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Hearing Parents of Children With Hearing Loss: Perceptions of the IEP Process

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This is to certify that the doctoral dissertation by

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Walden University
2016

Abstract

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BA, Montclair State College, 1974

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Special Education

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Abstract

Under federal guidelines, parents of school-aged children with hearing loss are required to attend an individualized education program (IEP) meeting on behalf of their child. However, it remains unclear how prepared hearing parents are to oversee development of IEPs that guarantee their children the best educational outcomes, as well as how much support parents receive from teachers during the law-driven IEP process. This phenomenological study investigated the nature and extent of the support parents received during IEP development. The study was informed by Bronfenbrenner's ecological systems theory. Participants, located in a Northeastern state, were 10 hearing parents of children who had been diagnosed with hearing loss at birth and were between ages 5 and 12. Data were in-depth interviews that were analyzed, coded, and organized into themes using an inductive approach to analysis informed by Hatch. Results indicated that parents believed they needed more guidance on what to expect during the first IEP meeting, that advocating for appropriate accommodations for their child was important, and that education professionals communicate in a more compassionate and less business-like manner when speaking with parents. Parents also indicated increased anxiety due to their perceptions that education professionals have inadequate knowledge about issues relating to hearing loss and hearing amplification technology. Based on these results, special education professionals and policy makers can focus on increased understanding of hearing loss and amplification use in order to help children with hearing loss achieve more positive educational outcomes effecting positive social change.

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Dedication

With love and admiration, this dissertation is dedicated to the children who have touched my life as I have tried to touch theirs. It is their inspiration that put me on the path to continued learning.

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Chapter 1: Introduction to the Study

Researchers have identified active parental involvement in a child's education as a key element for fostering positive outcomes in children requiring a special education (LaRocque, Kleiman, & Darling, 2011; Xu & Filler, 2008). Facilitating parental involvement in the special-education process is now considered a requirement by law as suggested by the Individuals with Disabilities Education Improvement Act (IDEIA) (IDEIA, 2004). Although the law authorizes collaboration with parents in the development and delivery of their children's special-education programs, these partnerships are not always cultivated. A disconnect exists between parents' perceptions of their involvement and needs during the process and the perspective of teachers, school administrators, and mediators during the same process (Lake & Billingsley, 2000). As Fish (2006) reported, the development of positive family/school partnerships does not meet the standard of practice recommended by IDEIA (2004). Although the recommendation is to establish mutual partnerships, collaboration between the parent and the education professional is not easily achieved (Hornby & Lafaele, 2011).

As reported in the research literature, parents often believe education professionals do not recognize or understand the importance of parental input at individualized education program (IEP) meetings and often devalue parent input (Fish, 2006, 2008; Reiman, Beck, Coppola, & Engiles, 2010). Even with clear empirical substantiation that parental involvement supports positive outcomes on a child's learning and success in school, parents have reported feeling unimportant and dissatisfied at IEP meetings (Spann, Kohler, & Soenken, 2003; Zeitlin & Curcic, 2013).

Although researchers have recognized the importance of educational-team collaboration among educators and families in the empirical literature, the research has been limited to parent perspectives of the educational system and IEP process during the school-age years. The predominant focus of research has been the perceptions of the educational community on parent-educator interactions and relationships (Yell, Ryan, Rozalski, & Katsiyannis, 2009). Children who have disabilities, along with their families and professionals who work with the child, present significant challenges during the educational process and IEP development (Rous, Hallam, Harbin, McCormick, & Jung, 2007; Villeneuve et al., 2013). During the elementary years, annual IEP conferences are held in which the educational teams, including the parents, formulate an individualized educational program for their child’s upcoming school year. The development of this plan can be daunting (Mueller, Singer, & Draper, 2008). The nature and severity of a particular child’s needs may require special considerations that special educators might be unfamiliar with. This lack of knowledge is true with regard to children who are deaf or hard of hearing, which has been recognized by the secretary of the U. S. Department of Education (2005).

Children who are deaf or hard of hearing have unique educational needs that must be addressed for them to reach their maximum potential. Parents, educators, and school districts must ensure these students’ needs are met, yet the members of the IEP team often misunderstand these exceptional learning needs. Because only 1% of students who receive special-education services are deaf or hard of hearing, many IEP team members and staff do not have adequate knowledge regarding the educational needs of hearing loss

(Government Accountability Office, 2011).

Though the research is replete with information investigating the lived experiences of students with various disabilities, limited research exists regarding hearing parents raising a child of elementary-school age with hearing loss (Gilliver, Ching, & Sjahalam-King, 2013; Jackson, Wegner, & Turnbull, 2010; Jamieson, Zaidman-Zait, & Poon, 2011). In addition, the majority of literature within the past 5 years has focused on the early intervention and preschool population of children with hearing loss. Although the information gleaned from these studies can provide valuable information to educators, the studies did not address parental needs and perceptions beyond the early intervention and preschool years. The parents' stories may impart information that will inform special educators of the need to change current practices related to parental involvement in the special-education process. Parents have valuable input that will create professional awareness regarding attitudes and perceptions of the parents toward the IEP process, as well as add strength to the discussion about the unique educational needs of children with hearing loss. Empowering parents to become more involved in their child's education could also influence social change by positively affecting student academic performance.

Intentional and meaningful parent involvement in their children's education has become a highly desired and acceptable practice in today's educational arena. Research has shown that parental involvement plays a significant role in successful educational outcomes for children with and without disabilities (Turnbull, Turnbull, Erwin, Sodak, & Shogrun, 2011; Xu & Filler, 2008). However, for children who receive special-education services, parental involvement is critical (Kibaara & Ndirangu, 2014).

To build balanced and productive partnerships, the perceptions of parents must be explored to promote understanding of parental needs. Therefore, the focus of this study was the perceptions of hearing parents of children between the ages of 5 and 12 years who were diagnosed with hearing loss from birth, as the parents negotiated the education system and IEP process. The children had a classification of hearing impairment or deafness only, as indicated on their IEP. The information obtained from this study fills the gap in the body of literature regarding hearing parents' experiences with the educational system as they raise their children who have hearing loss. The results can help special educators support parents of school-age students with hearing loss.

Chapter 1 includes the background of the study, the problem statement, the purpose of the study, and the significance of the study. Chapter 1 also includes the nature of the study, the research questions, the theoretical foundation and conceptual framework, and definitions of terms. I conclude the chapter by describing and identifying the scope of the study, assumptions, limitations, delimitations, and summary of the main points of the chapter.

Background

Hearing loss in babies is one of the most common birth abnormalities in the United States. Approximately 3 in 1,000 babies, or more than 12,000 babies a year, are born with a permanent hearing loss (American Speech-Language-Hearing Association [ASHA], 2008; Centers for Disease Control and Prevention [CDC], 2010; Ross, Gaffney, Green, & Holstrum, 2008). Nearly 92% of children born with a permanent hearing loss are born to two parents with normal hearing (CDC, 2010). Though congenital hearing loss is a common birth occurrence, it is considered a low-incidence disability. According to IDEIA (2004), a low-incidence disability can be defined as a disability that occurs in 0.5% to 1.0% of the school's population of the students with a disability.

