplification and communication (Jackson et al., 2008).

In addition to initial emotional changes, parents of children with hearing loss have also identified increased disability-specific needs such as increased burden on finances, school decisions, numerous doctor appointments and medical care, child’s communication system, and awareness of technological issues (Burger et al., 2005; Ledergerg & Golbach, 2002; Munoz, Blaiser, & Barwick, 2013; Vohr et al., 2008b). Their informational needs are also related to disability-specific areas and the unique needs of their child (Fitzpatrick et al., 2008; Joulaie, Abdollahi, Darouie, Ahmadi, & Desjardin, 2019;). These information areas include unbiased information about amplification and communication choices, information about audiological needs, information about long term expectations, information about specific therapies, and contact with individuals who are raising a child with a similar hearing loss (Gilliver, Ching, Sjahalam-King, 2013; Yucel et al., 2008). However, research shows that some parents of children with hearing loss continue to face difficulties in accessing pertinent information which demands that Early Intervention providers ensure that they are trusted, unbiased, and reliable.

Parent identified needs also extend into supports in accessing services outside of the Early Intervention process and creating a program of long-term support for their child (Haddad et al., 2019). Hearing parents have expressed a desire for support in accessing services from different agencies in the community and ways to include their child in the events and programs within their community (Jackson et al., 2010). This reflects a desire for parents to have assistance that extends beyond the immediate supports related to their child’s hearing loss, and a need to ensure that they are set up for long term success.

Despite similarities that have been noted in areas of parental need, research has found differences between hearing parents of children with hearing loss and deaf parents of children with hearing loss. Deaf parents, while still reporting the desire for needs and supports similar to that of their hearing peers, have reported not experiencing the same levels of shock and grief during the initial diagnosis (Gilliver et al., 2013). Additionally, families with more than one child with a hearing loss (Gilliver et al., 2013), differences in the child’s age at diagnosis (Inger & Dromi, 2009), different chosen methods of communication (Inger & Dromi, 2009), and differences in amplification choice (Most & Zaidman-Zait, 2001; Zaidman-Zait, 2008) have demonstrated differences in their needs and expectations of Early Interventions.

Research has also found differences among family-identified needs based on characteristics specific to family units. For example, levels of support in their families and communities, levels of parental education, communication among family members, and socioeconomic status all influence the needs of a family (Eyalati et al., 2013; Inger & Dromi, 2009). Disability literature, in general, highlights that these differences influenced not only the
type of information and support that parents received, but also how they wanted that information and support provided to them (Most & Zaidman-Zait, 2001). When focusing on parents of children with hearing loss, some parents preferred information be provided through professionals with experience in hearing loss and other parents reporting a need and desire for support through social networks and parents with children with similar experiences to their own. The level of variation within the research among parent identified need in families of children with hearing loss dictate that Early Intervention programs are cognizant of these differences and thorough when identifying parent need.

The numerous areas of family life that are impacted by a diagnosis, combined with the variety of needs related to supporting child development in a child with hearing loss as well as research that demonstrates variables within parent identified needs mandate that Early Intervention programs are properly identifying family needs and supporting them through the early development stages.

**Hearing loss and communication choices.**

One of the initial decisions that parents are faced with after a diagnosis of hearing loss is communication method. This is based on a variety of factors and families can try one communication method and switch to an alternate communication method at a later date. However, the degree and configuration of the hearing loss can influence the parents’ choice due to the effect on a child’s ability to benefit from auditory input and their ability to hear speech sounds. The countless number of possible combinations of hearing loss are taken into consideration when a family chooses a method of communication and can also change the services and supports that a family needs throughout Early Intervention.
The degree of a child’s hearing loss can play a role in the mode of communication that families choose to pursue, either oral communication, manual communication (e.g. American Sign Language, Signed English, Signed Exact English), Cued Speech, or a combination of oral and manual communication (referred to as Simultaneous Communication). Early access to a robust language environment is the key to providing a child with early language. Thus, it becomes imperative for Early Intervention professionals to work closely with families of young children with hearing loss to ensure that they are fully supported and educated in how to engage in adequate communication with their child and to ensure that the child’s environment is saturated in language no matter what a family’s chosen method of communication.

**Hearing loss and amplification decisions.**

In addition to communication choices, parents are faced with important amplification decisions early in the diagnosis process and often they are made prior to parents fully understanding the needs of their child. The options sway along a pendulum that includes anything from surgical options such as cochlear implants to choosing to forgo amplification completely. However, the decision to purchase hearing aids or to undergo a cochlear implant itself is fraught with stress. Either choice places demands on parent finances due to inadequate insurance coverage for both hearing aids and cochlear implants in many states (State Insurance Mandates for Hearing Aids, 2021). Additionally, amplification remains an area of discord within the deaf community among many deaf adults (Mauldin, 2012). This can place additional stress and burdens on the parents and becomes a factor in the Early Intervention process.

**Recommended Practices**

Across the domains of both general Early Intervention as well as Early Intervention for children with hearing loss, researchers, academics, and professional organizations have worked
to ensure that professionals are providing intervention in a way that has been recognized and supported by research. Those have resulted in recommendations for Early Intervention practices as well as recommendations for Early Intervention for children with hearing loss.

**Children Birth-to-Three with Disabilities and Their Families**

In an effort to ensure the best outcomes for all children, the Division of Early Childhood (DEC), for the Council for Exceptional Children (CEC), published updated recommendations for Early Intervention practices in 2014 (McLean, Sandall, & Smith, 2016). These encompass three basic themes related to families: (1) family-centered practice, which includes treating families respectfully, being responsive to the individual needs of the family, and providing families with complete and unbiased information, (2) capacity-building practices, which includes providing families with opportunities to gain new skills to enhance their self-efficacy, and (3) collaboration practices, which include building relationships between families and professionals to develop and achieve mutually agreed-upon goals for the family and the child (Division for Early Childhood of the Council for Exceptional Children, 2014).

Within these basic themes, the DEC (Santos, 2015) focuses on seven different areas: assessment, environment, family, instruction, interaction, teaming and collaboration, and transition. Although family is identified as its own specific area, the role of the family is included throughout all seven areas. For example, DEC recommends that within assessment, practitioners work with families in identifying preferences for assessment processes, gathering assessment information, and reporting results in a way that parents can easily understand. Additionally, within environment, practitioners should work with the family to promote learning within the natural environment and during daily routines including the possibility of assistive technology or changes to the environment itself. The DEC also recommends that practitioners should remain
sensitive to cultural, linguistic, and socioeconomic diversity while recognizing the family strengths and provide families with up-to-date information including information about formal and informal resources that will help build their parenting skills and support the overall development of the child.

**Children Birth-to-Three with Hearing Loss and Their Families**

In addition to the DEC (Santos, 2015) recommendations, professional organizations identified other recommended practices for children who are deaf or hard of hearing. To continue the positive impact of early identification, the Joint Committee on Infant Hearing (JCIH) issued a position statement in 2007 (American Academy of Pediatrics, 2007) and then revised it in 2013 when they issued the *Supplement to the JCIH Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child is Deaf or Hard of Hearing*. This position statement identified 12 goals for all states to progress towards. In addition, JCIH further identified best practices for early identification and medical intervention as well as recommended practices for family-centered Early Intervention programs.

The JCIH reaffirmed and updated their earlier recommended practices in 2019 (JCIH, 2019). A close examination of the 12 JCIH recommended practices from the 2007 position statement, the 2013 supplement, as well as the recent 2019 statement shows that the recommendations address both medical diagnosis as well as Early Intervention support, providing guidance to two distinct communities of professionals who provide supports for children with hearing loss and their families. A summary of the recommended practices shows that family support, including parental education and peer support, is a central element. The practices related to family-based services can be summarized as (1) ensuring that families of children with hearing loss have access to timely Early Intervention services, (2) access to
comprehensive and purposeful information to make informed decisions including access to service coordinators who have the specialized knowledge related to working with individuals who are deaf or hard of hearing, (3) access to providers who have the knowledge and skills to support families and their children in their chosen method of communication, (4) access to all providers who may support the family’s decision making and emotional health including other families with children who are deaf or hard of hearing and adults who are deaf or hard of hearing who are trained to provide mentorship.

Statement of the Problem

Researchers have determined that a child’s early experiences play a crucial role in early development (Anda, Felitti, Bremner, Walker, Whitfield, Perry, Dube, & Giles, 2006; Walker, Wachs, Grantham-McGregor, Black, Nelson, Huffman, Baker-Henningham, Chang, Hamadani, Lozoff, Meeks Gardner, Powell, Rahman, Richter, 2011). Those early experiences are impacted by intrinsic factors such as the introduction of a disability (including hearing loss) and by extrinsic factors such as their environment, family members, and parenting styles. Research has found that extrinsic factors, specifically parenting styles (Hutchinson, Feder, Abar, & Winsler, 2016) and parent-child relationships, are negatively influenced when a parent has statistically significant levels of stress. High levels of stress can result in delays in areas such as the social and emotional development of children (Dirks & Reiffê, 2019; Hwa-Froelich et al., 2008; Sipal & Sayin, 2013). In relation to children with a hearing loss, parents face increased disability stressors such as the child’s communication, cost of hearing aids and maintenance, cochlear implant expenses, and school choice (Burger et al., 2005; JCIH, 2019). However, research has found that stress, and the resulting negative impact on child development, can be reduced when perceived parental need is sufficiently addressed (Poon & Zaidman-Zait, 2012). Early
Intervention attempts to address this connection by supporting the family as well as supporting the child with a hearing loss.

When parental needs are not being met, the development of the child may be at risk. Because birth-to-three programs were among the first programs to offer consistent intervention services for a child and family, careful inspection of those services and supports is critical. One way to determine their effectiveness is to ask families if their concerns, priorities, and needs are being met by the programs. Limited research is available regarding how well Early Intervention programs are meeting the needs of parents of children with hearing loss.

**Purpose Statement**

The purpose of this study is to develop a deeper understanding of parent perceptions of Early Intervention programs for children with hearing loss from birth-to-three. Families of children with hearing loss face unique issues and concerns. For successful intervention, programs must be tailored to the needs of each family. Recommended practices have been developed to help improve Early Intervention services for children with hearing loss. Therefore, this study will identify the concerns and priorities of parents of children with hearing loss from their perspective and determine if those identified needs correlate with recommended practices.

**Significance**

When supports and services address the needs of children with hearing loss and their families, outcomes are positive, therefore impacting the families’ quality of life. Understanding the concerns of families from the parents’ perspective allows professionals to focus their supports and services in relevant areas of need. When families feel their concerns and needs are met, they are better able to provide high quality care for their children.
**Research Questions**

In order to understand the concerns and needs of families of children with hearing loss, several research questions are proposed:

1) From a parent’s perspective, what are their primary needs and concerns related to their child from birth-to-three years old with hearing loss and their family?

2) From a parent’s perspective, how well do the services and supports received through Early Intervention meet their identified needs?

3) To what extent do the services and supports that families received through Early Intervention align with DEC and JCIH recommended practices for children from birth-to-three years old with hearing loss and their families?

**Chapter 2**

**Literature Review**

**Introduction**

Child development does not work in a vacuum, free from influences. Rather, child development is a complex interaction between a child’s predetermined genetics and chromosomal makeup as well as the influences of the child’s environment, including parenting, socio-economic factors, and outside influences (National Research Council, 2000). Much of this development occurs during the early years of life, when the brain goes through a level of growth that is not seen again in an individual’s lifetime. During this rapid stage of development, the foundational structures for much of the neurological function is laid. Early Intervention, supports provided to families from birth-to-three, seeks to capitalize on this rapid growth by supporting families in their role as the primary caregivers and influencers in a child’s life and further enhancing their ability to support optimal growth during the early years of development.
When a child experiences a disability and development delays, the parents and family are impacted by a growing demand on their resources including tangible resources such as finances and intangible resources such as emotional reserves and coping abilities. However, when services and supports, like those provided through Early Intervention, address those areas where families are feeling the most impact, the parents’ ability to support their child’s development is enhanced and the child’s ability to benefit from positive parenting behaviors is strengthened. Together, this can create a positive influence on the child’s development and can create a stable foundation for future development. In fact, the basis of Early Intervention, as written into legislation, is to “enhance capacity of families to meet the special needs of their infants and toddlers with disabilities” (Individuals with Disabilities Education Act Amendments, 2004).

Research has focused on how to enhance child development during these critical early years of development. The Division for Early Childhood (DEC) developed recommendations for practitioners to help develop “the most effective ways to improve learning outcomes and promote the development of young children” who are at-risk for developmental delays and disabilities” (Santos, 2015 p. 3). Within this scope, research has identified specific needs for some children and their families based on their identified disability. For children with hearing loss, the understanding of environmental and biological impact led to federal legislation and recommendations, such as Early Hearing Detection and Intervention legislation and the Joint Committee on Infant Hearing’s twelve-point recommendations updated in 2013 (Joint Committee on Infant Hearing, Muse, Harrison, Yoshinaga-Itano, Grimes, Brookhouser, Eptein, Buchman, Mehl, Vohr, Moeller, Martin, Benedict, Scoggins, Crace, King, Sette, Martin, 2013). The JCIH recommendations clarified the importance of early identification, early amplification if desired, and comprehensive support for families of children with hearing loss. In particular, the
goal of JCIH recommendations is to not only ensure that children with hearing loss have adequate access to their environment and language learning opportunities, but to also ensure that the families have the appropriate support and education to navigate life as a parent of a child with hearing loss and to best support their child’s development.

Together, the guidance from DEC and JCIH forms a cohesive network of supports for parents of children with hearing loss based on the needs of families of children with hearing loss found in previous research. The cornerstone of Early Intervention is to support the family based on the family’s expressed needs and intervention plans are determined in conjunction with the contributions of the family as primary participating members in the Individual Family Service Plan (IFSP). This allows parents the opportunity to express their needs based on the resources at their disposal and to seek a partnership with Early Intervention which best meets their needs. By addressing parent identified needs, Early Intervention seeks to meld information gained from previous research and the unique needs of the family to provide children with comprehensive supports in early life.

**Family-centered Early Intervention**

The intentional focus on the needs of the parents and family unit is often referred to as “family-centered” and it has been the main delivery method of Early Intervention in the United States since 1986. It is further defined as an “approach to intervention in which [the] primary emphasis is on collaborating with and supporting parents” (Mahoney & Bella, 1998). The Individuals with Disabilities Education Act (1986), which allowed for the education of all children with disabilities within the public school system, was extended to include Early Intervention for children from birth-to-three years old through “Part H” of the same law and
called for parents and families to be a central component in the Early Intervention process (McEwen, 2002).

Early Intervention seeks to improve the development of children with identified delays or at-risk of delays by supporting their physical, social, cognitive, and communicative development as well as supporting the parents and families in their role as primary caregivers. Children spend the largest amount of time with their family unit engaging in everyday activities and routines (Bruder, 2000). Supporting parents and extended family in their caregiving roles benefits the child and facilitates improved parental efficacy (Punch & Hyde, 2010). The Early Child Outcome (ECO) Center identified ways in which an Early Intervention program should seek to support parents: help families understand their children’s strengths, abilities and special needs; help families know their rights and how to advocate effectively for their children; help families support their child’s development; and help families gain access to services and build support systems (Bailey & Bruder, 2005).

In regards to children with hearing loss and their families, a review of legislation such as the Individuals with Disabilities Education Act (IDEA) and Early Hearing Detection and Intervention (EHDI) Act (2010) and recommendations for best practices such as those published by the JCIH (2007, 2013, & 2019) and the International Consensus Statement (Moeller, Carr, Seaver, Stredler-Brown, Holzinger, 2013) shows that there are two distinct tracks taken to address the needs of parents of children with hearing loss: (1) through support delivered by a service provider, such as educational therapy sessions and audiological care, and (2) through support provided by social constructs such as parent-to-parent programs and mentorship programs.
Legislation

In 1985, the Department of Education presented a consensus agreement which concluded that infants with disabilities who receive Early Intervention services benefit educationally, emotionally, and intellectually (Florian, 1995). This report contributed to the passage of PL 99-457, the Education of the Handicapped Act Amendments which created a grant program for all states to develop Early Intervention programs for children with established disabilities and/or developmental delays from birth-to-three (Part C) and from birth-to-five (Part B). This effectively created a nationwide continuum of assistance from birth-to-three to preschool programs for children with disabilities or developmental delays (Roush & McWilliam, 1990; Shonkoff and Meisels, 1990).

In 1990, two federal laws, Education for All Handicapped Children Act and Education of the Handicapped Act Amendments of 1986, were rewritten into PL 101-476, also known as the Individuals with Disabilities Education Act or IDEA. This purposeful alteration represented the changing views of people with disabilities perpetuated by society and reflected the change from a focus on the disabling condition of the child to the concerns, priorities, and resources of the family related to the child. This comprehensive legislation included both the preschool programs encompassed in The Education for All Handicapped Children Act and the birth-to-three programs provided by the 1986 Amendment to the Education of the Handicapped Act. In 1997, the regulations that addressed birth-to-three officially became known as Part C. The legislative foundations of Early Intervention have remained relatively unchanged since then.

Environment and Brain Development in the Early Years

One reason for the heavily weighted benefit of support and intervention during the first few years of life is the rapid biological development of the human brain. During the infant and
early childhood period, the brain experiences its largest period of growth and change, creating nearly a million neural connections each second. By five years old, the brain has already reached approximately 90% of its overall capacity (Nowakowski, 2006). Supporting positive academic, social, and communicative growth during this time is important to all children, but it becomes increasingly advantageous when an infant or child experiences a disability, such as hearing loss.

Though brain capacity is not a predictor of later academic success, researchers have found that deficiencies in multiple environmental areas throughout the critical child rearing years can negatively impact development and in extreme cases can lead to lifelong deficits (Hair, Hanson, Wolfe, Pollak, 2015; Kundakovic & Champagne, 2015; Luby, Belden, Botteron, Marrus, Harms, Babb, Nishino, & Barch, 2013). Deficiencies in areas such as nutrition, health, social interaction, and maternal connection have all been linked to lower achievement across areas of development such as social-emotional, communication, cognition, and adaptive skills (Johnston, Ishida, & Ishida, Matsushita, Nishimura, & Tsuji, 2009; Rowe, Raudenbush & Goldin-Meadow, 2012). A 2006 study demonstrated that environmental factors do not simply affect outward displays such as school achievement and later success, but that children who experience deficiencies in their environment, such as those that are associated with long term poverty, show deficiencies in specific neurocognitive systems (Farah, Shera, Savage, Betancourt, Giannetta, Brodsky, Malmud, and Hurt). This was repeated in a 2012 study (Noble, Houston, Kan & Sowell) which found that socio-economic status correlated with differences in volumes of the hippocampus, amygdala, left superior temporal gyrus, and the left inferior frontal gyrus. These areas are associated with learning, memory, social-emotional development, and language learning. This demonstrates that environmental factors have a direct effect on brain development,
reinforcing the importance of Early Intervention and support through the early years of development as a way to mitigate the potential harmful effects on the brain.