The nature of hearing impairment is complex and heterogeneous. Parents raising a child who is deaf or hard of hearing face a variety of challenges specific to having hearing loss. The educational needs of children with hearing loss must take into account many factors: (a) age at onset of hearing loss; (b) type and degree of hearing loss; (c) ability to use residual hearing; (d) communication abilities; (e) comorbidity factors; (f) audiological follow-up (yearly audiological evaluations, hearing aid and/or cochlear implant maintenance); and (g) classroom amplification needs (Berndsen & Luckner, 2012; NCAIM, 2012; Quittner et al., 2010). As such, IDEIA (2004) supports separate definitions for deafness and hearing impairment:

> Deafness means a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification. . . . Hearing impairment means impairment in hearing, whether permanent or fluctuating, that adversely affects a child's educational performance but that is not included under the definition of deafness. (IDEIA, 2004, Sec. 1414 [d] [3] [B])

A wide range of service and program options currently are available to the student who is deaf or hard of hearing: (a) general-education classroom with hearing peers, (b) general education with resource-room support, (c) general-education classroom with itinerant support, (d) self-contained classroom in a general-education setting, (e) special day school, (f) residential school, and (g) home instruction (Gallaudet University, 2014). According to the Gallaudet Research Institute (2011), in 2010, 48.6% of New York State students who were deaf or hard of hearing received their education in a special or center-based school. The next common placement was in a general education setting with hearing students at 41.2%, followed by 13.2% in a self-contained classroom in a general-education school and 4.3% in a resource room. Last, 1.6% were home schooled, and 3.4% were classified as other. Per the Government Accountability Office (2011), the majority of children who were classified as deaf or hard of hearing received services in the general-education environment for some or all of their instructional day, as specified in IDEIA Part B (2004).

IDEIA (2004) comprises many components. Two concepts are central to the purpose of this study: (a) "to provide an education that meets a child's unique needs and prepares the child for further education, employment, and independent living," and (b) "to protect the rights of both children with disabilities and their parents" (Wright & Wright, 2010, p. 20). Parental rights to full participation in the special-education process are mandated in IDEIA. Section 614 of IDEIA substantiates the participation of parents in several areas: (a) identification for services, (b) development of an individualized education program (IEP), and (c) assessment of student progress. In addition, IDEIA authorizes that parents be availed of the necessary knowledge for full participation in their child's special-education process.

The law mandates that the IEP team is composed of specific individuals who should include, but not be limited to the following: (a) parents/guardians, (b) special-education teachers, (c) teachers, (d) paraprofessionals, and (e) related service providers. As the IEP team members develop an IEP for a student with a hearing disability, the team must take into account the unique needs of the hearing impaired population as dictated by IDEIA (2004). The unique characteristics of the hearing-impaired population can present major challenges to members of the IEP team who have limited knowledge regarding hearing impairment, communication needs of individuals with hearing loss, and the diverse technology individuals who are deaf or hard of hearing use (Berndsen & Luckner, 2012; Szymanski, Lutz, Shahan, & Gala, 2013).

According to the IDEIA (2004), in the development, review, and revision of an IEP, the team members must

> (iv) consider the communication needs of the child, and in the case of the child who is deaf or hard of hearing, consider the language and communication needs, opportunities for direct communication with peers and professionals in the child's language and communication mode, academic level, and full range of needs including opportunities for direct instruction in the child's language and communication mode, and (v) Consider whether the child requires assistive communication devices and services. (IDEA, 2004, Sec. 1414 [d] [3] [B])

As the law requires, the IEP team members should practice shared responsibility for the formation of an effective education plan for a child, with each member of the team providing valuable perspective to the process. That parent involvement in their children's educations is central to positive outcomes in school is one IDEIA (2004) initiative reflecting a central tenet of Bronfenbrenner (1979). Bronfenbrenner (1974) argued parent participation was critical to a good education and firmly believed that family involvement must be sustained to foster positive outcomes. Unfortunately, parental perceptions of the IEP process reflect feelings of dissatisfaction and an unequal balance of power (Reiman et al., 2010). Garguilo (2012) suggested the committed educator must learn how to effectively listen to parents to allow them to express their feelings. The informed educator must also uphold the tenets of IDEIA by recognizing that ongoing collaboration is a requisite for maintaining positive feelings of involvement among parents.

The present study is unique in that it focused on hearing parents' perceptions of the special education and IEP process of children between the ages of 5 and 12 years with hearing loss who are classified as school age (Turnbull & Turnbull, 1990). The children had a classification of hearing impairment or deafness only, as indicated on their IEP. The parents' stories may lead to more effective and positive parent/school practices as recommended by IDEIA (2004; see also Fish, 2006). Professionals who compose the multidisciplinary team working with the parents may benefit from the perceptions of the parents gathered in this study.

Problem Statement

Researchers have studied parental perceptions of the special-education and IEP planning process of children with various disabilities (MacKichan & Harkins, 2013). Research is inadequate about hearing parents' perspectives of the special-education and IEP process among school-age children who are deaf or hard of hearing. In addition, recent research about hearing parents of children with hearing loss has focused on parental perspectives of the early-intervention process and preschool years (Dunst, 2010; Jackson, 2011; Muse et al., 2013). I intended this study to extend prior early childhood studies.

Increased knowledge of parental perceptions of the IEP process and experiences with the special-education system is valuable to education professionals and researchers about practices that can enhance parent/school collaboration. In addition, the resulting understanding among parents and professionals may result in actions that embrace the tenets of IDEIA (2004). Since the reauthorization of IDEA in 2004, parents have been dissatisfied and frustrated with the IEP process (Fish, 2006, 2008; Rehm, Fisher, Fuentes-Afflick, & Chesla, 2013). This added research can assist educators in recognizing parental challenges, which, in turn, could affect changes in policy and practice and create positive outcomes for student success.

Purpose of the Study

The purpose of this phenomenological study was to understand, describe, and explore the perceptions of hearing parents toward the education system and IEP process of a child between the ages of 5 and 12 years with hearing loss. The children had a classification of hearing impairment or deafness only, as indicated on their IEP. I identified (a) parent perceptions of and experiences with the education system; (b) parent perceptions and experiences with the special-education process, including the IEP process; and (c) the types of educational and emotional support parents need from special-education system providers as they nurture their children’s needs and their own needs. Given the complex nature of students with hearing loss, understanding parent perceptions of their experiences with special education and the IEP process is critical.

Research Questions

The four research questions are the following:

1. How do hearing parents of children between the ages of 5 and 12 years with hearing loss only describe their experiences with the educational system?
2. How do hearing parents of children between the ages of 5 and 12 years with hearing loss only perceive their experiences with the special-education process as their children proceed through the education system?
3. What patterns of coping do hearing parents of children between the ages of 5 and 12 years with hearing loss only identify as most helpful in managing the stress related to their experiences with the educational system?
4. What do hearing parents of children with hearing loss only want professionals in the special-education school system to know?