**Parental Stress and Brain Development**

Parental stress is an environmental factor that has been directly linked to changes in parenting behaviors which hinder brain development in young children. (Essex, Boyce, Hertzman, Lam, Armstrong, Neumann, & Kober, 2013; Guarjardo, Snyder, & Peterson, 2009; Guralnick, 2005) and later academic achievement (Duncan & Brooks-Gunn, 2000; Goodman, Rouse, Long, & Brand, 2011; Hair et al., 2015). This connection further justifies the importance of Early Intervention for children who have, or who are at-risk of having, developmental delays, including children who are born with hearing loss or who develop hearing loss.

**Young Children with Disabilities and their Families**

Studies have identified a link between parenting a child with a disability, including children with hearing loss, and an increase in parental stress similar to that which is associated with parenting a child in poverty (Burger et al., 2005; Hayes & Watson, 2012; Hwa-Froelich et al., 2008; Rao & Beidel, 2009). For example, Rao & Beidel (2009) found that parents of children with high-functioning autism had significantly higher total parental stress than the control group and these parents had significantly higher scores on the child domain than on the parent domain. An increase in stress related to parenting a child with a disability was also found in a study of parents of children with a diagnosis of Attention Deficit Hyperactivity Disorder (Theule, Wiener, Tannock, & Jenkins, 2013). Research also shows that parents and families experience changes and stress related to the process of acceptance of the diagnosis (Graungaard & Skov, 2006), stress related to the increases in need in different areas of parenting (Rao & Beidel, 2009; Sen & Yurtsever, 2007), as well as changes to their reported quality of life (Wang, Turnbull,
Summers, Little, Poston, Mannan, & Turnbull, 2004). These changes can impact the parent-child interaction (Howe, 2006; Potharst, Schuengel, Last, van Wassenaer, Kok, & Houtzager, 2012) and the ability of the parent to fully support and enhance child development (Osborne, McHugh, Saunders, & Reed, 2008) creating a need for research to identify ways to best support parents in the early years of their child’s development.

**Impact of Hearing Loss on Child Development**

To create interventions that are beneficial to children and their families, it is important to understand how a disability impacts child development. Hearing loss that occurs during the crucial early childhood years has been shown to have a wide-ranging effect on all areas of development (Kral & O’Donoghue, 2010; Lieu, 2004; Moeller, Tomblin, Yoshingago-Itano, Connor, & Jerger, 2007; Tharpe, 2008). Researchers attribute this to difficulties that the deaf and hard of hearing individual has in acquiring and accessing language in the same way as their hearing peers (Pittman, Lewis, Hoover, & Stelmachowicz, 2005).

**Language and Communication Development**

Research has found that despite the level of hearing loss, communication style, or amplification choices, children with hearing loss have a language deficiency ranging from one to three years behind their hearing peers (Blamey, Sarant, Paatsch, Barry, Bow, Wales, Wright, Psarros, Rattigan, & Tooher, 2001; Lieu, Tye-Murray, Karzon, & Piccirillo, 2010). In their study, Sarant, Holt, Dowell, Rickards, and Blamey (2008) found that half of the participants continued to demonstrate a delay in both receptive and expressive language at three years old and only 28% demonstrated age-appropriate language skills. Other studies have shown that this deficit is even more pronounced in a child who has a moderate to profound hearing loss when compared with children who have a mild loss (Vohr et al., 2008a). Research has also shown that
children with unilateral loss, who were once believed to be insulated from the effects of hearing loss due to their amount of residual hearing, also experience delays in their language development when compared to their hearing peers (Lieu et al., 2010).

This delay is compounded when children with hearing loss are engaged in learning language through American Sign Language but are not exposed to American Sign Language on a consistent and coherent basis within the home. This happens most often in homes with hearing parents. It takes time to learn and become proficient in a second language and the delay means that deaf children who are born to hearing parents are not engrossed in an ideal language environment in the same way as their hearing peers. Additionally, Delana, Genry, and Andrews (2007) found that half of hearing parents of children learning American Sign Language did not sign. Researchers discovered that this pattern was consistent even in homes outside of the United States where only 27% of Norwegian parents reported using sign language within the home (Arnesen et al., 2008 as reported by Lederberg, Schick, & Spencer, 2013). Both the low use of consistent sign language by hearing parents of children with hearing loss and the amount of time it takes for someone to become proficient in the language contributes to many of the language delays that are seen in children with hearing loss who are born to hearing parents and reinforces the need to support parents in their communication needs

**Language and communication development in deaf children of deaf parents.**

However, research has shown that children who are deaf (severe to profound hearing loss) and born to parents who are also deaf do not face the same degree of difficulty as children with hearing loss who are born to hearing parents. Research has shown that deaf children with hearing parents are very language delayed in their use of American Sign Language when compared to deaf children with deaf parents (Lederberg et al., 2013). This is related to the ability
of children who are deaf to receive consistent language input and exposure from fluent language models (Spencer & Marschark, 2010). Additionally, deaf parents use communication styles that naturally enhance a deaf child’s visual learning skills and different communication needs (Koester & Lahti-Harper, 2010; Spencer & Harris, 2006). These distinct differences contribute to language development which parallels early spoken language development trends and demonstrates the need for studies which focus solely on children with hearing loss who are born to hearing parents.

**Social-Emotional Development**

Social-emotional development requires a complex interaction between multiple factors including language, communication, and empathy and includes the ability to understand feelings of oneself and others. Children, including children with hearing loss, who lack proficient language will struggle to gain age-appropriate social-emotional skills. Additionally, children who lack an appropriate language base show “greater impulsivity and poorer emotional regulation” (Calderon & Greenberg, 2003, p. 195). This can manifest in behavior problems both within the home and within the classroom. Stevenson, McCann, Watkin, Worsfold, Kennedy, and the Hearing Outcomes Study Team (2009) found that children with hearing loss demonstrated higher levels of behavior problems. This increased level of behavior challenges was especially marked in children with lower levels of language development. This has been repeated in studies that measured both observed behavior as well as parent reported behavior problems (Quittner, Barker, Cruz, Snell, Grimley, Botteri, & the CDaCI Investigative Team, 2010). As with language and cognitive delays, children with unilateral hearing loss have also demonstrated an increase in perceived behavior problems (Lieu, 2004).
Adaptive Skills

Adaptive skills are the skills that are necessary for an individual to appropriately take care of their needs within their environment. While minimal research has been conducted on the impact of hearing loss on adaptive skills, some research has shown that children with hearing loss can face deficits in this area. In a 2010 study (Ching, Crowe, Martin, Day, Mahler, Young, Street, Cook, & Orsini), children with hearing loss showed difficulty with simple everyday tasks and skills. This same study found that children whose parents had lower levels of educational achievement demonstrated a greater deficit in adaptive skills when compared to children with hearing loss whose parents had achieved post-secondary education levels. Though hearing loss is most often associated with language and communication concerns, research has shown that a deficit in language skills can later impact all other areas leading to delays across the spectrum of development, including in adaptive skills.

Cognitive Development and Academic Achievement

Cognitive development and academic achievement are interconnected, and yet remain two distinct areas of study. Mayberry (2002) states that cognitive development is the “product of the child’s attempts to understand family, neighborhood, school, and the world at large” (p. 71). This demonstrates the ability of hearing loss to impact not just one small facet of child development, but to impact a complex interaction between ability to perceive, ability to understand, and the ability to react to those understandings in a way which results in delays when compared to hearing peers.

The struggle with cognitive development, the ability to think and reason, combined with delays in other areas of child development such as communication, social-emotional, and adaptive skills have shown to result in academic struggles for students with hearing loss. In their
comparison of Stanford Achievement Test Reading Comprehension scores, researchers found that profoundly deaf students performed at a “below basic” level when compared to their hearing peers (Qi & Mitchell, 2012). Analysis of state-wide standardized testing also demonstrates a discrepancy between students with hearing loss and their hearing peers with deaf students also performing worse than hard-of-hearing students (California Department of Education, 2007 as reported by Qi & Mitchell, 2012). Academic concerns are noted even among children with mild or unilateral hearing loss. Children with a mild hearing loss or unilateral hearing loss experience some negative impact on their academic performance including the need for academic assistance and perceived behavior issues within the classroom (Lieu, 2004).

When reviewing data specifically from schools for the deaf, schools which provide an environment where students are immersed in an environment using American Sign Language, research has identified similar performances among the deaf and hard of hearing population when compared to their same grade level peers across the state. For example, only 15.6% of students scored proficient in reading and only 31.3% scored proficient in math at the Louisiana School for the Deaf in 2007, drastically different from the results of their hearing peers across the state (Johnson & Mitchell, 2008). The same comparisons are found across all subject areas (Marschark, Shaver, Nagle, & Newman, 2015; Qi & Mitchell, 2012).

The Emotional Effects of Parenting a Child with a Hearing Loss

Research has identified that parents who raise a child with a disability, including hearing loss, experience different components of stress including a grief response and periods of relative acceptance (Gilliver et al., 2013; Haddad et al., 2019). Through this period and throughout various stages of identification and parenting, research has also demonstrated that parents of children with a disability, including hearing loss, experience stress related to the specific needs
of the disability (Burger et al., 2005; Quittner, et al., 2010; Vohr et al., 2008b). This connection has been identified at a variety of ages and has been reported across the hearing loss spectrum with stress being reported in hearing parents of children with cochlear implants, parents of children with hearing aids, those that use oral communication method and those that use American Sign Language (Fitzpatrick, Grandpierre, Durieux-Smith, Gaboury, Coyle, Na & Sallam, 2016; Roberts, Sands, Gannoni, Marciano, 2015; Vohr et al., 2008b; Zaidman-Zait, 2008).

Parents of children with hearing loss do not necessarily show higher levels of general parenting stress but have demonstrated a significantly greater amount of stress specifically related to the child’s hearing loss needs as well as increases on their parenting needs as a result of the hearing loss (Eisenhower et al., 2005; Haddad et al., 2019; Quittner et al., 2010). For example, studies have shown that age at diagnosis, extent of hearing loss, language abilities, mode of communication, amplification needs, and amount of perceived social support have been linked to stress in parents of children with hearing loss (Åsberg, Vogel, Bowers, 2008; Pipp-Siegel, Sedey, Yoshinaga-Itano, 2002; Sarant & Garrard, 2014). Feelings of grief and loss, making choices about amplification, and scheduling therapies have also been connected to increased stress after a diagnosis of hearing loss in a child (Anagnostou, Graham, & Crocker, 2007). Additionally, when parents were asked to rank known stressors in order of importance, they found that hearing parents of children with hearing loss ranked communication, educational concerns, maintaining hearing aid devices, and serving as a language teacher for their child as their top stressors (Quittner et al., 2010). The Quittner (2010) study was intriguing not just in its demonstration that parents of children with hearing loss were unique in their needs, but that the responses were exactly the same from research that had been conducted 20 years earlier using
the same measurement tool (Quittner, 1992; Quittner, 1991). Context specific stressors have been identified in other studies throughout the various stages of identification of a hearing loss (Vohr et al., 2008b).

**Diagnosis and Decision Making**

Once a child is diagnosed with a hearing loss, the family must immediately make a series of decisions, including amplification and communication, that they feel are best for their child and their family with limited understanding of the impact of the disability on their decisions. In a 2015 (Roberts et al.) qualitative study on parent perceptions of support, parents reported that they initially experienced a multitude of significant decisions that continued well beyond the initial years after a diagnosis. Some of those choices, amplification and communication, include multiple options and varieties such as cochlear implants, hearing aids, or no amplification, and American Sign Language, Spoken English, or Cued Speech. Also, they are contentious subjects within the deaf community with many viewing medical interventions such as hearing aids or cochlear implants and spoken language as an assault on their community and culture (Mauldin, 2012). This divide between the deaf community (mainly composed of deaf adults), and parents of children with hearing loss (often composed of hearing adults), add to the already difficult decision-making process.

The unique needs of the deaf and hard of hearing community related to technology and mode of communication become critical decisions for parents. Advancements in technology and the increased availability of cochlear implants have made this an area of stress and need that is unique to this population. Specifically, the decision to get cochlear implants is particularly stressful (Richter, Spahn, Zschocke, Leuchter, Laszig, & Lohle, 2000). Hyde, Punch, and
Komesaroff (2010), found that nearly half of parents stated the decision to get a cochlear implant for their child was extremely stressful. One mother described her experience as follows:

“We had hearing people telling us we were neglecting our child if we didn’t go with the implant, and on the other side we had the deaf community saying that it was a form of abuse if we implanted our child. I had many tears and many a sleepless night, changed my mind that many times...it was a really stressful time, and there was no way around that... but yes it was stressful, fearful.” (Hyde et al., 2010).

**Financial Repercussions**

In addition to the initial choices of amplification and communication, finances can play a role in the decision-making process by adding an additional cost of care. The diagnosis of a hearing loss and the ensuing therapies and equipment can have a significant impact on the financial stability of the family (Haddad et al., 2019). According to the President’s Council of Advisors on Science and Technology (PCAST), the average cost of a single hearing aid is approximately $2300 (President’s Council of Advisors on Science and Technology, 2015). Hearing aids are usually replaced every 5 to 7 years and events such as a dramatic change in hearing, severe damage to the hearing aid, or misplacing a hearing aid can cause a person to pay for new hearing aids at a more frequent rate. In addition, Medicaid and numerous insurance policies do not cover the full cost of hearing aids, hearing aid batteries, or related services and some insurance policies do not offer any coverage at all. Gains have been made in this area, but the most recent data shows that only 24 states addressed this issue and passed laws that mandated coverage for hearing aids for children (State Insurance Mandates for Hearing Aids, 2021). The lack of a universal federal mandate ensuring coverage for amplification for children have resulted in inconsistent coverage that is dependent on the state that a family resides in. Families
also face the additional costs of numerous doctor visits, upkeep of the hearing aids, speech therapies, special schooling, and even special equipment for the home.

**Child’s Communication Needs**

Communication needs cause specific stress in families both for the direct impact on parent-child communication, but also due to its impact on other development areas. Quittner and others (2010) found that both the child’s language delays as well as resulting behavior concerns impacted parents’ reported levels of stress. Their study also found that parents reported communication needs as a primary area of concern. This concern was also identified in other studies (Gilliver et al., 2013).

**Social Support and Information Gathering**

In addition to needs directly related to the child and the disability, needs such as information and social support are needs that are directly linked to the parent. An initial reaction to a diagnosis is to begin gathering information. In a technology saturated society, the internet can play a role in that initial stage. Gilliver and others (2013) found that parents reported turning to the internet for information. Parents also report a need for ongoing and up-to-date information especially about technology and the impact of the prognosis in the long term (Fitzpatrick et al., 2008).

Social support is related to the discussion of parent needs because it is one way that provides a buffer to the impacts of stress on parents (Sipal & Sayin, 2013). Although it is not the only way support is provided, it is the main source of support stated in Early Intervention guidelines. Porter and Edirippulige (2007) found that 55% of parents in their study turned to the internet to search for information about parent support groups. In their 2019 study, Haddad,
Steuerwald, and Garland found that parents specifically desired support from other parents in their same geographic area as opposed to larger national organizations.

**Early Hearing Detection and Intervention**

For children with hearing loss to take full advantage of Early Intervention programs, their unique needs, including screening, diagnosis, and technological intervention, need to be addressed. Young, Gascon-Ramos, Campbell, and Bamford (2009) stated that “early detection leading to early diagnosis is of little consequence unless deaf children and their families receive services which are able to optimize the advantages of that very early recognition (Young & Tattersall, 2007). Medical interventions, such as early diagnosis of hearing loss and early amplification through hearing aids or cochlear implants, as well as educational interventions such as exposure to sufficient language systems, work together to benefit language and communication development which influence other areas of development (Grey, Deutchki, Lund, & Werfel, 2021).

**Newborn and Infant Hearing Screening and Intervention Act of 1999**

Research has shown that children with hearing loss benefit more in areas such as communication, social-emotional development, adaptive skills, and ultimately in academic learning when amplification, hearing aids or cochlear implants are provided early (Nicholas & Geers, 2007; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). This follows the “use it or lose it” philosophy and has been supported by imaging of the brain which shows that further brain development in critical areas related to auditory input and speech production are “arrested without stimulation” (Gordon, Jewell, Wong, & Yoo, 2011 pg. 208). This requires an early screening and an early diagnosis. Unfortunately, prior to 1988, the average age of diagnosis was 2 to 3 years old, preventing children with hearing loss from benefiting from the birth-to-three
Early Intervention programs and forcing them to lose out on the most important years of development (Commission on the Education of the Deaf, 1988). To remedy this, in 1990, organizations including the Joint Committee on Infant Hearing and the National Institutes of Health issued statements that recognized the importance of screening children for hearing loss at birth and recommended the establishment of hospital or birthing center-based programs (White 2014). With the assistance of federal grants, currently, 45 states have mandated newborn hearing screening and more than 95% of all babies born in the United States are screened at birth (National Conference of State Legislatures, 2021) resulting in the decrease of the mean age for diagnosis of hearing loss decreased from 12 to 13 months to 3 to 6 months (USPSTF, 2001 as reported by Yoshinaga-Itano, C., 2004).

**Joint Committee on Infant Hearing Position Statements**

Tasked with making recommendations concerning newborn hearing screening, the Joint Committee on Infant Hearing (JCIH) was formed. JCIH is an organization composed of representatives from medical fields that impact the various needs of children with hearing loss including audiology, otolaryngology, pediatrics, and nursing (History of the Joint Committee on Infant Hearing, 2021). In their position statement released in 2000 (Year 2000 Position Statement), the JCIH reiterated the importance of screening all children for hearing loss shortly after birth. The JCIH further stated that children should be officially diagnosed and begin medical intervention by 3 months of age and be enrolled in Early Intervention programs by 6 months of age. This became known as the 1-3-6 plan.

However, problems persisted including a loss-to-follow up rate of approximately 50%, a shortage of facilities and personnel with appropriate expertise, a failure to present information in a culturally sensitive way, and a lack of comprehensive state tracking systems (Joint Committee
on Infant Hearing, 2013). The JCIH issued an updated position statement in an attempt to clarify recommendations and to ensure that all at-risk children were receiving the appropriate care and follow-up. The 2007 position statement expanded previous definitions of at-risk infants and explained recommendations on audiological and medical evaluation and follow-up. The 2007 position statement also expanded the recommendations for Early Intervention to include children with all levels of hearing loss, highlighted the importance of including individuals with expertise in the field in the process, and reaffirmed the importance of family choice guiding the process.