Conceptual Framework

Though the family is the "principal context in which development takes place, it is but one of several settings in which developmental processes can and do occur" (Bronfenbrenner, 1986, p. 723). Bronfenbrenner (1979, 1986) posited that both immediate or distal processes and contexts influence the development of a child. Parents, family members, and peers are considered immediate contexts with which children have direct contact. Distal contexts are those contexts not in direct contact with a child but are influential to development, such as community resources or the parents' workplace. Bronfenbrenner's (1994, 2005) ecological systems theory (EST) of human development brings an understanding to the important role parents play in their children’s educations and serves as the conceptual framework for this study.

The original ecological systems model Bronfenbrenner (1979) described consisted of four interconnected systems. These levels of interactions, or systems, are referred to as the following: the (a) microsystem, (b) mesosystem, (c) exosystem, and (d) macrosystem. In 1994, Bronfenbrenner extended the original theoretical model by adding a fifth system called the chronosystem, renaming the theoretical model the bioecological model. Bronfenbrenner posited that the ecological environment was like “a set of nested structures, each inside the next, like a set of Russian dolls” (Bronfenbrenner, 1979, p. 3). At the center is the child, who is surrounded by a set of concentric circles, or spheres of development, which represent the different levels of interaction: The layered contexts that have the most profound effect on a child’s life are the parents, the school, and the school community (Turnbull et al., 2011). For the purposes of this study, the conceptual framework was built on the ecological contexts, which include the parents, the school, and the school community—specifically, the microsystem and the mesosystem.

Bronfenbrenner’s (1979) theory emphasized the idea that children’s development is shaped and influenced by their different environments, including parental influences and involvement. As such, if a child presents with characteristics consistent with those of a typically developing child, expectations of unmarred development and function seem reasonable. However, if a child presents with characteristics atypical to developmental patterns, it is reasonable to conclude that development and function could be compromised (Johnson, 1994). Hence, the unique characteristics of children with hearing loss and the interactions the parents have with schools and educators may have profound influences on children's development.

Nature of the Study

I used a phenomenological approach to highlight specific information and identify phenomena experienced and perceived by those who are involved in life situations. Denzin and Lincoln (1994) posited that "qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (p. 2). Patton (2002) suggested that the qualitative researcher using a phenomenological approach is engaging in a "study of essences" and "is one that focuses on descriptions of what people experience and how it is that they experience what they experience" (pp. 106–107). In qualitative research, meaning emerges from the participants in the observable, naturalistic setting. I obtained deep and rich data from the research participants about their experiences and added to the pool of scholarly literature.

To accomplish this goal, I collected rich data by conducting in-depth interviews with the individuals who had lived the experience to study the educational perceptions of hearing parents raising children with hearing loss. To gain that individual perspective, interviews were undertaken "to find out what is in and on someone else's mind, to gather their stories" (Patton, 2002, p. 341).

According to Hatch (2002), "phenomenological studies usually combine both interpretive/hermeneutic methods and descriptive/phenomenological methods for the purpose of examining the lived experiences or lifewords of people being studied" (p.

228). I examined the experiences of the participants in this study through a series of interviews guided by key research questions and interview questions of a probing, but not leading, nature. These questions were based on the relevant ecological contexts posited in the conceptual framework used in this study. I analyzed the data I gleaned from the interviews using an inductive approach as posited by Hatch. One leading proponent of the interviewing technique, Janesick (2011), posited that the rewards of the interview process surpass any substitute for the process in understand and explore experiences that enable the researcher to describe the reality of the interview participants in the most exact way. If the goal of the phenomenological approach is to gain the deepest, richest, and most descriptive understanding of the everyday experiences of those who are studied and to understand the everyday experiences of the participants, it is critical to understand their world from their perspective and in their own words.

I used the unstructured interview, otherwise known as the informal conversational interview, to gather the data. Patton (2002) posited that the unstructured interview gives the research interviewer the flexibility to probe for information and follow the direction of the interviewee's flow of words on an individual basis. The nature of the conversational method of interviewing requires the interviewer and the interviewee to be available for a series of interviews. I informed the participants of the importance of participating in more than one interview, if necessary, to achieve the purpose of extracting the essence of their experiences and telling their stories in the most accurate and meaningful way possible.

I used purposeful intensity sampling of 10 information-rich cases (Mason, 2010;

Patton, 2002), in combination with snowball, or chain sampling, as strategies for this study. The sample comprised parents without hearing loss raising children with hearing loss in the 5- to 12-year-old age range. Each child had a classification of hearing impairment or deafness only, as indicated on their IEP. Recognizing that “the validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than the sample size,” I analyzed data to the point of saturation (Patton, 2002, p. 245).

Definitions

Audiogram: An audiogram is a graph that shows the softest sounds a person can hear (dB) at different pitches or frequencies (Hz). An *O* often is used to represent responses for the right ear, and an *X* is used to represent responses for the left ear (ASHA, 2011a).

Deafness: Deafness means a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification (IDEA, 2004; Authority: 20 U.S.C. 1401[3]; 1401[30]).

Degrees of hearing loss: This refers to the severity of the hearing loss: normal (-10–15 dB), slight (16–25 dB), mild (26–40 dB), moderate (41–55 dB), moderately severe (56–70 dB), severe (71–90 dB), and profound (91+ dB) (ASHA, 2011b).

Free appropriate public education (*FAPE*): A free appropriate public education (FAPE) means that the child with disabilities will receive the same education as a child without disability or handicap (Special Education News, 2015).

Hearing impairment: Hearing impairment means impairment in hearing, whether permanent or fluctuating, that adversely affects a child's educational performance but that is not included under the definition of deafness (IDEA, 2004; Authority: 20 U.S.C. 1401[3]; 1401[30]).

Individual with Disabilities Education Act (*IDEA, 2004*): The Individuals with Disabilities Education Act (IDEA) is a federal law enacted in 1990 and reauthorized in 1997 and 2004. It is designed to protect the rights of students with disabilities by ensuring that everyone receives a free appropriate public education (FAPE), regardless of ability. Further, IDEA strives not only to grant equal access to students with disabilities, but also to provide additional special-education services and procedural safeguards (National Resource Center on ADHD: A Program of CHADD, 2015).

Individuals with Disabilities Education Improvement Act (*IDEIA*)*:* President George W. Bush signed the Individuals with Disabilities Education Improvement Act (IDEIA), which reauthorized the IDEA, on December 3, 2004. It is also commonly referred to as IDEA 2004 (NYSED.gov, 2014).

Individualized educational program (*IEP*): The individualized education program (IEP) is a written document required for each child who is eligible to receive special-education services. It is provided to a student who has been determined first to have a disability, and second, to need special-education services because of that disability (Education.com, 2009).

Least restrictive environment (*LRE*): A least restrictive environment (LRE) means that the child with special needs be grouped in a classroom with peers where they will achieve the highest academic and social progress (Special Education News, 2015).

School age: This is the second stage of a four-stage family cycle, which designates school age as being children between the ages of 5 and 12 years (Turnbull & Turnbull, 1990).

Assumptions

Two assumptions guided this study. First, I assumed that the participants would describe their experiences accurately and their statements reflected their perceptions of their experiences. Second, I assumed the parents were secure in the confidentiality of the study, which fostered a level of comfort when relaying their stories.