In 2013, the JCIH issued a supplement to their 2007 position statement, clarifying the previous statement. It also clearly defined and outlined recommended practices for an Early Hearing Detection and Intervention (EHDI) program. It recommended that all children, despite levels or variations in hearing loss, have access to Early Intervention services, monitoring, and follow-up services when appropriate. Additionally, it stated that families should have access to other families with children with hearing loss and families should have access to individuals who are qualified to address the unique needs of children with hearing loss. These qualifications included professionals who were able to identify developmental benchmarks and teach language through a family’s chosen mode of communication. Also, it recommended that adults with hearing loss, including deafness, be included in the development of state programs and recommendations (JCIH, 2013).

The JCIH was again updated in 2019. Rather than rewrite previous recommendations, the JCIH reaffirmed their previous statements and provided some guidance on the changing landscape of the family caused by an ever expanding access to the internet and social media (JCIH, 2019). The 2019 statement addressed the possibility of improving early access to Early Intervention by decreasing the previously accepted six-months old to an earlier three-month goal.
Also, the importance of information was clarified, stating that it is not sufficient to simply provide information on all options, but to provide comprehensive information from multiple facets which incorporate an explanation about future impacts on the child and family. A parent’s and family’s emotional health and the role that increased stressors from all aspects of life was also emphasized, explaining that the Early Intervention programs should ensure that supports are appropriately tailored to meet the needs of each unique family. The role of the internet was also a key focus of the most recent position statement. It was recommended that Early Intervention programs for children who are deaf or hard of hearing should understand and utilize the role of the internet, social media, and increased accessibility features to further tailor a program to best meet the unique identified needs of each family.

The collection of JCIH recommendations forms the basis of what the profession views as comprehensive recommendations which will lead towards greater language growth and academic success for children with hearing loss.

**Early Hearing Detection and Intervention Programs**

Congress continued to authorize funding for early hearing detection initiatives. As focus began to shift away from simply identifying hearing loss and towards ensuring appropriate interventions, these programs became known as Early Hearing Detection and Intervention, or EHDI programs. The Early Hearing Detection and Intervention Act (EHDI) was signed in December 2010 and was reauthorized in 2017. Statistics show that 97% of all newborns in the United States are now screened prior to leaving the hospital, over 70% are diagnosed before 3 months, and about 70% are enrolled in Early Intervention programs (Center for Disease Control, 2017). Thus, the EHDI program provided earlier detection and intervention for young children (Yoshinaga-Itano, 2004).
Supports and Services for Families

The role of Early Intervention is to improve child development by expanding the capacity of parents to support their child with a disability within the home. One way to support parents is to meet their identified concerns and needs. Furthermore, in his application of Developmental Systems Theory to Early Intervention, Guralnick (2001) stated that child outcomes are governed by three family interactions: parent-child, family-orchestrated child interactions, and care-taking, demonstrating that Early Intervention is not simply about providing for the child, but is about supporting parents (Guralnick, 2001, p. 2). This was supported by Mauldin (2012, p. 535) when she stated that Early Intervention is “not only about providing speech or various therapies for the infants enrolled, but it is a parent-centered program” meant to support the parent in everything from learning new ways of interacting with their child to learning how to advocate for their child. The term “family support” is used interchangeably to refer to multiple resources that are provided to the family in an effort to enhance their ability to support their child, including “resources that address the family’s needs related to emotional well-being, health, material well-being, parenting, disability-related considerations, and family interactions” (Jackson, 2011, p. 344).

Families’ Identified Supports and Services of Parents of Children with Disabilities

When asking parents to identify their needs, research has demonstrated that parents of children with disabilities identify areas that are specific to their child’s disability and are unique from general parenting stress that many parents perceive. Guralnick (2005) identified four areas related to a disability diagnosis which impact the parent-child interactions and later child development: 1) information needs (Palisano et al., 2010), 2) interpersonal, family distress, and reevaluation of family goals and routines, 3) resource and/or financial needs, and 4) confidence
in parenting role. Another study identified areas such as 1) access to information and supports 2) financial barriers 3) school and community inclusion and 4) family support (Resch et al., 2010).

Supports identified by parents and families show some differences among disability groups. For example, families of children with cerebral palsy (CP) perceived needs differed based on the child’s physical needs (Palisano et al., 2010). In their study comparing the reported needs of families of children with autism compared to families of children with ADD/ADHD, families of children with autism reported greater needs in child caring and support in involvement in the community (Lee, Harrington, Louie, & Newschaffer, 2008).

**Families-identified supports and services of parents of children with hearing loss.**

Research related to the services and supports of parents of children with hearing loss is not definitive. Some research concluded that areas such as communication and education options (Jamieson, Zaidman-Zait, & Poon, 2011; Most & Zaidman-Zait, 2001) were among the desired needs of parents while other research concluded that finances were among the most important (Fitzpatrick et al., 2008; Vohr et al., 2008b). Additionally, other studies showed that social support from other parents of children with hearing loss was found to be among the most important needs identified by parents (Fitzpatrick et al., 2008; Jackson et al., 2008; Zaidman-Zait, 2007). While numerous differences exist among research, some generalities are prevalent in terms of supporting families of children with hearing loss.

Several studies were conducted in an effort to identify the needs of some of the subgroups within the deaf and hard of hearing community. Jackson (2011) studied families of cochlear implant recipients in order to identify their unique needs and to determine how they differ from families of children that utilize hearing aids. Parents of cochlear implant recipients rated interacting with a parent of a child with hearing loss, as opposed to parents in general, high
on their desired list of supports (Jackson, 2011). The author hypothesized that this need to specifically interact and connect with other families with children with hearing loss reinforced their need for disability specific supports (Jackson, 2011). This study also found that families of cochlear implant recipients reported better quality of support than families of children that utilized hearing aids. Additionally, Hyde and others (2010) found that parents who were contemplating cochlear implants desired more information both in the form of textual information and information from other families. More than half of their surveyed parents sought out information from other parents of children with cochlear implants and an additional one-third sought information from the children themselves.

In a study of parents of children enrolled in Auditory-Verbal therapy, researchers found that many of the reported needs included information, emotional support, and financial support (Yucel et al., 2008). However, 60% of parents required more information about their child’s specific style of therapy and they were unsure of their abilities to reinforce the therapies at home. Also, researchers found that the vast majority (75.9%) of the participants in the study were concerned about future needs that extended beyond the Early Intervention period and 63.1% wanted more information in general. Over 70% of the participants requested emotional support in helping the family adjust to the child’s hearing loss and over 50% were concerned about their ability to meet the financial needs of their child’s hearing loss (Yucel et al., 2008).

Several similarities were found between the two studies, Fitzpatrick and others (2008), conducted in Ontario, Canada and Young, Jones, Starmer, Sutherland (2005), conducted in England. These studies focused on the identified needs of parents of children who were newly diagnosed in infancy. First, both studies reported that parents reiterated the importance of receiving support, either in the form of parent-to-parent peer support or through exposure to the
experiences of other parents, following identification (Fitzpatrick et al., 2008; Young et al., 2005). Secondly, both studies reported that parents felt the information presented to parents immediately after diagnosis was not always realistic, was not thorough enough, or it came from biased sources (Fitzpatrick et al., 2008; Young et al., 2005). Also, both studies reported that the participating parents were eager for information as well as eager for support in learning how to seek information on their own (Fitzpatrick et al., 2008; Young et al., 2005). In Young and others (2005), deaf parents of deaf children reported their frustrations with the assumption by the professional community that they did not require additional information and support simply because they themselves understood hearing loss. Thus, two studies from two different countries found parents reporting similar desires and needs.

In 2010, Jackson and others found that parents of children newly diagnosed with hearing loss desired support related to general emotional well-being such as stress relief and counseling. One parent recommended that marriage counseling was important to help families deal with grief, guilt, and stress. Additionally, parents desired social networks, parent support groups, and time to pursue individual interests.

Parent Perceptions of Supports for Children with Disabilities

Bailey and others (2005) studied parents of children with disabilities, their perceptions of Early Intervention and how those supports impacted their parenting. They found that at the end of the Early Intervention programs, most parents felt competent in caring for their children and advocating for services. However, they also found marked differences. Parents still struggled with their ability to deal with their child’s behavior problems and to gain access to community resources. Parents of minority ethnic backgrounds, parents of children with health problems, and single parents all continued to report higher levels of stress and lower quality of life. Epley,
Summer, and Turnbull (2011) studied family quality of life after enrollment in Early Intervention services. They found that the majority of participating parents were satisfied with the services that they received. However, parents who reported greater needs also reported lower quality of life.

**Parent perceptions of supports for children with hearing loss.**

Few studies have been conducted on parent perceptions of supports during Early Intervention programs for children with hearing loss in the United States within the last 15 years. However, previous research has been conducted. Harrison, Dannhardt, and Roush started a study in 1992 which was published in 1996. Within this study, 80% of participants stated that they were able to decide their level of involvement and 90% felt they were major decision makers. However, only 69% felt that their opinions were counted when there was a disagreement between themselves and the service providers and only 59.8% of respondents stated that they participated in the process of writing the Individual Family Service Plan. Additionally, while large percentages of participants reported wanting to meet other families with children with hearing loss or other deaf adults (83% and 66% respectively), those needs were not always met with only 76% stating they were supported in meeting other families and only 45% stated they were supported in meeting deaf adults. 36% of respondents stated that the program always or sometimes interfered with their daily routine.

Although programs and therefore experiences may differ between families in the United States and families in other countries, comparing parent evaluations is beneficial. In their study based in the United Kingdom, Gascon-Ramos, Campbell, and Young (2010) found that parents were more satisfied with the supports that they identified as helping them support their child as opposed to the services that they believed were meant to support themselves. Additionally, they
found that parents’ level of satisfaction with Early Intervention increased the longer families were enrolled in the program. In their study based in Tel Aviv, Ingber and Dromi (2009) found similar results with earlier studies based in the United States. For example, while parents were satisfied with the professionals’ attitude towards families and their heightened role in family-centered care, they also reported lower satisfaction with professionals’ encouraging them to take on that role.

**Theoretical Framework**

Family Systems Theory (Bowen, 1976) creates the foundation for this study. Family systems theory essentially states that a family is the sum of its parts. It explores the concept that one part of the family cannot be understood in isolation, nor can one part function without having an effect on the other parts (Bowen, 1976). In terms of this study, the child cannot be viewed independent of the parents and the parents cannot be viewed independent of the effects of raising a child with a disability. When needs of the child and the family are met, the impact on the child is positive. Conversely, when needs are unmet, the outcomes for the child may be negative. See Figure 1 which depicts this concept.
Summary

Research has established a connection between the birth of a child with a disability, including hearing loss, and an increase in emotional distress in parents. This increase in distress, caused by an increase in demands on a family’s emotional and financial resources, has been shown to potentially lead to negative impacts on child development through changes in the parent-child relationship when needs are not met. As a result, professional organizations have devised best practices to support families during the crucial early years of a child’s life leading to a creation of Early Intervention programs. In regards to children born with hearing loss, these Early Intervention programs were designed to meet the unique needs of their families. This allows the child to benefit from not only direct services but also an enhanced family unit.

To meet these needs, Early Intervention programs, developed using recommended practiced from professional organizations, work to tailor its services to the family and the child.
However, these programs work within the context of recommended practices and the framework of an individualized family service plan to meet the specific needs of children with hearing loss. The goal is to meet the identified needs of a specific family. To do this, it is necessary to continue identifying family needs as technology and resources for children with hearing loss continue to change.

Chapter 3

Methods

Preface

Due to the restrictions put in place by the COVID-19 pandemic, the methods for this study have changed from the original design of one-on-one in-person interviews to an online survey. All efforts were made to ensure that the content of data collected was similar. Updated IRB permission was obtained for this change which included permission to use Survey Monkey to send surveys to participants, an updated age range (changing from birth-to-three years old to birth-to-five years old), and an updated geographical pool (from one southern state to a nationwide search for participants).

Introduction

The purpose of this study was to gain a better understanding of the needs of parents of children with hearing loss and their experiences in birth-to-three Early Intervention programs. This study used a survey of hearing parents of children who were aged birth-to-five years old, identified as having hearing loss (including unilateral, bilateral, mild, moderate, severe, and profound) and who experienced Early Intervention (see Appendix A). The survey questions included questions to collect demographic information about the family (including participants' current age, gender, marital status, and highest level of education), demographic information
about the family during their time of enrollment in Early Intervention (including employment status, income, and type of community), information about the child (including age, age at diagnosis, type of hearing loss, degree of hearing loss, amplification choice, and communication choice), information about the child’s interaction with the birth-to-three intervention program (including age at enrollment in birth-to-three, time between diagnosis and beginning of interventions, length of enrollment, and types of services). Participants were also asked open-ended questions (including if they had prior knowledge of hearing loss, interaction with other families, interaction with deaf adults, if they found those interactions helpful/not helpful, professional assistance getting connected, a description of the services, how their concerns and needs were met, what was helpful, what was not helpful, any needs that were not addressed, and anything else they would like to share). The perspective of parents is critical to better understand how to deliver services and supports in the future.

**Qualitative Methodology**

This study will utilize a qualitative method in order to gain a better understanding of the unique experiences of families of children with hearing loss who are enrolled in an Early Intervention program. Qualitative research is essential to understanding the lived experiences of individuals (Lichtman, 2013) and utilizes various methods in an attempt to understand these experiences through the lens of the individual (Sherman & Webb, 2004).

Qualitative methodology is a widely accepted method of scientific study in the social sciences and takes into consideration the limitations of numerical data when trying to understand a field that deals significantly with complex humans and their experiences (Creswell, 2014; Lichtman, 2013; Rubin & Rubin, 2012). Understanding the needs of those that are directly impacted is crucial to advancing the knowledge of how the larger structures need to change.
Creswell (2014) states that it is appropriate to conduct qualitative research when a “problem or issue needs to be explored ... because of a need to study a group or population, identify variables that cannot be easily measured, or hear silenced voices” (p. 47). Also, Rubin and Rubin (2012) state that a qualitative approach allows a researcher to “extend their intellectual and emotional reach across a variety of barriers” and reconstruct events that the researcher has never experienced through the eyes of the very people involved (p. 3). In order to bring the experiences and emotions of the families and children who are deaf or hard of hearing to the forefront of the discussion and to answer the research questions, this study required the use of a more humanistic lens. It allowed those “silenced voices” to be heard at a crucial point in the delivery of services and supports with Early Intervention programs.

**Bracketing.**

One of the steps to exploring an individual’s phenomena is for researchers to explore their own experiences with and understanding of that same phenomenon, in this case, Early Intervention services and supports. This is often referred to as “bracketing” their biases and preconceptions (Patton, 1990 as reported by Hatch, 2002, p. 30). It is used to mitigate the potential effect of internal, and often unrecognized, biases and ensures that the findings are scientifically sound. This is a necessary step in the study as my own personal experiences as a parent of a child with hearing loss who received Early Intervention services need to be set aside in order to develop the survey and analyze the data.

One recommendation on how to bracket is to write down your personal experiences in your final report of your findings. My personal experiences with Early Intervention for children with hearing loss, though they occurred a decade ago, are presented to the reader to ensure that potential biases are recognized throughout the process. My middle child was diagnosed with a
hearing loss at birth and he went through approximately 24 months of Early Intervention services. Although it was my experiences with Early Intervention for children with hearing loss that initially piqued my interest in studying this phenomenon, my experiences are set aside in order to allow the families and data to speak for themselves.

**Web-Survey Research**

Qualitative research is essential to understanding the lived experiences of individuals (Lichtman, 2013) and utilizes various methods in an attempt to understand these experiences through the lens of the individual (Sherman & Webb, 2004). A subsection of qualitative research which has gained in popularity is surveys, or "the collection of information from...individuals through their responses to questions" (Check & Schutt, 2012, p 160). Though a variety of data collection options are available in a qualitative study, this study used a quasi-structured digital survey (Acharya, 2010) and included both open-ended and closed-ended questions.

Though the research question calls for a more humanistic lens, the use of a digital survey requires that some questions have limited answer choices. For example, demographic questions were asked using closed-ended questions. This reduced the need for unnecessary coding and reduced the potential for errors. Additionally, using closed-ended questions to collect demographic information reduced the participants' response fatigue and non-response errors by not requiring lengthy answers to questions that did not relate to their experience which is central to the purpose of the study. In addition, questions related to the participants’ experiences were asked using open-ended questions. This allowed the participants to answer more freely and to provide as much detail and context as they wished. Zuell (2016) states that “open-ended questions require respondents to formulate a response in their own words and to express it
verbally or in writing [and to not be steered] in a particular direction by predefined response categories” (See Appendix A).

In order to reduce the potential for some difficulties that plague qualitative survey research, this study used a web-based program, SurveyMonkey. By using a web-based program, the survey was distributed to a large population, increasing the coverage and reach of the survey. The web-based program also worked to reduce nonresponse errors by allowing participants to answer the questionnaire from the comfort of their own home or their location of choice, took approximately 10 minutes to complete, and used an engaging design to increase interactivity.

Participants

Using purposive sampling, a nonprobability sample, participants for this study were chosen from within the population of families who are currently receiving Early Intervention services or recently completed Early Intervention services in the United States. Children of participants were 5 years or younger. Nonprobability sampling is sampling that requires participants to be chosen based on the subjective judgement of the researcher rather than random selection. The topic of this research placed constraints on the necessary participants and purposive sampling allowed the researcher to choose participants which fit the needs of the study.

The data gathered from this sample set allowed the researcher to discover relationships or explain what occurred (Merriam, 2009, p. 77; Hatch, 2002). Purposive sampling, which requires the researcher to purposely choose the individuals that fit the criteria for the study (Lavrakas, 2008), allowed the researcher to identify individuals who experienced the identified phenomena of Early Intervention for children with hearing loss. Purposive sampling was used in this study.
due to the limited number of parents of children with hearing loss who experience Early Intervention.

Participants for this study included hearing parents whose children: (1) were diagnosed as having a hearing loss of any configuration, (2) were aged birth-to-five years old at the time of this study, and (3) experienced or are experiencing the Early Intervention system in any of the 50 states. Due to the statistical imbalance between the number of children with hearing loss born to hearing parents and those born to parents with hearing loss, as well as differences in the lived experiences of the two populations, this study included only hearing parents (Mitchell & Karchmer, 2004). Degree and type of hearing loss that was accepted included: mild, moderate, severe, profound, unilateral, bilateral, sensorineural loss, congenital malformations, conductive loss, or mixed losses. Approved children were those aided with hearing aids, bone conduction hearing aids, or cochlear implants; or they could be unaided. They could use American Sign Language, Cued Speech, manually coded English, or Spoken English. The Joint Committee on Infant Hearing in 2013 specifically states that Early Intervention should include children with all types of hearing loss including mild and unilateral. As a result, this study aimed to include a cross section of the entire population of children with hearing loss.

To gather appropriate participants, participants were contacted nationally through email and social media platforms using an introductory email that included information about the study as well as consent information (see Appendix B). The relevant platforms included organizations for individuals and families with hearing loss and deafness, individuals with special needs/disabilities, and parent support groups such as www.handsandvoices.org, www.babyhearing.org, www.beginningssvsc.org, and facebook.com. The administrator and/or contact person listed on websites from relevant loss of hearing/deaf programs were sent an email
to briefly describe the research project along with the letter of consent to show anonymity of the potential parents/subjects.

Additionally, participants were recruited via the administrator or contact person listed on websites for state Early Intervention programs, state schools for the deaf and hard of hearing, university audiology and teacher training programs. Participants in each geographic region, as designated by the Census Bureau, were contacted. These regions included the Midwest (Illinois, Indiana, Michigan, Ohio, Wisconsin, Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, and South Dakota), the Northeast (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, New Jersey, New York, and Pennsylvania), the South (Delaware, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, District of Columbia, West Virginia, Alabama, Kentucky, Mississippi, Tennessee, Arkansas, Louisiana, Oklahoma, and Texas), and the West (Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Utah, Wyoming, Alaska, California, Hawaii, Oregon, and Washington). These programs were located through websites such as www.infanthearing.org, www.gallaudet.edu, www.audiology.org, www.audiologist.org, and www.deafed.net. The contact person from these organizations were asked to share the survey with parents within their networks.

These sites were chosen specifically because their work with families and children with hearing loss would fit the criteria required for this study. Rubin and Rubin (2012) explained four reasons why a site is chosen: it is relevant, the researcher can gain access, it allows the researcher to test explanations, and it helps researchers to possibly apply findings elsewhere. As a result of this criteria, sites are often chosen for practical reasons, including location and population, which makes the possibility of completing the research feasible.

Survey procedures and data collection.
Prior to participants’ completion of the survey, they were notified in writing of the purpose of the study, that their participation was completely voluntary, and that they could choose to not answer any question or choose not to complete the survey at any point (See Appendices B and C). Completion of the survey served as the participants’ virtual signature for consent.

Data was collected through the digital platform SurveyMonkey. The survey initially collected demographic information including gender, age of interviewee, current age of child, age of child at the start of Early Intervention, marital status, level of education, employment, income level, and type of community the family lives in. Questions (See Table 1) about the families’ background and experience with Early Intervention allowed the participants to provide more detailed information. The questions were developed through a review of the literature, the researcher’s personal experiences, DEC and national hearing loss organization, Joint Committee on Infant Hearing (JCIH), recommendations.

There are several themes that have been identified as areas of need for families of children with hearing loss, including information about hearing loss, information about expectations related to hearing loss, access to other families, and unbiased information about options on topics such as amplification and communication (Âsberg et al., 2008; Pipp-Siegel et al., 2002; Quittner et al., 2010). The research also shows that when parents have their needs met, they are better able to cope with the changes they encounter with the diagnosis and are better able to support the development of their child in the home. Support and resources are most beneficial when they are provided in areas of need that have been identified by the parent and family (Dunst, 2002; Guralnick, 2001).
Table 1: Interview Questions and Justifications

<table>
<thead>
<tr>
<th>Questions</th>
<th>Justification and related research question</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographic data about the parents and family:</strong></td>
<td></td>
</tr>
<tr>
<td>Age of interviewee, gender of interviewee, marital status, level of education, employment, income, community type</td>
<td>Studies have shown that child development is influenced by socioeconomic status. For example, deficiencies in nutrition, health, social interaction, and maternal connection, often brought on by long term poverty, have all been linked to deficiencies in social-emotional, communication, cognition, and adaptive skills development (Johnston et al., 2009; Rowe et al., 2012). Level of parental education has also been shown to impact development. (Ching et al., 2010; Johnston et al., 2009). Although this is not related to a research question, this aims to gather demographic information of families.</td>
</tr>
<tr>
<td><strong>Background information about the child with hearing loss:</strong></td>
<td>The umbrella of hearing loss diagnosis is complex and filled with a mix of type of loss, degree, and configuration of loss. Within the diagnosis category, there are a variety of communication and amplification options that families choose which impact a family's experience in Early Intervention (The Facts About Hearing Loss, 2021; Vila &amp; Lieu, 2015). Although this is not related to a research question, it aims to gather demographic information about the child.</td>
</tr>
<tr>
<td>Current age, age when diagnosed, type of hearing loss, degree of hearing loss, type of amplification, main mode of communication</td>
<td></td>
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</tbody>
</table>
Table 1 (continued): Interview Questions and Justifications

<table>
<thead>
<tr>
<th>Prior knowledge of hearing loss: Did you have knowledge about deafness and hearing loss before your child’s diagnosis? Please explain.</th>
<th>90% of children diagnosed with a severe hearing loss are born to parents who have no prior exposure to individuals who are deaf or hard of hearing or the deaf community which creates unique needs within the family. (American Speech-Language-Hearing Association, 2008; Mitchell &amp; Karchmer, 2004). Related to research question 3 and aims to gather data on how well Early Intervention services align to recommendations.</th>
</tr>
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<tbody>
<tr>
<td>Family experience with the Early Intervention program: What was the child’s age when he or she entered the birth-to-three intervention program? How much time was there between diagnosis and starting interventions? How long has your child been (or was) in the Early Intervention program?</td>
<td>In their review of research, Bailey and Bruder (2005) found that most of the reviewed studies stated that Early Intervention programs should: (1) help families learn about their child’s disability and things that they can do to help maximize the child’s development; (2) support families in gaining advocacy skills and confidence in their ability to seek and access services; and (3) help families build strong support networks, both formal and informal (p. 6). Additionally, JCIH (2007) recommended that identified children enter a birth-to-three Early Intervention program no later than six months, help parents meet other parents of children with hearing loss, and help parents meet deaf adults. (Continued)</td>
</tr>
</tbody>
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Table 1(continued): Interview Questions and Justifications

<table>
<thead>
<tr>
<th>Question</th>
<th>Justification</th>
</tr>
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<tbody>
<tr>
<td>What types of services does (or did) your child receive in the birth-to-three program? In your own words, how would you describe the services that your child and family receive? Have you met other families with children with hearing loss since your child’s diagnosis? Have you met other adults with hearing loss since your child’s diagnosis? Did any professional help you get connected to the program? What did not work for your child and family? As a parent, how were your concerns and needs met?</td>
<td>Related to research questions 1, 2, and 3 and aims to gather information on parents’ experiences with Early Intervention.</td>
</tr>
</tbody>
</table>
Table 1 (continued): Interview Questions and Justifications

<table>
<thead>
<tr>
<th>Question</th>
<th>Justification</th>
</tr>
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<tbody>
<tr>
<td>through the birth-to-three intervention program?</td>
<td></td>
</tr>
<tr>
<td>Overall, what was helpful for your child and family?</td>
<td></td>
</tr>
<tr>
<td>Why? Overall, what was not helpful for your child and family? Why?</td>
<td></td>
</tr>
<tr>
<td>Did you have any needs or priorities that you felt were not addressed or supported?</td>
<td></td>
</tr>
<tr>
<td>Please explain. Is there anything else that you would like to share?</td>
<td></td>
</tr>
</tbody>
</table>

Data Analysis

Data analysis occurred in two phases. First, demographic data, including information about the participant and the participant’s child was analyzed. Next, open-ended responses were coded. Specific words or phrases were highlighted that captured the individuals’ experiences and then transferred into an Excel file (Saldana, 2013). Words or phrases were identified based on how the individuals’ experiences aligned, whether similar or different, to the JCIH and DEC recommendations for Early Intervention. Using descriptive coding, these words and/or phrases were assigned a code word. The code words were used to identify patterns, themes, relationships, or explanations within the data (Charmaz, 2006). Creswell (2014) describes coding as
“aggregating the text or visual data into small categories of information” (p. 184) and a key process in data analysis (Babbie, 2020). Larger, overarching themes were then identified from the data based on “hunches, insights, and intuition” (Creswell, 2013, p. 187) or by applying the data within a construct of previous research, in this case, to previously identified recommendations for Early Intervention. Data from parents with children currently in Early Intervention was also compared to data from parents with children who exited Early Intervention within the previous 24 months, or between 37-months and 60-months-old.

By comparing the experiences of the parents to the recommendations of Early Intervention for children with hearing loss, the researcher was able to analyze the connections between the parents’ identified needs and the ability of the program to meet those identified needs.

Summary

This study utilized a web-based survey which included questions related to basic demographic data as well as open-ended questions related to the participants’ experiences in a birth-to-three Early Intervention program. Open-ended responses were coded and analyzed to identify overarching themes that emerged from participants’ responses. Then, responses were analyzed to determine how participants’ needs were or were not met during their time with the birth-to-three Early Intervention program. Parent identified needs were then analyzed alongside recommended practices. From this data analysis, parent needs and how well the best practices informed Early Intervention met those needs was determined.

Chapter 4

Results
The purpose of this study was to develop a deeper understanding of parent perceptions of Early Intervention programs for children with hearing loss from birth-to-three. Families of children with hearing loss face unique issues and concerns. For successful intervention, programs must be tailored to the needs of each family. Recommended practices have been developed to help improve Early Intervention services for children with hearing loss. Therefore, this study identified the concerns and priorities of parents of children with hearing loss in the United States from their perspective, determined if their identified needs had been met, and determined if those identified needs correlated with recommended practices.

**Recruitment**

In the beginning of 2020, 56 emails which included the survey were sent to points of contact in Louisiana, the initial focus of the study, in an attempt to garner perspectives from parents of children with hearing loss who were enrolled in a birth-to-three Early Intervention program. Due to a lack of sufficient numbers of participants and unexpected changes due to the global pandemic, the criteria was expanded to include all states and allowed parents to participate if their child had completed the Early Intervention program within the last two years. Therefore, over the course of three weeks in August 2020, an additional 605 emails were sent out to directors and leaders in the field in all 50 states and the District of Columbia which requested that they forward the information to parents and families in their group that met the new criteria. These directors and leaders were identified through the following websites: www.handsandvoices.org, www.babyhearing.org, www.beginningssvsc.org, www.facebook.com, www.infanthearing.org, www.gallaudet.edu, www.audiology.org, www.audiologist.org, and www.deafed.net. Of those emails, 99 were sent directly to EDHI state contacts, providers within Parent Infant Pupil programs, and preschools or early education
centers; 73 emails were sent to Hands and Voices, Guide by Your Side, parent support programs, parent support websites, and social media pages; and 217 emails were sent to schools for the deaf and hard of hearing or identified teachers of the deaf. The remaining 216 emails were sent to audiologists and college-based programs for audiologists and speech therapists. The survey remained active fourteen weeks after the last email was sent out. Originally, contacts and responses were tracked by geographic regions identified by the Census Bureau. Table 2 reflects the geographic regions, number of emails sent, and responses received.

Table 2: Recruitment data

<table>
<thead>
<tr>
<th>Geographic region</th>
<th>Emails sent</th>
<th>Responses received</th>
</tr>
</thead>
<tbody>
<tr>
<td>Midwest</td>
<td>160</td>
<td>13</td>
</tr>
<tr>
<td>Northeast</td>
<td>90</td>
<td>3</td>
</tr>
<tr>
<td>South</td>
<td>252</td>
<td>17</td>
</tr>
<tr>
<td>West</td>
<td>99</td>
<td>5</td>
</tr>
</tbody>
</table>

Demographics of the Sample

At the completion of the period when the survey remained active, it was determined that all geographic regions had a less than 10% response rate. Due to the limited responses from some of the regions, it was not possible to analyze data based on geographic regions. However, it is noted that more participants came from the South and therefore are a larger representation than other regions.

Family data.

In total, 52 responses were received. However, 14 responses were excluded because either the child or the parent did not meet the criteria. Twelve children who were older than 60 months, or a current age was not provided, were excluded to ensure that all parents had recent experiences with the birth-to-three Early Intervention program. Two parents who are deaf or hard
of hearing were also excluded due to their increased background knowledge about the needs of individuals who are deaf or hard of hearing. These exclusions were made to ensure that all participants were viewing their experiences with the birth-to-three Early Intervention program through the same lens. The remaining sample consisted of 38 responses (see Table 3). Of the remaining responses, 24 participants had children currently enrolled in the birth-to-three Early Intervention program, and 14 participants had children who aged out of the program in the last two years.

*Table 3: Parent Responses: Parent Demographics*

<table>
<thead>
<tr>
<th>Parent</th>
<th>Location</th>
<th>Parent Age</th>
<th>Marital Status</th>
<th>Education</th>
<th>Employment</th>
<th>Income</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>South</td>
<td>31-40</td>
<td>Married</td>
<td>Bachelor</td>
<td>Unemployed</td>
<td>&gt;$110K</td>
<td>Urban</td>
</tr>
<tr>
<td>2</td>
<td>Midwest</td>
<td>31-40</td>
<td>Married</td>
<td>Associate</td>
<td>Outside home</td>
<td>$90K-$110K</td>
<td>Urban</td>
</tr>
<tr>
<td>3</td>
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<td>31-40</td>
<td>Married</td>
<td>Bachelor</td>
<td>From home</td>
<td>$50K-$70K</td>
<td>Suburban</td>
</tr>
<tr>
<td>4</td>
<td>Northeast</td>
<td>31-40</td>
<td>Married</td>
<td>Bachelor</td>
<td>From home</td>
<td>&gt;$110K</td>
<td>Suburban</td>
</tr>
<tr>
<td>5</td>
<td>Northeast</td>
<td>31-40</td>
<td>Married</td>
<td>Bachelor</td>
<td>Outside home</td>
<td>$90K-$110K</td>
<td>Suburban</td>
</tr>
<tr>
<td>6</td>
<td>West</td>
<td>31-40</td>
<td>Married</td>
<td>Bachelor</td>
<td>Outside home</td>
<td>&gt;$110K</td>
<td>Suburban</td>
</tr>
<tr>
<td>7</td>
<td>Midwest</td>
<td>31-40</td>
<td>Married</td>
<td>Graduate</td>
<td>Outside home</td>
<td>&gt;$110K</td>
<td>Suburban</td>
</tr>
<tr>
<td>8</td>
<td>Midwest</td>
<td>21-30</td>
<td>Single</td>
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<td>&lt;$30K</td>
<td>Suburban</td>
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<td>Rural/Small town</td>
</tr>
<tr>
<td>11</td>
<td>Midwest</td>
<td>21-30</td>
<td>Married</td>
<td>High School</td>
<td>Outside home</td>
<td>No response</td>
<td>Rural/Small town</td>
</tr>
<tr>
<td>12</td>
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<td>21-30</td>
<td>Married</td>
<td>Associate</td>
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<td>31-40</td>
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<td>Suburban</td>
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<tr>
<td>14</td>
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<td>Bachelor</td>
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<td>Rural/Small town</td>
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<tr>
<td>16</td>
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<td>Bachelor</td>
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<td>Suburban</td>
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</table>

(continued)
Table 3 (continued): Parent Responses: Parent Demographics

<table>
<thead>
<tr>
<th>Parent</th>
<th>Location</th>
<th>Parent Age</th>
<th>Marital Status</th>
<th>Education</th>
<th>Employment</th>
<th>Income</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
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<td>Single</td>
<td>Associate</td>
<td>Outside home</td>
<td>&lt;$30K</td>
<td>Rural/Small town</td>
</tr>
<tr>
<td>18</td>
<td>West</td>
<td>51-60</td>
<td>Divorced/Separated</td>
<td>Graduate</td>
<td>Outside home</td>
<td>$50K-$70K</td>
<td>Urban</td>
</tr>
<tr>
<td>19</td>
<td>South</td>
<td>21-30</td>
<td>Married</td>
<td>Associate</td>
<td>Outside home</td>
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<td>Suburban</td>
</tr>
<tr>
<td>20</td>
<td>South</td>
<td>41-50</td>
<td>Married</td>
<td>Graduate</td>
<td>Unemployed</td>
<td>&lt;$30K</td>
<td>Urban</td>
</tr>
<tr>
<td>21</td>
<td>South</td>
<td>&lt;20</td>
<td>Married</td>
<td>Associate’s</td>
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<td>$70K-$90K</td>
<td>Rural/Small town</td>
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<tr>
<td>22</td>
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<td>31-40</td>
<td>Married</td>
<td>Bachelor’s</td>
<td>Outside home</td>
<td>$70K-$90K</td>
<td>Rural/Small town</td>
</tr>
<tr>
<td>23</td>
<td>West</td>
<td>31-40</td>
<td>Married</td>
<td>Graduate</td>
<td>From home</td>
<td>$70K-$90K</td>
<td>Suburban</td>
</tr>
<tr>
<td>24</td>
<td>South</td>
<td>31-40</td>
<td>Married</td>
<td>High School</td>
<td>Outside home</td>
<td>$50K-$70K</td>
<td>Rural/Small town</td>
</tr>
<tr>
<td>25</td>
<td>South</td>
<td>21-30</td>
<td>Single</td>
<td>High School</td>
<td>Unemployed</td>
<td>&lt;$30K</td>
<td>Rural/Small town</td>
</tr>
<tr>
<td>26</td>
<td>South</td>
<td>21-30</td>
<td>Married</td>
<td>Associate’s</td>
<td>Unemployed</td>
<td>&lt;$30K</td>
<td>Suburban</td>
</tr>
<tr>
<td>27</td>
<td>Northeast</td>
<td>31-40</td>
<td>Married</td>
<td>Bachelor’s</td>
<td>From home</td>
<td>&gt;$110K</td>
<td>Suburban</td>
</tr>
<tr>
<td>28</td>
<td>South</td>
<td>41-50</td>
<td>Married</td>
<td>Graduate</td>
<td>Unemployed</td>
<td>&gt;$110K</td>
<td>Suburban</td>
</tr>
<tr>
<td>29</td>
<td>West</td>
<td>51-60</td>
<td>Single</td>
<td>Associate’s</td>
<td>Outside home</td>
<td>$90K-$110K</td>
<td>Suburban</td>
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<td>30</td>
<td>Midwest</td>
<td>31-40</td>
<td>Married</td>
<td>High School</td>
<td>Outside home</td>
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<td>Suburban</td>
</tr>
<tr>
<td>31</td>
<td>South</td>
<td>41-50</td>
<td>Married</td>
<td>Associate’s</td>
<td>From home</td>
<td>$30K-$50K</td>
<td>Urban</td>
</tr>
<tr>
<td>32</td>
<td>South</td>
<td>31-40</td>
<td>Divorced/Separated</td>
<td>Bachelor’s</td>
<td>Outside home</td>
<td>$50K-$70K</td>
<td>Suburban</td>
</tr>
<tr>
<td>33</td>
<td>South</td>
<td>21-30</td>
<td>Married</td>
<td>Associate’s</td>
<td>Unemployed</td>
<td>$70K-$90K</td>
<td>Rural/Small town</td>
</tr>
<tr>
<td>34</td>
<td>South</td>
<td>31-40</td>
<td>Married</td>
<td>High School</td>
<td>Unemployed</td>
<td>$50K-$70K</td>
<td>Rural/Small town</td>
</tr>
<tr>
<td>35</td>
<td>South</td>
<td>21-30</td>
<td>Single</td>
<td>Associate’s</td>
<td>Outside home</td>
<td>$30K-$50K</td>
<td>Suburban</td>
</tr>
<tr>
<td>36</td>
<td>South</td>
<td>31-40</td>
<td>Single</td>
<td>Bachelor’s</td>
<td>Outside home</td>
<td>$50K-$70K</td>
<td>Suburban</td>
</tr>
<tr>
<td>37</td>
<td>South</td>
<td>&lt;20</td>
<td>Single</td>
<td>High School</td>
<td>Outside home</td>
<td>&lt;$30K</td>
<td>Rural/Small town</td>
</tr>
<tr>
<td>38</td>
<td>South</td>
<td>31-40</td>
<td>Married</td>
<td>Graduate</td>
<td>Outside home</td>
<td>$70K-$90K</td>
<td>Suburban</td>
</tr>
</tbody>
</table>

Of the responses, 100% were female. The age, marital status, and level of education of the participants is summarized in Table 4. The majority (53%, 20/38) of the participants were between 31 and 40 years old. Ten participants (26%) were between 21 - 30 years. Other age groups were represented by smaller population sizes. Married participants represented the
majority of responses at 74% (28/38), seven (18%) were single, and three of 38 (8%) were divorced/separated. The level of education was dispersed more evenly among high school, associate degree, bachelor degree, and graduate degree. The largest representations were bachelor degrees at 32% (12/38) and associate at 29% (11/38).