Scope and Delimitations

A lack of empirical research existed regarding parental perceptions of the IEP process specific to hearing parents of children with hearing loss. The scope was narrowed and limited to hearing parents of a child who is between the ages of 5 and 12 years with a hearing loss classification of hearing impairment or deafness only, as indicated on their IEP. I recruited the participants from two counties in Long Island, New York. A purposeful sample ensured that the participants were information-rich cases. According to Patton (2002) the researcher must devise a strategic approach that is carefully planned to obtain those information-rich cases that are most appropriate for the study. Thus, all participants for this study met the following criteria: (a) both parents had normal hearing, (b) their child was classified as deaf or hearing impaired only, as defined under IDEIA and has an IEP; and (c) their child was between the ages of 5 and 12 years.

I conducted one interview with each of the participants to glean lived experience stories, which I analyzed to discover common themes and categories. These qualitative data ensured a detailed exploration of the parents' stories. The results of this study provide important information to the professional population concerning needs of normally hearing parents raising children with hearing loss and contribute to closing the gap in the literature.

In terms of transferability, the qualitative researcher has the responsibility to do a detailed job of describing phenomena so readers and researchers can judge the applicability of research findings to their own contexts (Lincoln & Guba, 1985). I enhanced transferability by providing thick description of the data enabling readers to decide for themselves if this study's results are transferable to their own contexts.

An exhaustive search of current and past peer-reviewed research regarding interactions between parents, school, and the school community revealed use of several conceptual frameworks suited for exploration among those contexts. However, variation in the research problems led me to build the present conceptual framework using Bronfenbrenner's (1979) ecological systems theory. I initially considered incorporating Epstein's (1985) spheres of overlapping influence as part of the conceptual framework, but concluded that Bronfenbrenner's theory supported the linkage between family and school most appropriately. I did, however, include a review of Epstein's theory. Other theories supporting various conceptual frameworks that I reviewed but did not select for use in this study were Shea and Bauer's (1997) family systems theory and Cochran's (1992) parent empowerment theory.

Limitations

This study had five limitations. The first limitation was the small sample size: 10 hearing parents from 10 families. A larger sample size could have generated different information. The second limitation was that the participant sample was taken from a local region. A more diverse sample could have generated a more diverse range of responses. The third limitation was that participants may have had preconceived notions about the educational process, which may have hindered the study. The fourth limitation was that the findings are only as accurate as the perceptions of the participants. The fifth limitation was related to small sample size and the possibility that different degrees of hearing loss affected parental responses. If such were the case, a sample size equally representing degrees of hearing loss could have generated different information.

In addition, my responsibility to my research was to keep my biases in check. I realized that my experiences as a team member in numerous IEP meetings could have affected my interpretation of participant feedback. For this reason, I embraced the principles of epoche and bracketing to eliminate preconceptions, feelings, viewpoints, or assumptions concerning the phenomenon under investigation (Creswell, 2007).

Significance of the Study

The present study is significant for several reasons. Parental participation in the special education and IEP process has typically been investigated through gaining the perspective of the education professionals. In this study, I investigated parent involvement investigated through the eyes of the parents. Moreover, I focused on students who are deaf or hard of hearing only, a population that had received little attention in the research literature with respect to perceptions of parental involvement. Learning the perceptions of hearing parents raising school-age children with hearing loss adds valuable information to the pool of current research literature. In addition, with hearing impairment being a low-incidence disability, the multidimensional needs of the hearing impaired population may be misunderstood among members of such children's educational teams. Shedding light on the heterogeneity of the population in terms of the unique needs of each student with regard to degree of hearing loss and use of assistive technology adds to the knowledge base of professionals collaborating with hearing parents of children with hearing loss. Further, to safeguard the futures of children with hearing loss and their families, special-education professionals must recognize the individual needs of each child and family to realise his or her full potential. The steps to ameliorate the special-education system can only be taken if the special-education community listens to the parents' stories and acknowledges that certain changes are required to support parental needs. I hope that these changes will be instrumental in providing an improved special-education system that supports future generations of children with hearing loss and their families.

Implications for Social Change

My intent was to support Walden's mission and uphold the commitment of effecting positive social change by revealing significant data critical to the discipline of education of individuals who are deaf and hearing impaired. Increasing awareness of the hearing parents' journeys with their children is critical for the professional community. In order to provide appropriate and unbiased educational guidance, available resources, and emotional support specific to each parent's needs, increasing awareness in the professional community is elemental. The information gleaned from the parental experiences can be used to inform and enlighten those educators who become members of the educational teams responsible for meeting the needs of children born with hearing loss.

Summary

Through a phenomenological interview and analysis process, I investigated the experiences of 10 hearing parents from 10 families raising children with hearing loss only, as indicated on their IEP. The interview data unveiled common themes and categories that can increase educators' awareness of parental perceptions of their involvement with the special-education and IEP process. The conceptual framework upon which this study was based posited the critical nature of parental involvement in a child's education, as well as the importance of school and school-community involvement. Bronfenbrenner's (1979) EST posited that the parents, the school, and the school community not only have a profound effect on a child's education but also nurture positive educational outcomes for the child when families and schools develop positive partnerships.

Chapter 1 included an introduction to the phenomenological study of hearing parents raising children with hearing loss and their perceptions of the special-education and IEP process, including the background of the problem, research purpose and questions, conceptual framework, and significance of study. Chapter 2 includes a literature review of research pertaining to hearing parents raising children with hearing loss, with an emphasis on education law and parental perceptions of special education and the IEP process. Chapter 3 summarizes the methodology used in this study. Chapter 4 includes findings from this phenomenological study, and, finally, Chapter 5 contains an interpretation of the findings.

Chapter 2: Literature Review

Introduction

This chapter contains the necessary clinical information to achieve a basic understanding of deafness, types and degrees of hearing loss, and hearing aids and cochlear implants, all of which are pertinent to the population addressed in this study. Information regarding a child's special-education classification, amplification needs, and accommodations associated with those needs are included on the IEP. One of the criteria for inclusion in this study is that the child be congenitally deaf or hearing impaired only and between the ages of 5 and 12 years. Thus, each of the parents in this study had prior experience with early hearing detection intervention (EHDI) and early intervention. As such, those two topics will also be included in the literature review. Attention is also given to parental reactions to an initial diagnosis of hearing loss in their child, as this is an event that occurred in each one of the sample participant's lives. Moreover, as research has indicated, resolution over grief of having a child with hearing loss may be a lifelong pursuit (English, 2010; Luterman, 2006). Additional topics I will examine include (a) a historical review of special-education law, (b) the IEP process and parental involvement, and (c) Bronfenbrenner's (1979) EST as it relates to parent/school relationships.

The purpose of the proposed phenomenological study is to understand, describe, and explore the perceptions of hearing parents of a child between the ages of 5 and 12 years with hearing loss toward the education system and IEP process. The child must have a classification of hearing impairment or deafness only, as indicated on their IEP. I intend to identify (a) parent perceptions and experiences with the education system, (b) parent perceptions and experiences with the special-education process including the IEP process, and (c) the types of educational and emotional support parents need from special-education system providers as they nurture their children's needs and their own needs.

The majority of literature within the past 5 years regarding hearing parents raising children with hearing loss has focused on the parental perceptions of EHDI, the early-intervention (EI) process, and cochlear implants (Sass-Lehrer, 2012; Young & Tattersall, 2007). I have duly noted that the research regarding the experiences of the parents over the familial lifetime is limited (Day & Brice, 2013; Hintermaier, 2006; Kobosko, 2011). My intention was to add necessary information to the research pool regarding parental perceptions of special education and the IEP process during the elementary school-age years in an effort to begin to close the noted gap in the empirical literature. The literature consistently notes that parental involvement in a child's education contributes to the child's academic success (Bogenschneider & Johnson, 2004). To accomplish the purpose of this study and discover answers to the research questions, I researched and analyzed the literature to the point of saturation.

The professionals who share the everyday responsibilities in the education of hearing-impaired children must understand the needs of the parents. The parents must continually make educational, medical, and technological decisions related to their children throughout their tenure in school. If the educational specialists are to provide the necessary support to assist these parents, the parents and professionals must maintain a positive relationship. The educational team must acknowledge that the needs of the parents extend far beyond the initial diagnosis of deafness in their child and early education years.

Literature Search Strategy

The primary sources of literature for this review included peer-reviewed journal articles from professional journals. I found these journals in the databases of Academic Search Complete, CINAHL Plus with Full Text, ERIC, EBSCO, Education Research Complete, Education from SAGE, Web of Science, Science Direct, PsychInfo, Wiley Online Library, SAGE Research Methods Online, and Sage. In addition, I researched dissertations from Walden Dissertations and ProQuest. I accessed these databases from the Walden University Library, libraries from other universities, and Google Scholar. Professional organization websites, such as ASHA, the Alexander Graham Bell Association (A. G. Bell), and American Academy of Audiology (AAA), were also sources for the literature I reviewed.

I began my multiple database search using the broad search terms *hearing parents raising a deaf child*. I found this to be insufficient, as it did not provide ample recent research literature. However, as I read the abstracts of the journal articles that were relevant to this study, I noted the key words used in those studies and branched out in my search. It was through this process I discovered the most relevant databases and performed searches one by one. In addition to using the multiple databases available through the library system and directly speaking with several librarians, I accessed the available resources outside of the databases. It was during this iterative search process that I affirmed the gap in the research literature posited for this research study.

To optimize the search related to the purpose and problem statement, I engaged in citation chaining using Science Web and Google Scholar databases to ensure saturation of the literature. I did this prior to and on July 8, 2015. I used the key terms *disabilities studies, IEP parent participation, parental perceptions of special education, parental perceptions of IEP process, hearing parents, parental supports in special education, education law, parental involvement in special education, parental barriers in special education, elementary special education, parental dissatisfaction in special education, parental dissatisfaction in IEP process, the law and special education, school and home connections in special education, parent-educator collaboration* and *strengths and weaknesses of IEP team.* As of July 8, 2015, I did not find any additional peer-reviewed journal articles that could be included in the literature review for my study. Therefore, I maintain that saturation of the research literature was achieved.

Topics Related to Hearing Loss and Amplification

A child who is deaf or hard of hearing presents education professionals with numerous considerations when planning an appropriate educational program. The diverse nature of hearing loss and individual performance specific to each child’s profile can be perplexing to educators unfamiliar with students classified as deaf or hearing impaired (Seaver & DesGeorges, 2004). According to the “Deaf Students Education Services Policy Guidance Report” as cited in Seaver & DesGeorges, 2004, p. 11), there was “not widespread understanding of the educational implications of deafness, even among deaf educators.” The following topics are deemed critical for educators in understanding basic concepts integral to students who are deaf or hard of hearing.

The Basics of Understanding Hearing Ability

Deaf, hearing impaired, hard of hearing, hearing impairment, and *partially deaf* are a few terms used interchangeably, and sometimes improperly, when discussing persons who have various types and degrees of hearing loss. The initial step to understanding hearing ability and listening performance in children is to understand the diverse nature of hearing loss, and the associated factors relating to individual hearing ability. Some of the significant influences on hearing ability and performance in children include age and onset of hearing loss; age at diagnosis of hearing loss; cause of hearing loss; implementation of educational services and supports; development of language, mode of communication; and degree, type, and pattern of hearing loss (Luterman, 2006; Shemesh, 2013).

The multifaceted nature of hearing loss can be overwhelming to parents and family members who are dealing with a child diagnosed as deaf or partially hearing for the first time. No degree of book learning can prepare one for the unique nature of hearing loss as it manifests in each individual child. Although two children may present with similar results on a hearing assessment, their performance in real-life situations may not be similar at all.

The commonly used terms of *hearing impaired*, *deaf*, and *hard of hearing* refer to a broad range of circumstances and conditions that influence a child's ability to listen. The three characteristics used when describing a hearing impairment are (a) type of hearing loss, (b) degree of hearing loss, and (c) configuration of hearing loss. Hearing loss can be defined by how much hearing a person has or does not have or by how the individual functions with the hearing he or she does have with and without assistive listening devices (Madell & Flexer, 2008; Shemesh, 2013).

Understanding Hearing Loss

The three essential characteristics of hearing loss used to clinically define the loss are (a) type, (b) degree, and (c) configuration of hearing loss. The type of hearing loss refers to what part of the auditory system is compromised; the degree of hearing loss refers to the severity of the hearing loss; and the configuration of hearing loss refers to the range of affected frequencies (pitches) of the hearing loss. The combination of these three characteristics constitutes the visual representation of hearing loss, which is recorded on an audiogram during a hearing test by an audiologist. Hearing loss can be categorized as (a) conductive, affecting the middle ear, (b) sensorineural, affecting the inner ear, and (c) auditory nerve or central, affecting auditory centers of the brain. Mixed hearing loss also exists, which affects the conductive and sensory components of the ear simultaneously (ASHA, 2013; Clark, 1981; Shemesh, 2013).

Different types and degrees of hearing loss result from different causes of hearing loss, some temporary and some permanent (Marschark, Young, & Lukomski, 2002). A conductive hearing loss, which affects the middle ear, is often reversible. The type of hearing loss that is permanent, known as a sensorineural hearing loss, is one that cannot be resolved but can be assisted with technology. A sensorineural hearing loss is one in which the little hair cells in the cochlea are dead or not present and/or the auditory nerve is not functioning properly. This type of hearing loss is the most severe (Marschark et al., 2002). In a third type of hearing loss, a mixed hearing loss, presence of a sensorineural hearing loss with the addition of a conductive component exists. Children with sensorineural hearing losses often have a middle ear infection, or fluid, compounding their hearing loss (ASHA, 2013; Shemesh, 2013).

The third attribute of hearing loss is the degree, or severity, which can be categorized as mild, moderate, moderately severe, severe, or profound. Hearing loss is commonly explained in decibels (dB), the unit used to measure the intensity of a sound (ASHA, 2013; Shemesh, 2013). According to the CDC (2010), severity of hearing loss is categorized as mild (26 dB–40 dB), moderate (41dB to 55dB), moderately severe (56dB to 90dB), severe (71dB to 90dB) and profound (over 90 dB).