Table 4: Parent Demographics

<table>
<thead>
<tr>
<th>Parent Demographic</th>
<th>Percentage (count) (n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;20</td>
<td>5 (2)</td>
</tr>
<tr>
<td>21 – 30</td>
<td>26 (10)</td>
</tr>
<tr>
<td>31 – 40</td>
<td>53 (20)</td>
</tr>
<tr>
<td>41 – 50</td>
<td>11 (4)</td>
</tr>
<tr>
<td>51 – 60</td>
<td>5 (2)</td>
</tr>
<tr>
<td><strong>Relationship</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>74 (28)</td>
</tr>
<tr>
<td>Single</td>
<td>18 (7)</td>
</tr>
<tr>
<td>Divorced/Widowed</td>
<td>8 (3)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>21 (8)</td>
</tr>
<tr>
<td>Associate’s</td>
<td>29 (11)</td>
</tr>
<tr>
<td>Bachelor’s</td>
<td>32 (12)</td>
</tr>
<tr>
<td>Graduate</td>
<td>18 (7)</td>
</tr>
</tbody>
</table>

Information about the participants during the time that their child was enrolled in the birth-to-three Early Intervention program is summarized in Table 5. This information included their employment, their level of income, and a description of the community that they lived in during this period of time. The majority of participants, 66% (25/38), worked out of the home during the time their child was enrolled in a birth-to-three Early Intervention program. The remaining responses were almost evenly split between unemployed (42%, 7/38) or worked from home (16%, 6/38). Twenty-six percent (10/38) of the total participant population earned between $50,000 and $70,000 annually. The others ranged from four of 38 (11%) participants earning
between $30,000 - $50,000 to seven of 38 (18%) participants earning more than $100,000. One participant did not answer this question. The majority of participants (53%, 20/38) described their community as suburban and six of 38 (16%) described their community as urban, making it the type of community with the smallest representation among the participants.

*Table 5: Employment and Community Demographics*

<table>
<thead>
<tr>
<th>Employment and Community Demographics</th>
<th>Percentage (count) (n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment</strong></td>
<td></td>
</tr>
<tr>
<td>Worked outside of home</td>
<td>66 (25)</td>
</tr>
<tr>
<td>Worked from home</td>
<td>42 (16)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>18 (7)</td>
</tr>
<tr>
<td><strong>Family income</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;$30,000</td>
<td>16 (6)</td>
</tr>
<tr>
<td>$30 - $50,000</td>
<td>11 (4)</td>
</tr>
<tr>
<td>$50 - $70,000</td>
<td>26 (10)</td>
</tr>
<tr>
<td>$70 - $90,000</td>
<td>16 (6)</td>
</tr>
<tr>
<td>$90 - $110,000</td>
<td>11 (4)</td>
</tr>
<tr>
<td>&gt;$110,000</td>
<td>18 (7)</td>
</tr>
<tr>
<td><strong>Community description</strong></td>
<td></td>
</tr>
<tr>
<td>Suburban</td>
<td>53 (20)</td>
</tr>
<tr>
<td>Rural/Small town</td>
<td>32 (12)</td>
</tr>
<tr>
<td>Urban</td>
<td>16 (6)</td>
</tr>
</tbody>
</table>

*Child and hearing loss data.*

Information specific to the child’s current age (in months) and data about the child’s hearing loss were gathered at the time of the study (see Table 6). Twelve of 38 children (32%) were between the ages of 13 and 24 months. All of the other age ranges were represented by either six or seven children.
Table 6: Child and Hearing Loss Data

<table>
<thead>
<tr>
<th>Parent Knowledge</th>
<th>Prior Knowledge</th>
<th>Current Age at dx (mths)</th>
<th>Age at dx (mths)</th>
<th>Type of HL</th>
<th>Degree of HL</th>
<th>Amplification</th>
<th>Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, media</td>
<td>Yes, family</td>
<td>16</td>
<td>0</td>
<td>Sensorineural</td>
<td>Severe</td>
<td>Hearing aid(s)</td>
<td>Signed Language</td>
</tr>
<tr>
<td>No</td>
<td>59</td>
<td>0</td>
<td>Sensorineural</td>
<td>Profound</td>
<td>No amplification device is used</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>48</td>
<td>0</td>
<td>Sensorineural</td>
<td>Profound</td>
<td>Cochlear implant(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>35</td>
<td>2</td>
<td>Sensorineural</td>
<td>Profound</td>
<td>Hearing aid(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>42</td>
<td>16</td>
<td>Sensorineural</td>
<td>Profound</td>
<td>Cochlear implant(s)</td>
<td>Spoken Language</td>
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</tr>
<tr>
<td>No</td>
<td>54</td>
<td>1</td>
<td>Sensorineural</td>
<td>Profound</td>
<td>Cochlear implant(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>Yes, family</td>
<td>46</td>
<td>21</td>
<td>Sensorineural</td>
<td>Moderate</td>
<td>Hearing aid(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>Yes, family</td>
<td>3</td>
<td>0</td>
<td>Mixed</td>
<td>Moderate</td>
<td>BAHA(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>Yes, work</td>
<td>56</td>
<td>0</td>
<td>Sensorineural</td>
<td>Moderate</td>
<td>BAHA(s)</td>
<td>Spoken Language</td>
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</tr>
<tr>
<td>No</td>
<td>48</td>
<td>0</td>
<td>I don't know</td>
<td>Moderate</td>
<td>Hearing aid(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>60</td>
<td>48</td>
<td>I don't know</td>
<td>Mild</td>
<td>Hearing aid(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>36</td>
<td>11</td>
<td>Sensorineural</td>
<td>Moderate</td>
<td>Hearing aid(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>2</td>
<td>Sensorineural</td>
<td>Severe</td>
<td>Hearing aid(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>2</td>
<td>Sensorineural</td>
<td>Profound</td>
<td>BAHA(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>16</td>
<td>0</td>
<td>Sensorineural</td>
<td>Moderate</td>
<td>Hearing aid(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>53</td>
<td>20</td>
<td>Sensorineural</td>
<td>Severe</td>
<td>Hearing aid(s)</td>
<td>Spoken Language</td>
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</tr>
<tr>
<td>No</td>
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<td>4</td>
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<td>Profound</td>
<td>No amplification device is used</td>
<td>Signed Language</td>
<td></td>
</tr>
<tr>
<td>Yes, family</td>
<td>22</td>
<td>7</td>
<td>Sensorineural</td>
<td>Profound</td>
<td>Cochlear implant(s)</td>
<td>Spoken Language</td>
<td></td>
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<tr>
<td>No</td>
<td>13</td>
<td>1</td>
<td>Sensorineural</td>
<td>Profound</td>
<td>Cochlear implant(s)</td>
<td>Spoken Language</td>
<td></td>
</tr>
</tbody>
</table>

(continued)
Information about the child’s hearing loss included the age (in months) when the child was diagnosed with hearing loss, the type of hearing loss, and the degree of hearing loss (see
Table 7). A diagnosis of hearing loss was confirmed within the first three months of life in 68% (26/38) of the children. The majority of participants’ children (79%, 30/38) have a sensorineural hearing loss. The others have either a conductive or mixed hearing loss. Children with a profound hearing loss are the largest representation (45%, 17/38) of degree of hearing loss. Moderate and severe degrees of hearing loss are represented by 10 and eight (26% and 21%) children respectfully.

Table 7: Child Demographics

<table>
<thead>
<tr>
<th>Child Demographics</th>
<th>Mean (count) (n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current age (months)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;12</td>
<td>16 (6)</td>
</tr>
<tr>
<td>13 – 24</td>
<td>32 (12)</td>
</tr>
<tr>
<td>25 – 36</td>
<td>16 (6)</td>
</tr>
<tr>
<td>37 – 48</td>
<td>18 (7)</td>
</tr>
<tr>
<td>49 – 60</td>
<td>18 (7)</td>
</tr>
<tr>
<td><strong>Age at diagnosis (months)</strong></td>
<td></td>
</tr>
<tr>
<td>0 – 3</td>
<td>68 (26)</td>
</tr>
<tr>
<td>4 – 6</td>
<td>11 (4)</td>
</tr>
<tr>
<td>7 – 12</td>
<td>8 (3)</td>
</tr>
<tr>
<td>&gt;12</td>
<td>13 (5)</td>
</tr>
<tr>
<td><strong>Type of hearing loss</strong></td>
<td></td>
</tr>
<tr>
<td>Sensorineural</td>
<td>79 (30)</td>
</tr>
<tr>
<td>Conductive</td>
<td>5 (2)</td>
</tr>
<tr>
<td>Mixed</td>
<td>5 (2)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>11 (4)</td>
</tr>
<tr>
<td><strong>Degree of hearing loss</strong></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>5 (2)</td>
</tr>
<tr>
<td>Moderate</td>
<td>26 (10)</td>
</tr>
<tr>
<td>Severe</td>
<td>21 (8)</td>
</tr>
<tr>
<td>Profound</td>
<td>45 (17)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3 (1)</td>
</tr>
</tbody>
</table>
**Information about decisions related to diagnosis.**

Information about parent knowledge of hearing loss and decisions that were made in response to the child’s diagnosis and anticipated needs are summarized in Table 8. A large percentage of participants (76%, 29/38) did not have prior knowledge about hearing loss. In open-ended responses, participants identified a history of hearing loss in extended family, media, social relationships, and work-related experience as ways that they were previously introduced to hearing loss.

Information about the chosen amplification and the chosen mode of communication is summarized in Table 7. Most participants chose either hearing aids (45%, 17/38) or cochlear implants (32%, 12/38) for their child. A smaller percentage (13%, 5/38) of participants’ children used a Bone Conduction Hearing Aid(s) (BAHA) or did not utilize any amplification (11%, 4/38). Of the 38 participants, the vast majority (79%, 30/38) stated that their family’s main method of communication was spoken language and eight of 38 (21%) used manual or signed language.

*Table 8: Decisions Related to Diagnosis*

<table>
<thead>
<tr>
<th>Decisions Related to Diagnosis</th>
<th>Percentage (count) (n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Amplification</strong></td>
<td></td>
</tr>
<tr>
<td>Hearing aid(s)</td>
<td>45 (17)</td>
</tr>
<tr>
<td>Cochlear Implant(s) (CI)</td>
<td>32 (12)</td>
</tr>
<tr>
<td>Bone Conduction Hearing Aid(s) (BAHAs)</td>
<td>13 (5)</td>
</tr>
<tr>
<td>No amplification used</td>
<td>11 (4)</td>
</tr>
<tr>
<td><strong>Main Mode of Communication</strong></td>
<td></td>
</tr>
<tr>
<td>American Sign Language (ASL)</td>
<td>21 (8)</td>
</tr>
<tr>
<td>Spoken Language</td>
<td>79 (30)</td>
</tr>
</tbody>
</table>
Family, child, and early intervention.

Information related to the families’ engagement with the birth-to-three Early Intervention program, including information about the child and the parent, was collected (see Table 9). The majority of children (58%, 22/38) entered birth-to-three Early Intervention prior to six months of age. The remaining children entered Early Intervention at six months of age or later or parents did not respond to this question. Almost all (97%, 37/38) of participants’ children were enrolled in the birth-to-three Early Intervention program for longer than six months. Only one (3%) participant’s child was enrolled for less time.

Table 9: Parent Responses: The Family, Child, and Early Intervention

<table>
<thead>
<tr>
<th>Parent</th>
<th>Age at start of EI (mths)</th>
<th>Time in to EI (mths)</th>
<th>Contact with EI</th>
<th>Therapies and Supports</th>
<th>Other families</th>
<th>Deaf adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>12 - 24</td>
<td>Hospital</td>
<td>2: OT, Speech</td>
<td>Yes, helpful</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>24 – 36</td>
<td>Family doctor</td>
<td>3: Audiology, PT, Speech</td>
<td>Yes, helpful</td>
<td>No</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>24 - 36</td>
<td>No</td>
<td>1: Speech</td>
<td>Yes, helpful</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>24 - 36</td>
<td>Audiologist</td>
<td>1: Speech</td>
<td>Yes, helpful</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>17</td>
<td>12 - 24</td>
<td>No response</td>
<td>3: Audiology, Speech, Technology</td>
<td>Yes, helpful</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>6</td>
<td>3</td>
<td>24 - 36</td>
<td>Pediatrician</td>
<td>3: Audiology, PT, OT</td>
<td>Yes, not helpful</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>7</td>
<td>24</td>
<td>12 – 24</td>
<td>Audiologist</td>
<td>3: Audiology, Speech, Technology</td>
<td>Yes, helpful</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>8</td>
<td>1</td>
<td>24 - 36</td>
<td>Audiologist</td>
<td>1: Speech</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>26</td>
<td>12 - 24</td>
<td>Self</td>
<td>2: OT, Speech</td>
<td>Yes, helpful</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>10</td>
<td>11</td>
<td>24 - 36</td>
<td>No response</td>
<td>1: Speech</td>
<td>No</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>11</td>
<td>&lt; 3</td>
<td>No response</td>
<td>2: OT, Speech</td>
<td>Yes, helpful</td>
<td>No response</td>
<td>No</td>
</tr>
<tr>
<td>12</td>
<td>12</td>
<td>24 - 36</td>
<td>Audiology</td>
<td>2: Audiology, Speech</td>
<td>Yes, helpful</td>
<td>No</td>
</tr>
</tbody>
</table>

(continued)
<table>
<thead>
<tr>
<th>Parent</th>
<th>Age at start of EI (mths)</th>
<th>Time in to EI (mths)</th>
<th>Contact with EI</th>
<th>Therapies and Supports</th>
<th>Other families</th>
<th>Deaf adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>3</td>
<td>6 – 12</td>
<td>Hospital</td>
<td>4: Audiology, Speech, OT, PT</td>
<td>Yes.</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>14</td>
<td>3</td>
<td>12 - 24</td>
<td>No response</td>
<td>4: OT, PT, Speech, Technology</td>
<td>No response</td>
<td>No response</td>
</tr>
<tr>
<td>15</td>
<td>2</td>
<td>12 – 24</td>
<td>Audiologist</td>
<td>4: Audiology, Speech, PT, Technology</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>16</td>
<td>19</td>
<td>12 - 24</td>
<td>Pediatrician</td>
<td>3: PT, OT, Speech</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>17</td>
<td>12</td>
<td>24 - 36</td>
<td>Pediatrician</td>
<td>3: Audiology, PT, Speech</td>
<td>Yes, helpful</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>18</td>
<td>8</td>
<td>24 – 36</td>
<td>Self</td>
<td>3: Audiology, Speech, Technology</td>
<td>Yes, helpful</td>
<td>Yes, not helpful</td>
</tr>
<tr>
<td>19</td>
<td>1</td>
<td>6 - 12</td>
<td>Audiologist</td>
<td>3: Audiology, Speech, Technology</td>
<td>Yes, helpful</td>
<td>No</td>
</tr>
<tr>
<td>20</td>
<td>2</td>
<td>12 – 24</td>
<td>Speech therapist</td>
<td>2: Audiology, Speech</td>
<td>Yes, helpful</td>
<td>Yes, not helpful</td>
</tr>
<tr>
<td>21</td>
<td>7</td>
<td>6 - 12</td>
<td>Audiologist</td>
<td>2: Audiology, Speech</td>
<td>No</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>22</td>
<td>2</td>
<td>24 – 36</td>
<td>Audiologist</td>
<td>2: Audiology, Speech</td>
<td>Yes, helpful</td>
<td>Yes, not helpful</td>
</tr>
<tr>
<td>23</td>
<td>9</td>
<td>6 – 12</td>
<td>Self</td>
<td>2: Audiology, Speech</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>24</td>
<td>5</td>
<td>6 – 12</td>
<td>Audiologist</td>
<td>2: Audiology, Speech</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>25</td>
<td>4</td>
<td>12 - 24</td>
<td>Audiologist</td>
<td>3: Speech, OT, PT</td>
<td>No response</td>
<td>No response</td>
</tr>
<tr>
<td>26</td>
<td>2</td>
<td>6 – 12</td>
<td>No response</td>
<td>1: Speech</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>27</td>
<td>5</td>
<td>12 – 24</td>
<td>Audiologist</td>
<td>1: Speech</td>
<td>Yes, helpful</td>
<td>No</td>
</tr>
<tr>
<td>28</td>
<td>5</td>
<td>24 - 36</td>
<td>Self</td>
<td>4: Audiology, Speech, Technology, Transportation</td>
<td>Yes, helpful</td>
<td>Yes, helpful</td>
</tr>
<tr>
<td>29</td>
<td>1</td>
<td>24 - 36</td>
<td>Audiologist</td>
<td>3: Audiology, OT, Speech</td>
<td>Yes</td>
<td>Yes, not helpful</td>
</tr>
<tr>
<td>30</td>
<td>6</td>
<td>24 - 36</td>
<td>Hospital</td>
<td>4: Audiology, PT, OT, Speech</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
Participants were asked to document the therapies and supports that their child and their family received through Early Intervention. All of participants’ children received one or more therapies (summarized in Table 10). Most received either two (26%, 10/38) or three (34%, 13/38) therapies. The other participants reported that their children received only one (18%, 7/38) therapy or four or more (21%, 8/38) therapies. Of the therapies and supports offered by Early Intervention, all but one of the families (97%, 37/38) received speech and language therapy. The majority of families (63%, 24/38) received audiology supports. Occupational therapy and physical therapy were represented by 14 of 38 and 13 of 38 (37% and 34%) families respectfully.
Table 10: Therapies Received

<table>
<thead>
<tr>
<th>Therapy Received</th>
<th>Percentage (count) (n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech</td>
<td>97 (37)</td>
</tr>
<tr>
<td>Audiology or vision</td>
<td>63 (24)</td>
</tr>
<tr>
<td>Occupational</td>
<td>37 (14)</td>
</tr>
<tr>
<td>Physical</td>
<td>34 (13)</td>
</tr>
<tr>
<td>Technology</td>
<td>24 (9)</td>
</tr>
<tr>
<td>Medical</td>
<td>5 (2)</td>
</tr>
<tr>
<td>Transportation</td>
<td>3 (1)</td>
</tr>
<tr>
<td>Social Work/ Psychological</td>
<td>3 (1)</td>
</tr>
</tbody>
</table>

Participants were asked to report how they were connected to the birth-to-three Early Intervention program. According to their open responses, about one-third (34%, 13/38) of participants stated that their audiologist connected them to the program. Other participants’ responses varied from being connected by the hospital, therapist, or doctor to connecting to the program on their own.