Hearing Aids, Implants, and FM Systems

Individuals who are deaf or hard of hearing have a variety of assistive technologies available to them that provides improved auditory access in a range of settings. Students classified as deaf or hearing impaired performs differently in how they use their residual hearing. For those families who choose to promote listening and spoken language in their child, the child must be exposed to consistent access to the auditory signal. Families who choose this route will typically be aligned with professionals who can assist them in making the appropriate amplification choices for their child. This section is not written for the purpose of advocating one technology over the other, or about promoting listening and spoken language or a manual communication system. This information is provided for the purpose of imparting a general familiarity with the types of assistive technology students who are deaf or hard of hearing use. The three basic technologies that are critical to the child's access to sound are hearing aids, cochlear implants, and FM amplification systems (Felzien & Harrison, 2009; Madell & Flexer, 2008).

There are four primary types of hearing aids: (a) behind-the-ear (BTE), (b) in-the-ear (ITE), (c) in-the-canal (ITC), and (d) implantable hearing aids. The audiologist will assist the parents with the selection of the most appropriate hearing aid or aids for their children with regard to their ages and types and degrees of hearing loss. The type of hearing aid typically chosen for children is the BTE. Follow-up visits to the audiologist must be maintained to ensure proper hearing-aid performance to give the child the most appropriate access to sound. The majority of individuals with hearing loss use hearing aids; however, for those individuals who cannot make use of their residual hearing and are severely to profoundly deaf, cochlear implants may provide them with a more optimal option. As hearing aids can only make sound louder in an auditory system that is damaged, a cochlear implant bypasses the damaged system and changes sound energy into electrical energy that stimulates the auditory nerve (Felzien & Harrison, 2009; Madell & Flexer, 2008).

Children who gain little or no benefit from hearing aids, have a severe to profound hearing loss, and are at least 12 months of age may be candidates for a cochlear implant. The Food and Drug Administration (FDA) provides strict guidelines and protocols for individuals seeking candidacy for an implant. Although the FDA recommends that a child be at least 12 months old to receive an implant, some implant centers have implanted babies as young as 6 months old with positive results (Felzien &

Harrison, 2009). A cochlear implant is a surgically implanted device that changes sound energy into electrical stimulation, which the auditory nerve processes. The implant consists of two parts: the surgically implanted receiver/stimulator and the external microphone and transmitting coil that magnetically attaches to the outside of the head, along with a speech processor that is programmed to each individuals' hearing profile. The implant bypasses the damaged and destroyed hearing hair cells and stimulates the auditory nerve to restore partial hearing (Felzien & Harrison, 2009; Madell & Flexer, 2008).

As with hearing aids, the consistent and diligent attention to maintenance and programming of the device is imperative to successful listening outcomes. Hearing aids and cochlear implants are not cures for deafness and hearing loss. Individuals must be committed to hard work at home to carry over skills learned in school and therapy. Appropriate habilitation is necessary to optimize listening skills (Madell & Flexer, 2008).

Although both hearing aids and cochlear implants are beneficial to individuals with hearing loss, they do have limitations when listening in a noisy environment. The student who is deaf or hard of hearing in a classroom environment is at a disadvantage, even while wearing his or her own amplification devices. Although technology has provided improved devices, hearing aids, cochlear implants, and other advances are limited in their abilities to cut out background noise. The FM amplification system is a suitable answer for decreasing the competing noise signal for the hearing aid and implant wearer (Northern & Downs, 2014).

A variety of systems are available that are suitable for classroom needs. All work using the same principle. Each FM system consists of two components: a transmitter and a receiver. The person talking wears an FM transmitter and a microphone, and an FM receiver is attached to the child's personal hearing device. The FM system minimizes the background noise because the microphone is worn close to the teacher's mouth, amplifying the teacher's voice over the background noise. The FM system is a wireless system, which enables the teacher to move freely around the classroom without any interruption of the auditory signal. Again, as with hearing aids and implants, the FM system needs monitoring to ensure it is in optimal working order (Madell & Flexer, 2008; Northern & Downs, 2014).

From the Beginning: Early Identification and Early Intervention

Early Hearing Detection Intervention

The importance of early identification of hearing loss has been recognized for years (Arehart & Yoshinaga-Itano, 1999; Butler, 2012; Holte et al., 2012; Matthijs et al., 2012; Patel & Feldman, 2011). Demographic analysis reveals the incidence of severe to profound hearing loss in the United States as being between 1.1 and 3 per 1,000 live births, 33 infants per day, or between 12,000 and 16,000 babies yearly (Gracey, 2003; McGrath, Vohr, & O'Neill, 2010).

The movement to develop effective methods of identification began with the establishment of the Joint Committee on Infant Hearing (JCIH) in 1969. Representatives from ASHA, the American Academy of Ophthalmology and Otolaryngology (AAOO), and the American Academy of Pediatrics (AAP) formed the initial committee to address the need for early identification of hearing loss for those children who presented in high-risk categories, and for the screening of newborns. The committee’s initial position statement in 1970 could not support implementation of mass hearing screening because of a lack of efficient testing methods (JCIH, 2008).

Extensive research and development of testing methods and protocols that would fulfill the needs for recognizing hearing loss in the infant as soon as it was physiologically possible accompanied the continued commitment to early detection of hearing loss. The JCIH amended its initial position regarding early detection as technology caught up to the need for sound infant-hearing procedures and appropriate testing equipment (JCIH, 2008).

The 1990s was a time of increased recognition and rapid expansion of initiatives to support the need for early detection of hearing loss. Both the National Institute of Health Development Program (1993) and the JCIH (2008) supported and recommended that all infants be screened for hearing loss before leaving the hospital based on the goal of detecting infant hearing loss prior to 3 months of age and enrollment in an intervention program by 6 months of age. The committee continued to grow to where it is today, with representation from the AAP, ASHA, the American Academy of Otolaryngology–Head and Neck Surgery, the American Academy of Audiology, the Council on Education of the Deaf, and Directors of Speech and Hearing Programs in State Health and Welfare Agencies (JCIH, 2008; National Center for Hearing Assessment and Management, 2012). This comprehensive involvement led to the JCIH recommendations in 2000 for universal hearing loss screening prior to infants leaving the hospital. The system that was established and is in place today involves three critical components: (a) screening before discharge from hospital, (b) follow-up screening and diagnosis, and (c) enrollment in early intervention (JCIH, 2008).

Although extensive progress has been made regarding the legislation and regulations the federal government with regard to each state's EHDI programs, several areas of weakness remain. To inform the professional community where improvements are needed and to better serve children, White, Forsman, Eichwald, and Munoz (2010) highlighted the following areas of weakness: (a) availability of pediatric audiologists, (b) implementation of effective tracking and data-management systems, (c) program evaluation and quality assurance, (d) availability of appropriate early-intervention programs, and (e) linkages with medical home providers.

To increase awareness and strengthen EHDI programs in the United States, Houston, Bradham, Munoz, and Guignard (2011) conducted a strengths, weaknesses, opportunities, and threats (SWOT) analysis of 49 state EHDI coordinators regarding universal newborn hearing screening (UNHS) practices. Their findings supported those of White et al. (2010), specifying the need for well-trained pediatric audiologists, early-intervention providers, teachers of the deaf, and speech and language pathologists to assist with effective follow-up procedures. These findings and recommendations will assist state coordinators of EHDI programs in strengthening their present hearing screening efforts.

Understanding Parental Reactions to Initial Diagnosis of Hearing Loss

As parents anxiously await the arrival of their newborn baby, most dream of an idealized family unit commonly written and spoken about. For some parents, the dream of having the perfect baby is shattered when they are told that their baby has been born with a permanent hearing loss. Parents who have normal hearing who are raising an infant who has been diagnosed as deaf or hard of hearing are about to enter a world of unknowns. The initial reaction to the diagnosis of hearing impairment can include feelings of fear, despair, guilt, anxiety, grief, insecurity, and shock (Feher-Prout, 1996; Luterman, 2006; Jackson et al., 2010). The original feelings of elation are often replaced by intense emotions, as well as the additional responsibilities of needing to seek the most appropriate intervention models, hearing health-care professionals, medical specialists, and support services. For parents who are hearing and who have limited, if any, experience with individuals who are deaf, the responsibility of raising a child who is deaf can seem overwhelming.

Not only must the parents manage to cope with their children's diagnoses of deafness and their reactions to the challenges before them, they are also learning about the potential roadblocks to the natural acquisition of the English language. Additionally, parents will deal with a plethora of new information pertaining to hearing loss and its effect on social and emotional development (Antia, Jones, Luckner, Kreimeyer, & Reed, 2011; Baker, 2012; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003).

The present study is unique in that it will explore parental experiences when raising older children, which the literature suggests has been inadequately researched. (Jamieson et al., 2011; Luterman, 2004). Zaidman-Zait (2008) stressed the importance of investigating parental coping experiences and how the effect of those experiences overlap with ecological theory. Luterman (2004), Zaidman-Zait (2008), and Jamieson et al.

(2011) recognized the need for families to have the appropriate combinations of resources, including social, informational, and support services, to help families cope with the stressors associated with parenting in general and parenting a child who is deaf or hearing impaired. Although the research literature is replete with studies documenting the initial reactions and experiences of parents with normal hearing upon initial diagnosis of their children's hearing loss, an evident lack of research exists regarding the experiences of the parents as their children grow.

> Becoming a special needs parent is not an experience the average person seeks out. And it's transformative, whether or not you actually wanted to be transformed. Like it or not, you are on your way to becoming an entirely new person. (Birnbaum, 2013, para. 3)

The mother of a child with disabilities growing up in New York City spoke these words. Although Birnbaum's child was not born with a hearing impairment, her words echoed the thoughts and feelings expressed by many normally hearing parents upon finding out their newborn had hearing loss.

Parenting a Child Diagnosed as Having Hearing Loss

The parenting journey for the hearing parent whose child has been identified as having hearing loss and subsequently diagnosed as deaf or hard of hearing will be altered in ways they could not have imagined. Their initial feelings of elation will be compounded by the emotional effect of a diagnosis of hearing loss in their child. English (2010) referred to the emotional journey as a "rollercoaster of emotions," which was based on feedback she received from her counseling encounters with hearing parents.

In her work with families of children with disabilities, Eichenstein (2014) also stressed the unique emotional journey parents of children with disabilities experience. She pointed to the lack of attention to parental well-being in past practices and the shift toward fostering parental and family well-being in present practices. This philosophical shift supported the tenets of Bronfenbrenner's (1994) bioecological model of human development, as the professional community recognized the powerful effect the diagnosis of hearing loss in a child had on the parents, as well as on the entire family unit (Meinzen-Derr, Lim, Choo, Buyniski, & Wiley, 2008).

The feelings hearing parents experience after a diagnosis of deafness in their children are often intense and paralyzing. Many researchers have classified these intense feelings as grief reactions. The dream of having "the perfect child" has been shattered and the life they were expecting to live has now been lost to a new reality. As one father of a 15-year-old with hearing loss stated:

> At the time of diagnosis a host of uncomfortable feelings usually emerge, among them fear, inadequacy, anger, guilt, vulnerability, and confusion. When you first find out your child is hard-of-hearing, it really hurts and then it becomes a dull ache that never goes away. (Luterman, 2006, para.12)

Bosteels, Van Hove, and Vandenbroeck (2012) interviewed 10 normally hearing parents of children with hearing loss living in the Flemish region of Belgium. This study is significant in that the 10 parent participants were the first generation whose children participated in a universal newborn hearing screening (UNHS) program. The initial reactions to a diagnosis of deafness evoked intense personal and emotional reactions to the diagnosis. A frequent theme that appeared was the clarity with which parents could recall the details and events of the diagnostic procedures and affirmation of diagnosis:

> At first it was a bomb, you cannot believe it, but then, you have to. I was completely out of it. Half of the time, coming home, I had to ask my husband, “what was it again they said about that, and that?’ During those weeks, months really, I was in a different world, the shock. (Bosteels et al., 2012, p. 989)

A parent’s reaction to their child’s hearing loss is uniquely individual. Yoshinago-Itano and de Uzcategui (2001) examined the reactions of parents soon after their newborns failed the hearing screening. Parents reported feelings of fear (52%), shock (42%), confusion (42%), depression (37%), frustration (31%), anger (22%), loneliness (16%), and blame (16%), all of which are feelings commonly associated with feelings of grief (Kurtzer-White & Luterman, 2003). At least as noteworthy are the feelings of guilt the parents experience. Mothers typically express guilt regarding the cause of the hearing loss, while the father relates his feelings of guilt toward his inability to keep his family protected from pain (Luterman, 2009).

As a result of her work at a school for the deaf and from information gleaned from parent interviews, Mapp (2004) revealed that the majority of parents reported feelings of grief and pain in response to hearing the news that their children were deaf. One parent expressed the need to learn coping behaviors to deal with his or her child’s deafness and believed that a parent never truly accepts their child’s hearing loss.

Although a large portion of the research literature related to diagnosis of hearing loss in a newborn of hearing parents has revealed negative emotions regarding the diagnosis, evidence exists of positive adjustment and outcomes in parents who have adopted adaptive coping behaviors. At the time of identification and immediately following, parents are faced with critical decision-making processes. This time can be overwhelming, stressful, challenging, and emotional for some parents; on the other hand, parents who exhibit resilience and adaptation to coping mechanisms, and who have a strong family support system, manage the diagnosis of deafness in their newborn with a more positive outlook (Plotkin, Brice, & Reesman, 2013; Calderon & Greenberg, 2000; Quittner et al., 2010).

Whittingham, Wee, Sanders, and Boyd (2013) reported that parents demonstrate various degrees of grief at different times and during different occasions in their children's lives in response to the challenges of parenting children with disabilities. Such information is critical for health care providers and teaching professionals. Parents require ongoing support and guidance as their children pass through different stages in their lives. As Huang, Kellett, and St. John (2010) emphasized, parents need support at the time of initial diagnosis and after diagnosis to continue to understand the needs of their children. The provision of emotional support and information related to their children and family should be provided on an ongoing basis.