Participants were also asked to report additional information about their engagement with the program including if they met other families with children with hearing loss and if they met deaf adults (see summary in Table 11). The majority (71%, 27/38) of participants stated that they met other families with children with hearing loss. About two-thirds (67%, 18/27) of participants reported meeting families through the Early Intervention program or programs associated with it (ex. Hands and Voices, Deaf Mentor). However, almost one-third (33%, 9/27) of participants reported connecting to families through social media or social groups. Of the 27
families that stated that they were connected to other families, the majority (78%, 21/27) of participants explained that this experience was helpful. These responses were almost evenly split between participants whose children were currently enrolled in Early Intervention and those that were exited from Early Intervention.

Additionally, participants were asked if they met deaf adults during the time they were participating in Early Intervention, how they were introduced, and if they considered this experience helpful or not helpful. The majority (53%, 20/38) of participants explained that they met deaf adults while 14 (37%) participants stated that they had not. Of the 20 participants that answered how they met, half stated that they met them through programs associated with the birth-to-three Early Intervention program. When asked if the experience was helpful or not, the majority (75%, 15/20) of these participants, including those that met deaf adults through Early Intervention and those that met deaf adults through other resources, stated that they found this experience helpful and five (of 20) stated that they did not find the experience helpful.

Table 11: Parent Experiences and Early Intervention

<table>
<thead>
<tr>
<th>Parent Experience</th>
<th>Percentage (count) (n=38)</th>
<th>Percentage (count of yes or no responses)</th>
<th>Percentage (count of helpful or not helpful responses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Met other families</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>71 (27)</td>
<td></td>
</tr>
<tr>
<td>Helpful</td>
<td></td>
<td>78 (21/27)</td>
<td>(n=21)</td>
</tr>
<tr>
<td>Enrolled in EI</td>
<td></td>
<td>48 (10/21)</td>
<td></td>
</tr>
<tr>
<td>Exitd from EI</td>
<td></td>
<td>52 (11/21)</td>
<td></td>
</tr>
<tr>
<td>Not Helpful</td>
<td></td>
<td>11 (3/27)</td>
<td>(n=3)</td>
</tr>
<tr>
<td>Enrolled in EI</td>
<td></td>
<td>66 (2/3)</td>
<td></td>
</tr>
<tr>
<td>Exitd from EI</td>
<td></td>
<td>33 (1/3)</td>
<td></td>
</tr>
</tbody>
</table>
**Table 11 (continued): Parent Experiences and Early Intervention**

<table>
<thead>
<tr>
<th>Met deaf adults</th>
<th>(n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>53 (20)</td>
</tr>
<tr>
<td>Helpful</td>
<td>75 (15/20) (n=15)</td>
</tr>
<tr>
<td>Enrolled in EI</td>
<td>40 (6/15)</td>
</tr>
<tr>
<td>Exited from EI</td>
<td>60 (9/15)</td>
</tr>
<tr>
<td>Not helpful</td>
<td>25 (5/20) (n=5)</td>
</tr>
<tr>
<td>Enrolled in EI</td>
<td>80 (4/5)</td>
</tr>
<tr>
<td>Exited from EI</td>
<td>20 (1/5)</td>
</tr>
<tr>
<td>No response</td>
<td>1 (1/20)</td>
</tr>
<tr>
<td>Met through EI program</td>
<td>35 (7/20)</td>
</tr>
<tr>
<td>Met through other means</td>
<td>35 (7/20)</td>
</tr>
<tr>
<td>No</td>
<td>37 (14) (n=14)</td>
</tr>
<tr>
<td>Enrolled in EI</td>
<td>71 (10/14)</td>
</tr>
<tr>
<td>Exited from EI</td>
<td>29 (4/14)</td>
</tr>
<tr>
<td>No response</td>
<td>11 (4)</td>
</tr>
</tbody>
</table>

**Parent Experiences in Birth-to-Three Early Intervention**

Open ended questions not related to demographics were asked. Participants answered questions about the support they received during birth-to-three Early Intervention program as well as what they found most helpful and a general description of their experience. Participant responses to these questions were first coded and then categorized on a spreadsheet in order to
identify overarching themes.

**Parent Identified Needs**

Based on the identified needs of participants that emerged from the coded responses, three overarching categories emerged (see Table 12): support for the parent, communication support, and support for the child. Of these responses, 84% (32/38) of the total responses identified support for the parent making it the largest parent identified need. The two remaining categories were split evenly at 82% (31/38) each. Within each overarching category, subcategories were identified. In support for the parent, advice and emotional support (94%, 30/32), unbiased information and resources (81%, 26/32), and a connection to other parents (69%, 22/32) were identified by a majority of participants. In communication support, when specified, participants identified a need for spoken language (84%, 26/31) and manual communication (71%, 22/31). Some participants specified support for learning ASL (26%, 8/31). Support for the child was mainly distributed between therapies for the child (87%, 27/31) and knowledgeable providers (39%, 12/31). The majority of participants who identified support for the child as a need identified specific direct therapies (85%, 23/31) as a way to best meet their needs as a family.

*Table 12: Parent Identified Needs*

<table>
<thead>
<tr>
<th>Identified Need</th>
<th>Percentage (participants/total participants)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support for parents</td>
<td>84 (32/38)</td>
</tr>
<tr>
<td>Advice and emotional support</td>
<td>94 (30/32)</td>
</tr>
<tr>
<td></td>
<td>(continued)</td>
</tr>
</tbody>
</table>
### Table 12 (continued): Parent Identified Needs

<table>
<thead>
<tr>
<th>Need</th>
<th>Percentage (Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unbiased information and resources</td>
<td>81 (26/32)</td>
</tr>
<tr>
<td>Connection to other families</td>
<td>69 (22/32)</td>
</tr>
<tr>
<td>Deaf adults</td>
<td>44 (14/32)</td>
</tr>
<tr>
<td>Connection with local school for Deaf</td>
<td>19 (6/32)</td>
</tr>
<tr>
<td>Transition</td>
<td>9 (3/32)</td>
</tr>
<tr>
<td><strong>Communication Support</strong></td>
<td><strong>82 (31/38)</strong></td>
</tr>
<tr>
<td>Spoken communication</td>
<td>84 (26/31)</td>
</tr>
<tr>
<td>Manual communication</td>
<td>71 (22/31)</td>
</tr>
<tr>
<td>ASL</td>
<td>26 (8/31)</td>
</tr>
<tr>
<td><strong>Support for child</strong></td>
<td><strong>82 (31/38)</strong></td>
</tr>
<tr>
<td>Direct therapies</td>
<td>87 (27/31)</td>
</tr>
<tr>
<td>Knowledgeable providers</td>
<td>39 (12/31)</td>
</tr>
</tbody>
</table>

### Additional Information Related to Parents

Through the open-ended responses, participants provided additional information about their needs, including more detailed information about their needs as parents (see Table 12). For example, participants identified who they received advice and emotional support from. Support from other parents (see Table 13) accounted for the largest majority (66%, 21/32). Support from the providers themselves was also identified by 50% (16/32) of the participants who identified advice and emotional support as a need. To a smaller degree, participants (16%, 5/32) identified deaf adults as the source of support.
Table 13: Parent Need: Advice and Support

<table>
<thead>
<tr>
<th>Advice/emotional support</th>
<th>Percentage (count) (n=32)</th>
</tr>
</thead>
<tbody>
<tr>
<td>By other parents</td>
<td>66 (21)</td>
</tr>
<tr>
<td>By providers</td>
<td>50 (16)</td>
</tr>
<tr>
<td>By deaf adults</td>
<td>16 (5)</td>
</tr>
</tbody>
</table>

When discussing how the providers provided emotional advice and support, one participant stated that she “cried a lot and [her providers] were there to gently guide me and help me”. When explaining how the connection to other parents provided advice and support, some participants explained that it wasn’t just parent-to-parent support, but parents of children who were the same age or had the same type of hearing loss. The ability to relate to their experiences, such as the decision to get a cochlear implant or the worries about their child’s future, made this support more beneficial to the participants. For example, one participant stated that “it was helpful to relate with other parents who are going through the same experience” and that parents “support each other”.

Participants further clarified the type of unbiased information they needed (see Table 14). Primarily, participants identified a need for information to help them better understand hearing loss and their child’s related needs (81%, 21/26). A smaller percentage (31%, 8/26) of participants identified a need for outside resources including information about preschool options and doctors. Information about deaf culture and community was identified by a smaller group of participants.
When discussing a need for information about their child’s hearing loss, one participant stated that she needed information to “[understand] language milestones and when intervention was needed, understanding the transition to services at age three”. A participant also explained the importance of information because her daughter was the first deaf person in the family, stating “My daughter is the first deaf person in the family, so I was very worried and had lots of questions but the staff in early steps was absolutely amazing with helping me understand my daughters’ diagnosis, while also connecting me to Parent Pupil Organization and Hands & Voices.” When discussing information about outside resources, participants expressed a desire for information about resources outside of the therapy that they received from Early Intervention. For example, one participant stating, “our service coordinator has greatly helped us link with community resources – more so than medical professionals”.

**Additional Information about Communication Needs**

Thirty-one participants also identified a need for support and resources to help their child communicate. Within this, three specific areas emerged (see Table 15): Spoken language (55%, 17/31), both manual and spoken language (29%, 9/31), and manual, or signed language, only (16%, 5/31).
Table 15: Supporting Communication

<table>
<thead>
<tr>
<th>Supporting Communication</th>
<th>Percentage (count) (n=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spoken language</td>
<td>55 (17)</td>
</tr>
<tr>
<td>Both manual and spoken language</td>
<td>29 (9)</td>
</tr>
<tr>
<td>Manual language</td>
<td>16 (5)</td>
</tr>
</tbody>
</table>

Of these 31 participants, nine (29%, 9/31) identified a need for support in a mode of communication that was different than the mode of communication that was identified as the family’s main mode of communication (see Table 16). For example, of the nine participants, six stated that their chosen mode of communication was spoken language but also wanted support in learning a manual method of communication. One participant stated “we were able to provide language to our son until we made the decision regarding him getting a cochlear implant. Sign Language helped him acquire spoken language much faster”.

Table 16: Communication Needs Outside of Chosen Mode of Communication

<table>
<thead>
<tr>
<th>Identified Need Outside of Chosen Mode of Communication</th>
<th>Percentage (count) (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chosen mode of spoken language, but would like support in manual communication</td>
<td>67 (6)</td>
</tr>
<tr>
<td>Chosen mode of manual communication, but would like support in spoken language</td>
<td>28 (3)</td>
</tr>
</tbody>
</table>

Additional Information Related to the Child

A majority of participants used language associated with therapies to discuss their needs in the birth-to-three Early Intervention program. Within therapies, participants identified specific
subcategories that clarify how the therapies best meet their needs. These include therapies to address communication, therapies that they identified as being tailored to address their child’s needs, and a specific desired therapy (see Table 17).

Table 17: Desired Therapies

<table>
<thead>
<tr>
<th>Desired Therapies</th>
<th>Percentage (count)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Addresses communication need</td>
<td>63 (17)</td>
</tr>
<tr>
<td>Specific to child’s needs</td>
<td>59 (16)</td>
</tr>
<tr>
<td>Specific desired therapy</td>
<td>30 (8)</td>
</tr>
</tbody>
</table>

The majority of participants (63%, 17/27) who identified therapy as a need specifically identified therapy that prioritized their child’s communication needs. The need for a specific therapy was most often discussed in conjunction with the families’ chosen mode of communication. For example, a participant stated that their team “even made sure our SLP was on board with Total Communication”. Communication therapies during their participation in birth-to-three Early Intervention added to their satisfaction with the program.

The ability to set goals specific to the needs of the child and to tailor therapy towards those needs was important to participants. More than 50% (16/27) of participants identified needs that were specific and tailored to their child’s needs, noting that some therapies were not age-appropriate or needed by the child. For example, one participant stated that “physical therapy wasn’t necessary because he had been hitting all of those goals” leading her to believe that the program was not tailored to her child’s needs. Another parent stated that she didn’t realize the many other areas of development that were impacted by hearing loss and appreciated when additional therapists “stepped in” when her child’s needs became apparent.
Desired therapies also played a role in how participants explained their experience with birth-to-three Early Intervention. Most often, this was discussed in conjunction with statements about disagreements with the services provided. For example, if a parent wanted a service and it was not provided, they were more likely to determine that the program had not met their needs. Additionally, if a service was removed from an IFSP and a parent still felt that her child demonstrated deficits in the related area, then the participant was more likely to view her experience with the program negatively. For example, one participant stated “she started walking at 22 months so they cut out PT. This was frustrating because she has continued to have balance issues because of her hearing loss”.

One-third of participants identified a need for knowledgeable providers. Participants preferred to work with participants that had expertise in the needs of children with hearing loss. For example, one participant stated that “speech and language pathologists had absolutely no idea how to work with a deaf child with cochlear implants”. Other participants expressed a need for providers who were knowledgeable about cochlear implants and the implantation process. For example, one participant stated that she turned to the providers with “questions about the CI process” and other expressed how their providers helped them navigate through this process.

**Meeting Parents’ Needs**

Participants were asked to explain any needs they felt were or were not met during birth-to-three Early Intervention (see Table 18). Of the 37 participants that responded to this open-ended question, 68% felt their needs had been met through the supports provided during the Early Intervention program. On the other hand, 32% of participants stated that their needs had not been completely met by the supports offered to them through the program.
Table 18: Meeting Parent Needs

<table>
<thead>
<tr>
<th>Were your needs met?</th>
<th>Percentage (count) (n=37)</th>
<th>Percentage (count of enrolled or exited from EI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes/mostly yes</td>
<td>68 (25/37)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enrolled in EI 76 (19/25)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exited from EI 24 (6/25)</td>
</tr>
<tr>
<td>No/mostly no</td>
<td>32 (12/37)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enrolled in EI 25 (3/12)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exited from EI 75 (9/12)</td>
</tr>
</tbody>
</table>

Open-ended responses allowed parents to elaborate on what they felt was helpful for their child or their family. Of the 36 responses to this question, only two topics were mentioned by ten or more participants: information and resources (13) and emotional support (10) (see Table 19).

Table 19: What Was Helpful

<table>
<thead>
<tr>
<th>What was helpful?</th>
<th>Percentage (count) (n=36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and resources</td>
<td>36 (13)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>28 (10)</td>
</tr>
</tbody>
</table>

Through open-ended responses, parents provided more detailed feedback on their specified needs. This feedback differed from some participants’ overall rating of their experience with the birth-to-three Early Intervention program. As a result, 71% of participants identified one or more need that was not met despite some having an overall positive perception of their
experience with Early Intervention (see Table 20). The largest identified need was unbiased information with 47% of total participants stating that they felt they had received biased information from one or more of their providers or had not received enough information to meet their needs. Most of the other identified unmet needs were 34% (need for emotional support) and 39% (style of therapy).

*Table 20: Parent Needs Not Met*

<table>
<thead>
<tr>
<th>Parent Needs Not Met</th>
<th>Mean (count) (n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One or more need not met</td>
<td>71 (27)</td>
</tr>
<tr>
<td>Biased/insufficient amount of information</td>
<td>47 (18)</td>
</tr>
<tr>
<td>Child’s needs not met</td>
<td>39 (15)</td>
</tr>
<tr>
<td>Communication support/ASL</td>
<td>37 (14)</td>
</tr>
<tr>
<td>Lack of desired therapy</td>
<td>13 (5)</td>
</tr>
<tr>
<td>Service delivery model of therapy</td>
<td>39 (15)</td>
</tr>
<tr>
<td>Teletherapy</td>
<td>11 (4)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>34 (13)</td>
</tr>
<tr>
<td>Knowledgeable therapists</td>
<td>18 (7)</td>
</tr>
<tr>
<td>Transition</td>
<td>5 (2)</td>
</tr>
</tbody>
</table>

**Unbiased information or lack of information**

Almost half (47%, 18/38) of participants stated that they felt their need for unbiased information and resources was not met. In some cases, some participants felt they received
biased information when discussing their child’s needs with their provider such as one participant who stated, “biased information had us second-guessing ourselves a lot”. At other times, participants felt that their providers did not provide them with adequate information and resources. One participant even stated that there was a “lack of transparency”. Participants also identified their receipt of biased information with the deaf adults that they met through the Early Intervention program. This bias in large part influenced participants’ chosen mode of communication for their child.

Child’s Needs Not Met

Some (39%, 15/38) participants felt that, overall, their child’s needs had not been met. Some identified this as an unmet need due to a lack of progress in their child’s development. Others identified this as a general statement of discontent. For example, one participant stated that “it was hard to get all the services we needed. I felt like we had to pick and choose what we could get in order to make our service coordinator happy”. Another participant tied this unmet need directly to the lack of knowledgeable therapists stating, “it was frustrating”.

Communication support.

The participants who felt their child’s needs were not met (14/38) most often aligned this feeling with their child’s language and communication needs. One participant stated that “overall, I feel like our language needs were not taken care of which led to falling further behind”. Most participants who discussed a lack of communication support discussed a lack of support learning a signed, or manual mode of communication. Some participants simply expressed a desire for more “sign” supports, such as access to additional resources or providers knowledgeable in a manual mode of communication. Others stated that they felt forced to make a choice between support learning a manual mode of communication and support for spoken
language. For example, one participant stated, they “could only pick one ASL or speech”. Another participant explained that her experience with birth-to-three Early Intervention was “excellent” and the providers were “incredibly supportive”, but they “did not support us in finding ASL resources”. Some participants specified the desire for resources, support, and providers who are knowledgeable in American Sign Language.

**Lack of desired therapy.**

Of the participants that felt that their child’s needs were not met, about one-third associated this with a disagreement with their service provider over the therapies that their child received. For example, a participant stated that “they really fought us on having multiple services and wanted to only provide services through one generalist. I wanted specific therapists, but they were only available in an office setting”, and another stated “at first they made us choose only one type of professional…Later we successfully advocated for adding speech therapy as a separate service.”

**Service Delivery Model of Therapy**

Some participants (39%, 15/38) stated that they felt that certain service delivery models were less conducive to meeting their needs than others. For example, one participant stated that she preferred the therapy that they received while “in the office” over therapy received at home. Another participant stated that she felt the style of therapy was “draining and less helpful than the type of therapy that we receive in other settings”. She added that the parent led therapy made her feel that it was “more about quizzing me about what I’ve done or not done and less about direct interaction”.

A smaller subset (11%, 4/38) of participants identified teletherapy as a less desirable form of therapy. Though this was not a main focus, the pandemic that was occurring during data
collection forced therapy deliver to move from largely in-home to virtual, or tele-therapy. Of the participants that mentioned this style of therapy, all stated that they preferred other methods of therapy delivery. While some simply mentioned a dislike for tele-therapy, one participant stated that it was more difficult to determine if her child was benefiting from the tele-therapy services.

**Emotional Support**

About one-third of participants stated specifically that they lacked emotional support during their time in the birth-to-three Early Intervention program. Some participants aligned this with a lack of connection to other parents. For example, one participant stated that it was difficult to “not have other parents’ information that are going through things that we are going through”. Other participants did not specifically identify this as an unmet need.

**Knowledgeable Therapists**

When participants discussed a lack of knowledgeable therapists (18%, 7/38) all of them tied this directly to a lack of knowledge about the specific communication needs of children with hearing loss. For example, one participant stated they had “speech and language therapists who had absolutely no idea how to work with a deaf child with cochlear implants”. Another stated that it had been “extremely hard to find therapists that specialize in hearing loss”. Some participants also stated that it was difficult to find the “right” therapist, indicating that other factors, such as personality or ability to connect emotionally, may play into their perception of the adequacy of the therapist.

**Alignment with Recommended Practices**

For the purposes of this study, recommended practices from the DEC and JCIH were summarized and compared to the identified parent needs identified through the survey. While the DEC made recommendations for birth-to-three Early Intervention programs for all children with
or at risk of developmental delays, the JCIH recommendations specified how the broader recommendations aligned with the needs of children with hearing loss.

**Division of Early Childhood (DEC) Recommended Practices**

Recommendations from the DEC include leaders, assessment, environment, family, interaction, collaboration, and transition. Based on participants’ open-ended responses, the needs of families of children with hearing loss aligned with four of the eight DEC recommended practices: leaders, family, instruction, and collaboration. Participants’ views on transition, environment, and instruction either were not identified as a need by the participants or did not entirely align with the DEC recommended practices.

Of those areas that participants’ needs aligned with the recommended practices of the DEC, about one-third of the participants identified leaders, such as the providers or contacts with related programs, as an important need during their child’s enrollment in the Early Intervention program. However, participants specified that these leaders were more beneficial when they had a background in the needs of children with hearing loss. Participants also discussed the importance of the role of themselves and their family during their enrollment in the birth-to-three Early Intervention program and identified a need for emotional support for their family and collaboration between their family and the team about communication choice and therapy for the child. Options for active family participation in services and viewing families as the expert of their child is paramount in the DEC recommended practices. Participants also identified collaboration with outside resources, families, and deaf adults as an important component of their experience in the birth-to-three program. One participant stated that the connection to outside resources was especially beneficial for their family since they were new to the area and another stated that collaboration with the Deaf Mentor program provided them with information,
community, and communication support.

Additionally, three recommendations made by the DEC either were not identified as a need or the participants’ perceptions of the category differed from the DEC. These included transition, environment, and instruction. The DEC recommends that families receive the necessary supports during any significant transition for the child. For children with hearing loss, an important transition is between the birth-to-three Early Intervention program and a post-three program. Although transition support was not identified by enough participants to be identified as a need, three participants did discuss the need for supports during this transition period. One participant stated that her provider met with the teachers at her child’s new school and ensured that the teacher and environment were prepared. However, another participant stated that the lack of an official program during this transition period between birth-to-three Early Intervention and school-age was difficult for her family to navigate without the transition supports that she should have received from the Early Intervention program. The DEC recommends that services and supports be included in the child’s natural environment. About one-third of participants identified the importance of a convenient location, either the home, daycare, or local school for the deaf and hard of hearing. Two of these participants stated that they preferred office-based therapy over therapy in the home setting. These participants felt the office-based therapy sessions were more beneficial to the child than therapy sessions within the home which one participant described as “quizzing me about what I’ve done or not done and less about direct interaction”. Finally, participants identified instruction as a need through the lens of therapy that directly supported the child. The DEC’s recommendations focused on instruction that was embedded within the family’s routines and activities, but participant’s perceptions of how instruction benefits their family differed from the justification the DEC uses to recommend the best
instructional teaching strategies.

**Joint Committee on Infant Hearing Recommended Practices**

The DEC recommendations were further defined by the JCIH to reflect the specific needs of families with children with hearing loss. The JCIH recommendations include timely access, knowledgeable professionals, information, support for all modes of communication, meet other families with children with hearing loss, support for family mental health, transition, and meet deaf adults. Several of the participants’ identified needs were also reflected in the JCIH position statements although, for some, the participants’ reasons for identifying that need differed slightly from the JCIH’s justification.

Five of the participants’ identified needs were reflected in previous JCIH position statements or in the most recent recommendations from 2019. For example, participants wanted unbiased information about medical procedures and information about outside resources that support the needs of their family such as programs to learn ASL. Participants also expressed a need for connection to other families and connections to deaf adults. The JCIH recommends these connections to support family emotional health. Some participants associated this connection to their emotional well-being, a point discussed by the JCIH, but others stated that these connections helped their child feel like a part of a community and less alone or helped their family learn ASL, connections that were not discussed within JCIH. Both participants and the JCIH also identified the need for knowledgeable providers. The JCIH emphasized a need for providers knowledge in specific needs of children with hearing loss, the specific communication choice of the family, as well as the specific needs of children with multiple disabilities. Parents most often associated this knowledge only with their communication choice.

One area that differed slightly from the JCIH was the need for support for
communication. The JCIH identifies communication as an important recommended practice and places each communication choice in its own distinct category. For example, according to the JCIH, families that choose ASL as their main mode of communication should receive support in learning ASL. However, participants did not always remain entirely within one communication choice. One participant stated that while her family chose spoken English as their primary mode of communication, she found that the use of some signs helped the family communicate with her child while he was continuing to improve his speech. Other participants stated that they desired continued support for speech even though their family chose ASL as their primary mode of communication.

Overall, the participants’ identified need aligned with recommendations from the DEC and JCIH. However, some participants identified needs that directly contrasted best practices such as a parent who desired office-based therapy over home-based therapy and parents who desired support in multiple modes of communication rather than choosing only one. Also, some participants’ reasonings differed from the reasonings provided by the DEC and JCIH. Although this did not impact the alignment, it does introduce a need for caution when making assumptions about participant needs.

Summary

This chapter states the results of the surveys and connects those responses back to the research questions: 1) From a parent’s perspective, what are their primary needs and concerns related to their child from birth-to-three years old with hearing loss and their family?; 2) From a parent’s perspective, how well do the services and supports received through Early Intervention meet their identified needs?; 3) To what extent do the services and supports families received
through Early Intervention align with DEC and JCIH recommended practices for children from birth-to-three years old with hearing loss and their families?

Participants identified needs fell into three overarching topics: support for the parent, communication support, and support for the child. Within support for the parent, advice and emotional support, unbiased information and resources, connection to other families, connection to deaf adults, and connection to the school for the deaf emerged from the coded open responses. Additionally, the majority of participants identified communication support as a need. This included both support for the child to improve in their communication skills, such as through direct therapy, or support for the parent such as resources for learning ASL or recommendations for supporting spoken English within the home. For some participants, a desire for support in either ASL or spoken English was not dependent on their identified main mode of communication. Participants also identified a need for therapy for their child to support their development in areas of need. However, to the participants, it was critical that these therapies were provided by individuals who were knowledgeable in their chosen mode of communication and in the unique needs of children with hearing loss.

The majority of participants felt that their needs were met when asked to sum up their feelings about their experience with the birth-to-three Early Intervention programs. However, when asked to provide specifics about how their needs were met, the majority of participants had one or more need that was not met entirely. The largest unmet need was unbiased or sufficient information where the majority of participants felt that they received biased information or insufficient information that negatively impacted their ability to support their child’s needs. Other unmet needs, identified by more than one-third of the participants, included the child’s needs, style of therapy, and emotional support. About 20% of all participants also felt that their
providers were not versed in the needs of children with hearing loss or in their mode of communication.

Finally, when analyzing identified parent needs with the recommendations from the DEC and the JCIH, the majority of participants’ identified needs were also identified as best practices by one or both of the professional organizations. However, there were incidences of participants’ needs or reasonings not aligning with recommended practice.

The results of this study demonstrated that although there is a good understanding of the overall needs surrounding families of children with hearing loss and the birth-to-three intervention, there continues to be room for growth and improvement. Following the larger umbrella of research and conclusions made by professional organizations may not be sufficient to meet the needs of a specific family and reinforces the importance of a truly individualized family service plan.

Chapter 5
Discussion

The changing landscape of technology, medical understanding, society, and families in general requires a reassessment of the needs of families with children with hearing loss. This allows programs, including Early Intervention programs, to ensure that they are utilizing their personnel and resources to best meet the needs of the families and, as a result, to improve child development outcomes. The survey questions guided the parents to talk about their fulfillment of their needs and the needs of their children with hearing loss. The following research questions guided the investigation:

1) From a parent’s perspective, what are their primary needs and concerns related to their child from birth-to-three years old with hearing loss and their family?
2) From a parent’s perspective, how well do the services and supports received through Early Intervention meet their identified needs?

3) To what extent do the services and supports that families received through Early Intervention align with DEC and JCIH recommended practices for children from birth-to-three years old with hearing loss and their families?

**Parent Identified Need**

Three distinct categories of needs of parents of children with hearing loss in the birth-to-three Early Intervention program emerged from the data. Parent identified needs included support for the parent, communication support for their child, and support for the child. Within each category, subcategories and additional detailed information was identified through the open-ended responses. The subcategories that were identified included a need for advice and emotional support, unbiased information and resources, communication support, therapies for the child, and knowledgeable providers.

**Support for Parent**

In this study, participants placed a significant emphasis on needs of the parent. This is not a surprise. Parents bear the brunt of responsibility and increase in demands during a child’s early years which is amplified when raising a child with a hearing loss (Sarant & Garrard, 2014; Vohr, Jodoin-Krauzyk, Tucker, Johnson, Topol, & Ahlgren, 2008b). Frequently, parents (mothers, in particular) of children with hearing loss stay home with their young child and provide daily, ongoing care. The demands of their care can be stressful for parents and the stress of raising a child with a hearing loss is clearly reflected in the research (Gilliver et al., 2013; Quittner et al., 2010).
The three largest subcategories of support for the parent identified by participants in this study was advice and emotional support, unbiased information and resources, and connection with other families. These subcategories have a direct impact on parent’s self-efficacy. Research (Bloomfield & Kendall, 2012) has identified a connection between self-efficacy (a parent’s belief in their ability to competently overcome challenges) and improvements in parenting stress (Punch & Hyde, 2010). Understandably, participants in this study emphasized their need for advice and emotional support. Learning that your child has a hearing loss creates new and unexpected demands on a parent. Most of the parents in this study did not have prior experiences with a deaf individual, thus, adding to their emotional stress as well as the need for more knowledge and advice.

When discussing advice and emotional support, participants stated that they received this support primarily from other parents of children with hearing loss and Early Intervention providers. Parents often turn to their social networks, including family and friends, for emotional support. With the increase in social media, more parents have been able to connect to other families with similar needs which may contribute to the connection among parents with children with hearing loss. Professional organizations have recently identified the importance of social media connections among parents with children with similar needs (JCIH, 2019). Service providers also become a hearing parent’s first, and sometimes only, contact with the world of hearing loss. Therefore, it is not surprising that participants in this study identified providers as the individuals from whom they received support.

Another need that emerged from participant responses was the desire for unbiased information and a connection to community resources. This is often a focus in research associated with individuals with hearing loss due to a risk of bias when addressing medical
intervention options, school options, and communication choices (Kecman, 2019; Stewart, Slattery, & McKee, 2020). A continuous debate exists within the world of hearing loss about topics such as amplification and communication choice. These parents experienced some professional biases related to information they received. However, when they felt that they had received unbiased information, they felt empowered and more capable as a parent to make important decisions about their child. Parents expressed how information and a better understanding of their child’s needs helped their emotional well-being throughout the process. The connection between information and resources with parental feelings of competence has been found in previous research (Hintermair, 2006).

Though the overall sample size is small, almost half of all participants felt they had received biased information, a number that surpasses what one would hope to see. Families of young children typically rely on medical personnel when first provided with the diagnosis. Some of the information parents received was perceived as biased. The purpose of medical staff is generally to fix problems. However, among those in the deaf community, hearing loss is not something that needs to be fixed, which may contribute to feelings associated with receiving “biased information”. Without reviewing the information that was provided, it is difficult to determine if bias was truly present or if the information was simply an alternate opinion and option.

Along with a need for unbiased information, participants expressed a desire for information about outside resources which has been identified in previous research (Jackson et al., 2010). Families in this study determined that this was a need that was not met. There could be numerous reasons why some families felt that they were not provided adequate resources. For example, providers that are not well-versed in the community-based resources that are available,
as in the case of a provider without a background in deaf and hard of hearing children and families, may not know the direction to send parents. Also, a lack of outside resources, in some areas, that are specific to the needs of individuals with hearing loss may contribute to this need. Additionally, this study was conducted partially during a global pandemic and it is difficult to determine if this played a role in a lack of community resources provided to participants. Covid-19 created isolation of children and families and a reduction of available services. Participants’ responses may have been more positive if a pandemic was not a factor.

**Communication Support for the Child**

The second overarching category to emerge from participant responses was a need for resources to help the family in their quest to support their child’s communication. Clearly, research supports communication as a driver of Early Intervention for children with hearing loss (Decker & Vallotton, 2016; Moeller & Tomblin, 2015; White and Blaiser, 2011). What was interesting about this study was the desire for support in a particular mode of communication for the child that did not always match the family’s main mode of communication. For example, some families who identified spoken language as their families’ mode of communication discussed a need for additional support in learning manual mode of communication or ASL. Conversely, some families who used manual communication as their main mode of communication with their child expressed a desire to continue to support their child’s spoken language. Perhaps families did not feel competent in helping their child learn a different communication system than the one they were familiar with.

This finding shows that what has often been viewed as a clear divide between learning manual communication and supporting spoken language is not clear cut. Despite progress, a divide persists in the profession between those that believe manual communication may hinder
the development of spoken language and those that believe that all children with hearing loss should be exposed to manual communication (Humphries, Kushalnagar, Mathur, Napoli, Padden, Rathmann, & Smith, 2017; Snodden, 2008). However, this study demonstrated that some parents of children who use spoken language also want support in learning manual communication. Conversely, some parents whose children used manual communication wanted support to teach their child to use spoken language. It is possible that changes in society, as well as in available resources for learning manual communication, may be blurring this theoretical divide. For example, there has been an increased visibility of individuals with hearing loss in media, literature, and movies such as Switched at Birth (a T.V. series created by Lizzy Weiss); A Quiet Place (a screenplay by John Krasinski, Scott Beck, and Bryan Woods); and Wonderstruck (a book written and illustrated by Brian Selznick). Additionally, the “baby signs' phenomenon, such as websites like www.babysignlanguage.com, has been accessed by parents teaching their deaf child as well as those who have hearing infants (Ferry, 2016). This increase in positive visibility and easier access to manual communication may be a contributing factor in this study’s finding.

Support for Child

In addition to support for the parent and support for the child’s communication, participants also expressed a need for supports that directly impacted their child. These included direct therapy and knowledgeable providers.

Almost three-fourths of coded responses identified therapies for the child as a need. Of those individuals, parent perceptions of the effectiveness of Early Intervention were more positive when they felt their child had met or surpassed developmental goals through the direct therapy offered by the program. Parents who discussed continued difficulty or a lack of
improvement in their child’s development were more likely to say that they felt their needs had not been met. This is not a unique occurrence and prior research in other disability areas has shown that parent perceptions of the effectiveness of Early Intervention is often tied to the level of need of their child’s disability or to the relationships with the professionals and may not be a reliable analysis of true effectiveness of the program (Goin-Kochel, Mackintosh, & Myers, 2009; Palisano et al., 2010). Parents of young children often think that “more is better” when referring to direct therapy but that is not always the case.

Additionally, the significance that parents place on direct therapy for the child is contradictory to the foundation of Early Intervention which seeks to improve child outcomes through “coaching” the parent about how to interact with their child. Parents are with their child 24/7 while therapists visit one to two hours per week. Therefore, teaching parents is the mission of Early Intervention. However, despite the theory employed by Early Intervention of improved child outcomes through improved parental efficacy, most parents still want more direct therapy, believing that “more” is better. This is a current dilemma for parents in Early Intervention service delivery.

Participants also stated that they preferred providers who were knowledgeable in the needs of children with hearing loss. This falls in line with previous research (Rice & Lenihan, 2005) and recommendations by the JCIH and the International Consensus Statement (2013). Within this area of need, participants identified two specific areas of knowledge that they wanted providers to have: (1) knowledge about their chosen communication choice and (2) general knowledge about hearing loss. Of course, common sense tells us that parents would desire to have providers that are knowledgeable about their child’s disability (Moeller et al., 2013). Having an individual that presents with a wealth of knowledge in the needs of their child does
not only benefit the child but may benefit the emotional well-being of the parent by providing a sense of comfort in a time of heightened stress. Unfortunately, nationally, there is a shortage of individuals who are experts in hearing loss in children as well as a loss of training programs which may hinder access to knowledgeable providers.

**Early Intervention and Successfully Meeting Parent Needs**

Overall, the majority of participants expressed that, in general, their needs had been met through the Early Intervention program. Participants used general terms to describe this overall sense of contentment with their experience. Expressions of praise were most often included with statements about the information they received and the emotional support that was provided. These statements align with the Early Intervention goal of increasing parents’ ability to work effectively with their child for positive outcomes. By providing families with information and resources and ensuring that the family feels supported during this experience, providers are attempting to ensure that parents leave the Early Intervention experience with the tools necessary to continue supporting their child’s development.

However, over 70% of participants stated that they had one or more need that was not met. This is not a resounding victory and shows that there continues to be a need for improvement in the field of Early Intervention for children with hearing loss. Though parents may feel, in general, that their needs have been met, by stating that they have at least one unmet need, they are demonstrating that gaps still exist in the services they received. It may take years for parents to feel competent and as their child grows, their needs change. However, in family support literature, when the child is young, direct therapy and services for the child are almost always a priority versus needs and supports for the family, leaving a divide between the concept of best practices and the true implementation of family-centered practices.
This study demonstrated that there is a possible disconnect between parents’ general feelings about their experience and their feelings about how well their needs have been met. The disconnect between parents’ general assessments of their Early Intervention experience and their feeling about more specific needs has occurred in previous research (Bailey et al., 2005).

Additionally, of the parents that stated that their needs were met or mostly met, a majority were currently enrolled in Early Intervention. However, for parents that stated that their needs were not met or mostly not met, the majority were already exited from Early Intervention.

Hearing loss is a lifelong diagnosis and needs of families extend well beyond the birth-to-three age range. As parents exit out of Early Intervention, many families find themselves without continued support. Perhaps the continued presence of a disability such as hearing loss and the continued need to support a child’s development is magnified for families when there is no formal parent support program available.

Alignment with Recommended Practices

The identified needs of participants in this study mostly aligned with the recommended practices from professional organizations such as the DEC and the JCIH. For example, participants in this study identified a need for unbiased information and resources which is recommended by both the DEC and the JCIH. The DEC specifically recommends that practitioners help families access formal and informal resources. This is also recommended by the JCIH, though they gear their recommendation towards “unbiased” information to address needs specific to families of children with hearing loss.

Parents in this study also identified a need for emotional support and advice. Though this is not directly addressed specifically as “emotional support” by the DEC, their recommendations for a family-centered approach to enhance parent efficacy do impact the emotional well-being of
families. By providing parents with knowledge and advocacy tools, the DEC is indirectly impacting the families’ emotional well-being.

The JCIH directly addresses the need for helping parents build a supportive network around them by recommending that parents receive access to other families with children with hearing loss. The JCIH also specifically addresses the need to support parents’ emotional well-being in the 2019 update. This shows an improved alignment between the professional organizations and parent identified needs, though it may not be effectively implemented.

Some needs that were identified through this study were included in the recommended practices but did not align totally with parent need. For example, parents identified direct therapy, or therapy between the provider and the child, for the child as a need. While the DEC and JCIH include interventions, strategies, and techniques to be available for children and families, the organizations do not describe direct therapy. Parents of young children are learning new techniques and lean on professionals to help them. Some providers are more skilled than others in “coaching” parents. Many therapy programs focus almost exclusively on a “direct service” model versus indirect. Thus, a mismatch may occur when a provider in Early Intervention attempts to “coach” the parent without specific training in “how to”.

However, other recommended practices were experienced by the participants in this study. For example, nearly 70% of participants identified being connected to other parents who have a child who is deaf. Both the literature and the recommended practices encourage networking among parents who are experiencing similar situations, challenges, and rewards. In this study, the participants had this opportunity.

Another practice suggested by JCIH is facilitating a connection for parents with a deaf adult. Less than 40% of participants had this opportunity. Some parents may not request or value
this connection during these early years because thinking about the future for their baby may be too difficult or stressful. Additionally, a major focus on the birth-to-three Early Intervention programs is on improving child development. In regards to children with hearing loss, this often means improving communication through support for speech and language development. This is antithesis to the values of the Deaf community and a parent who is focused on development of speech may not expect or understand how the Deaf community will play a role in their child’s life. Often parents struggle with the day-to-day raising of their child and may not be able to make decisions that may impact their child further in the future and may not provide evidence of supporting the child or family in their current needs. An important distinction about the JCIH recommended practice is that they were created as guidelines for programs rather than guidelines for practitioners. The program recommendation of linking parents of a child with a hearing loss to a deaf adult may not be in alignment with the parents’ priorities.

Also, a provision of transition support from Early Intervention into preschool is recommended by both the DEC and the JCIH, but only 9% of participants identified this as a need. However, this low percentage may not necessarily mean that this is or will not be a need. The population of this study included more participants with children who are currently in Early Intervention (approximately 64%) compared to 24% participants whose children had already completed the transition out of the birth-to-three program. One of the mandates in an IFSP is transition planning for a child aging out of the Early Intervention program. The majority of participants in this study had not yet experienced transition to another program. Therefore, they are not aware of or have knowledge about the transition process.

One of the major areas of difference between participants’ identified needs and the recommended practices was the topic of communication support. As stated previously,
participants’ need for support in either ASL or spoken language was not always dependent on
their family’s chosen mode of communication. Professionals must rely on parents’ priorities as
their child learns a communication system. Professionals must avoid making assumptions about
family concerns and priorities about either ASL or spoken language. Parent acceptance and
feelings about their child’s disability and its ramifications plays a role in the Early Intervention
experience.

In general, there are gaps between the principles of Early Intervention and the needs of
children with hearing loss. Early Intervention places an emphasis on the role of the parent. While
this principal also supports children with hearing loss, the specific communication needs of
children with hearing loss requires specialties which individuals trained in general disability
programs do not have. This leaves a void between individuals with expertise in the needs of very
young children and their families and individuals with expertise in communication development
in children with hearing loss. Though some states have attempted to remedy this through the
creation of parent-infant-programs that are specific to the needs of families of children with
hearing loss, this study demonstrates that there continues to be gaps in the safety net of Early
Intervention for children with hearing loss.

Limitations

The unique circumstances of the COVID-19 pandemic and the changes made from one-
on-one in-person interviews to a web-based survey prevented follow-up questions from being
asked. A survey design does not allow for follow-up questions. However, the inability to ask
follow-up questions may have prevented the researcher from gathering additional data. For
example, this study did not gather information on the presence of additional disabilities and
participants did not volunteer this information through the open-ended questions. It is possible
that if there are additional mediating circumstances that impact child development this may alter parent perceptions. This was not able to be clarified through follow-up questions.

Also, due to the small sample size and the inconsistent disbursement across geographic regions, the study is limited in making assumptions or generalizations. At best, this study can identify areas that require further research and pose questions rather than provide answers. Additionally, this study is limited in its representation. For example, all participants were female. Though this may be a common result of families’ experiences, this may not be a true representation of families as a whole. Families come in all shapes and sizes which only emphasizes the need to be aware of each family’s unique needs and priorities. The lack of representation in research may cause a skewed understanding in the field and gear recommendations towards the assumed “mother as caretaker” and may miss needs that may occur in families where the father, grandparents, siblings, or even a family friend spend a significant amount of time with the child. Additionally, the broad range of differences in hearing loss and parent decisions, as identified by the variety in choices made by participants in this study which also limit the ability for this study to provide conclusions (Gilliver et al., 2013; Inger et al., 2009; Most & Zaidman-Zait, 2001).

Future Research

This study has reaffirmed previous findings but has also emphasized a continued need for improvement. Future research, focusing on the quality of programs from a parents’ perspective would provide additional understanding of strengths and weaknesses in programs. Additionally, future research should focus on improvement to the Early Intervention component of EHDI now that we have seen general success in early identification, earlier medical intervention, and earlier enrollment in Early Intervention.
Deafness/hearing loss is a low incidence disability, meaning a small number of individuals have this condition. While research in individual states is important, due to low numbers, research should be extended to include geographic regions as well as collecting national data. Early Intervention programs and professionals are expected to follow JCIH and DEC recommended practices. How these national recommendations/mandates are operationalized needs to be further studied.

The use of other methodologies besides surveys would allow researchers to gather more in-depth data. For example, interviews and/or single subject research would uncover details not available to survey research.

Summary

This study found that parents identified both positive and negative aspects of their Early Intervention experiences. Overall, parents were satisfied with services and the majority of children met identification and enrollment guidelines outlined by EHDI. The majority discussed most of their providers in positive terms and felt that their child’s development was supported through the program. However, parents also expressed a continued need for advice and emotional support, unbiased information, and knowledgeable providers. This study also found other areas that should be targeted for improvement including ensuring providers that are appropriately versed in the unique needs of children with hearing loss, different amplification choices, and various modes of communication. Additionally, findings such as a desire for resources to learn ASL despite a primary mode of communication of spoken language, reaffirm the need to ensure that parent voices are a part of the research regarding children with hearing loss.
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Appendix A

Please provide information about your experiences in the birth-to-three intervention program as a parent of a child with hearing loss.

1. What is your current age?
   - < 20 years
   - 21 - 30 years
   - 31 - 40 years
   - 41 - 50 years
   - 51 - 60 years
   - > 60 years

2. What is your gender?
   - Male
   - Female
   - Other

3. What is your current marital status?
   - Single
   - Married
   - Divorced/Separated
   - Widowed

4. What is your highest level of education?
   - High school
○ Associate's degree

○ Bachelor's degree

○ Graduate degree

5. What is or was your employment during your child participation in the birth-to-three intervention program?

○ Unemployed

○ Worked from home

○ Worked outside of the home

6. What is or was your approximate family's annual income during your child participation in the birth-to-three intervention program?

○ <$30,000

○ $30,000 - $50,000

○ $50,000 - $70,000

○ $70,000 - $90,000

○ $90,000 - $110,000

○ >$110,000

7. How would you describe the community where you lived during the time that your child's enrollment in the birth-to-three intervention program?

○ Rural/Small Town

○ Suburban

○ Urban

8. What is the current age of your child with hearing loss? (age in months)
9. What was the child's age when he or she was diagnosed with hearing loss? (age in months)

10. What was the child's age when he or she entered the birth-to-three intervention program? (age in months)

11. What type of hearing loss does your child have?
   - Sensorineural
   - Conductive
   - Mixed
   - I don't know

12. What is the degree of your child's hearing loss?
   - Mild
   - Moderate
   - Severe
   - Profound

13. If your child uses an amplification device, what type does he or she use?
   - Hearing aid(s)
   - Cochlear implant(s)
   - BAHA(s)
   - No amplification device is used

14. What is the MAIN mode of communication that your child and family use?
   - Signed Language
   - Cued Speech
15. Did you have knowledge about deafness and hearing loss prior to your child's diagnosis?

- Yes
- No

16. If you had prior knowledge about hearing loss, please explain.

17. Have you met other families with children with hearing loss since your child's diagnosis? If yes, how did that happen and to what extent was it helpful or not helpful? Please describe.

18. Have you met other adults with hearing loss since your child's diagnosis? If yes, how did that happen and to what extent was it helpful or not helpful? Please describe.

19. Did any professional help you get connected to the birth-to-three intervention program? If yes, what type of professional and how did they help you get connected? Please describe.

20. How much time was there between diagnosis and starting interventions?

- < 3 months
- 3 - 6 months
- 6 - 12 months
- > 12 months

21. How long has your child been (or was) in the early intervention program?

- < 3 months
- 3 - 6 months
- 6 - 12 months
- 12 - 24 months
- 24 - 36 months
22. What types of services does (or did) your child receive in the birth-to-three intervention program? Please check all that apply.

- Audiology or vision services
- Physical therapy
- Occupational therapy
- Speech and language therapy
- Social work/Psychological services
- Medical services
- Technology
- Transportation

23. In your own words, how would you describe the services that your child and family received?

24. As a parent, how were your concerns and needs met through the birth-to-three intervention program?

25. Overall, what was helpful for your child and family? Why?

26. Overall, what was not helpful for your child and family? Why?

27. Did you have any needs or priorities that you felt were not addressed or supported? Please explain.

28. Is there anything else that you would like to share?
Appendix B

To whom it may concern,

My name is Sara Chaddock. I am currently a Special Education Coordinator at a school district in Louisiana and worked for several years as a classroom teacher for students who are deaf and hard of hearing. I am a graduate student under the direction of Dr. Linda Flynn-Wilson in the Department of Curriculum, Instruction, and Special Education at the University of New Orleans and I am conducting a research study on the experiences of parents of children with a diagnosed hearing loss in Early Intervention services for children from birth-to-three years old. As a parent of two children who are deaf, I am interested in learning about the experiences in Early Intervention of other parents with a child who is deaf or hard of hearing.

I am recruiting parents of children who have a diagnosed hearing loss to participate in this study. Participation in this study will involve completion of a survey via Survey Monkey which will take approximately 10 minutes to complete. All individuals will be anonymous and no names will be used in the study.

https://www.surveymonkey.com/r/PV3NSQQ is the link to the survey to be completed by parents. Clicking on this link will indicate a parent’s consent as a participant in this study. A parent's participation is voluntary and they may refuse to take part in the research or exit the survey at any time without penalty. They are free to decline to answer any particular question that they do not wish to answer for any reason.

My purpose in this interview is to gather information from parents' perspectives about the Early Intervention experience of their child who was diagnosed with hearing loss. The questions are designed for information purposes only. The information gathered from this study will contribute to research that seeks to improve Early Intervention programs, the experiences of families, and the outcomes for children with hearing loss. Your participation may possibly benefit the experiences of families of children with hearing loss. The results of this research study may be published, but no identifying information will be published. Your information will remain confidential.

Survey answers will be sent to a link at SurveyMonkey.com where data will be stored in a password protected electronic format. Therefore, responses will remain anonymous.

Can you please forward this email to families with children who have a diagnosed hearing loss; have participated (or are participating) in developmental, educational, or therapy interventions through Early Intervention; and are 5 years or younger?

By completing the survey, parents are providing their consent to participate in this study. they may print a copy of this form for their records.
If you or parents have questions about this research, you may contact me, Sara Chaddock at scusiman@uno.edu or Linda Flynn-Wilson, PhD at lflynnwi@uno.edu.

I appreciate your support in my project and look forward to hearing from you.

Sincerely,

Sara Cusimano Chaddock
Appendix C

Dear Participant,

I am a graduate student under the direction of Dr. Linda Flynn-Wilson in the Department of Curriculum, Instruction, and Special Education at the University of New Orleans. I am conducting a research study to investigate the experiences of parents of children with hearing loss who received (or are receiving) Early Intervention services.

I am requesting your participation in this study. Your participation will involve completion of a 10 minute survey via SurveyMonkey. Your participation is voluntary and you may refuse to take part in the research or exit the survey at any time without penalty. You are free to decline to answer any particular question you do not wish to answer for any reason.

My purpose in this interview is to gather information from your perspective about your family’s experiences after your child was diagnosed with hearing loss and your experiences with the birth-to-three Early Intervention program. The questions are designed for information purposes only. The information gathered from this study will contribute to research that seeks to improve Early Intervention programs, the experiences of families, and the outcomes for children with hearing loss. Your participation may possibly benefit the experiences of families of children with hearing loss. The results of this research study may be published, but no identifying information will be published. Your information will remain confidential.

Your survey answers will be sent to a link at SurveyMonkey.com where data will be stored in a password protected electronic format. Therefore, your responses will remain anonymous.

If you or parents have questions about this research, you may contact me, Sara Chaddock at scusiman@uno.edu or Linda Flynn-Wilson, PhD at lflynnwi@uno.edu.

By completing the survey, you are providing your consent to participate in this study. You may print a copy of this form for your records.
Glossary

American Sign Language (ASL) – a signed language that is used by members of the Deaf community in the United States. It includes its own unique grammar and syntax rules.

Cochlear Implants – a surgically implanted electronic device that stimulates the auditory nerve, allowing some deaf people to perceive sounds.

COVID-19 pandemic – a worldwide outbreak of the novel Coronavirus-19 which resulted in global disruptions to life and economy.

Cued Speech – a method of communication in which the speaker combines both mouth movements and hand movements.

Deaf person – a person who identifies as a member of the deaf community and shares a common culture and language with the deaf community.

deaf person – a person with hearing loss who does not identify as part of the deaf community.

Deaf Community – a group of people comprised of deaf and hard of hearing individuals who share a common language, common experiences, and common values.

Deaf culture – unique characteristics found among deaf and hard of hearing individuals who share a common language, behavioral norms, values, and traditions.

Deaf Mentor – a qualified deaf or hard of hearing adult who interacts with families of children with hearing loss to support the family and child in learning about American Sign Language, Deaf culture, and Deaf community.

Degree of Hearing loss – the severity of the hearing loss that an individual experiences, ranges between mild to profound.

Direct therapy – services delivered by a provider directly to the individual in a formal therapy session or environment.
**Hard of hearing person** – a person or individual who experiences hearing loss

**Manual communication** – the use of the hands to communicate

**Manually coded English** – using the hands to communicate; follows English language words and phrasing

**Mode of communication** – the method of communication that is chosen

**Pidgin Signed English (PSE)** – a combination of some American Sign Language (ASL) signs and some Signed English signs

**Signed Exact English (SEE)** – a sign system that matches signs with the English language using signs and fingerspelling that incorporates every grammatical feature

**Signed English** – a sign system that follows the English language, but does not incorporate many articles and affixes

**Simultaneous Communication (SimCom)** – a technique that incorporates spoken language and manually communication language being used at the same time

**Total Communication** – an approach to communication that combines sign language, finger spelling, and oral
Vita

The author was born in Metairie, Louisiana. She obtained her bachelor’s degree in elementary education from the University of New Orleans in 2008. She earned her master’s of deaf education from the University of New Orleans in 2011 and joined the graduate program to pursue a PhD in special education in the following years.