English (2005, 2010), through her personal experiences as a practicing audiologist dealing with parents and their newly diagnosed children with hearing loss, also recognized the distinct patterns of grieving and coping that each parent experienced. English's experience and insight in the area of parental grief reactions and coping behaviors is valuable to the professional and critical to the field of deafness. The author addressed the question of whether parents ever achieve acceptance of their children's hearing loss or whether they learn to manage by developing coping behaviors that assist in maintaining emotional equilibrium. She also recognized the need for ramped-up professional training programs to include counseling courses in their curriculum so the professional can understand the parental journey, meet their needs, and acquire the knowledge to support these parents beyond the early years of identification of deafness, enrollment into EI, and transition into the school-age years.

Parental reactions to news about their children that will take them into an area of unknowns will likely change their lives in ways they could never have imagined. As Moses (1987) suggested, "Few would argue that facing the devastating and continuing loss of having an impaired child is among the most painful experiences that a person can confront" (p. 1). Through listening to the parents' stories and assuming a continuous dialogue with the parents, the professional can strengthen the processes by which they assist the parents. In his work with parents of children with disabilities, Moses (1987) found the communication exchanges between himself and parents to be revealing. "What followed was a remarkable outpouring of poignant, anguished human sharing that, to this day, serves as the foundation for understanding and working with parents of impaired children" (Moses, 1987, p. 2).

Early Intervention

The evolution of laws, perceptions, and awareness led to paradigm shifts where emphasis was placed not only on the early identification of individuals with hearing loss but also on the implementation of early-intervention programs. This shift led to philosophical changes in methodology and practices from a child-centered approach to a family-centered approach. It was not only the children with disabilities who needed nurturing and guidance—the parents also needed that nurturing and guidance, not only to manage their own emotions and expectations, but also to learn how to nurture their own children with a disability (Shea & Bauer, 1997).

The decades of the 1960s, 1970s, and 1980s proved to be times of change and rapid expansion in the field of special education. The Education for All Handicapped Children Act (EAHCA) was passed in 1975 when President Gerald R. Ford signed the legislation. The purpose of the EAHCA was to provide each child with a federally mandated "free and appropriate public education that emphasizes special education and receive services designed to meet their unique need and prepare them for further education, employment, and independent living" (Center for Public Education, 2009, para. 1). The EAHCA was amended 23 years later to include P.L. 99-457, which "supported the right to early intervention services for all infants, toddlers, and preschoolers with a disability to those at risk of having a substantial developmental delay." P.L. 99-457 was further amended, and in 1990, the original EAHCA went through major changes, which led to the creation of the IDEA. Two significant sections were specified in the IDEA, known as Part B and Part C (formerly Part H). Part B of IDEA was developed to include public-school system responsibility for providing services to eligible children ages 3 years to 21 years. Part C of IDEA was established to give states the option to provide early-intervention services for eligible infants and toddlers ages birth through 2 years (Dunst, 2007).

Today, infant and toddler services are authorized under Part C of the IDEIA (P.L. 108-446; 2004) with the guarantee of early-intervention services for those families with infants and toddlers with disabilities, birth through 2 years of age. The goal of Part C was to foster positive outcomes and enhance a readiness skill set for preschool and kindergarten (IDEA, 2004).

Early Hearing Detection and Intervention

Research studies conducted within the past 2 decades have documented a strong shift toward parental and family involvement during the early-intervention process, as well as the importance of parental and family involvement during the initial diagnosis of hearing loss in the newborn (Bagdi & Vacca, 2005; Dunst, 2000; 2007; 2010; Jackson, 2011; Moeller, 2000; Muse et al., 2013; Rice & Lenihan, 2005; Sass-Lehrer, 2012; Yoshinago-Itano, 2000). Though the implementation of EHDI has been a huge leap in the hearing health-care field, early detection does not guarantee optimal development and positive outcomes (Muse et al., 2013). EI should be an extension of the hearing screening process to provide the necessary tools to the child, parents, and family to support maximum growth (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013; Nelson, Bradham, & Houston, 2011).

Combining EHDI and EI is intended to optimize language and literacy development in each child who is deaf or hard of hearing. Before newborn screening was implemented in the United States, the average age of identification of hearing loss was 30 months. Such late diagnosis contributed to the child falling behind the same-age peers in the acquisition of speech and language (McGrath et al., 2010). Early identification and amplification by 6 months of age has resulted in significantly better language outcomes at age 5 (McGrath et al., 2010; Rice & Lenihan, 2005). Though varying opinions exist about specific strategies and methodologies that promote school readiness, researchers found that early identification and amplification together benefitted children with varying degrees of hearing loss in gaining a wider language base at an earlier age (Calderon & Low, 1998; Evans, 2008).

Critical responsibilities of early-intervention providers include educating parents about hearing loss, the use of amplification and/or cochlear implants, the importance of informed decision making, choices in communication modalities, and the development of early-literacy skills to decrease their children's achievement gaps and maximizing development (Evans, 2008; Matthijs et al., 2012). Research has shown that successful EI programs recognize the importance of familial and ecological factors. Family-centered early intervention enhances awareness and assists in creating a supportive environment for children with hearing loss to acquire skills such as word-learning and pragmatics necessary for school readiness (Calderon, Bargones, & Sidman, 1998; Sass-Lehrer, 2012).

Optimal early-intervention practices were found to be individualized based on family need. Muse et al. (2013) posited that the optimal EI team focused on the family and included professionals with pediatric experience. Carney and Moeller (1998) determined that four clusters of family characteristics influenced readiness for school: (a) family innovation and interaction, (b) guidance and knowledge, (c) the ambition for achievement, and (d) adaptation to deafness. Parents who adjusted to their children's hearing loss through acceptance and adaptation demonstrated increased expectations that positively affected their children’s achievements in reading and mathematics. Calderon and Low’s (1998) findings supported Carney and Moeller’s assertion that family dynamics and parental attitude toward deafness significantly correlate with the child’s achievement scores.

Jackson (2011) found the importance of family involvement in early intervention and identified three areas as having primary significance: (a) informational resources, (b) social-emotional support, and (c) educational advocacy. Initial referrals to early-intervention agencies can be overwhelming to a family of a child with hearing loss. The team of professionals within the agency will be determining the appropriate individualized program for each child and will coordinate program services and treatments that match each child’s needs, along with educating the parents about these services. According to Patton (2002), “Highly individualized programs operate under the assumption that outcomes will be different for different clients. Not only will outcomes vary along specific common dimensions, but outcomes will be qualitatively different and will involve qualitatively different dimensions” (Patton, 2002, p. 154). Individualization of each program for each family and child is the goal of EI; however, outcomes and milestone attainment will vary along a continuum of development.

Program Planning and Parental Involvement in Early Intervention: The IFSP

A parent’s initial collaboration with the special-education system occurs after his or her child is evaluated and found eligible for EI services. A plan must be devised for each child that will meet his or her needs and the family’s needs. This plan is called the *individualized family service plan*, or IFSP. The IFSP is a written document that specifies the EI services that your child and family will receive. A team devises this document. The team consists of the parents, other family members, if requested, a parent advocate, service coordinator, persons involved in the child's evaluation, and early-intervention education providers (Center for Parent Information and Resources, 2014).

Each state has specific guidelines for the coordination of an IFSP, which are explained by the family's service coordinator. Each IFSP must include the following: (a) the child's present level of functioning in all areas of development, (b) family information, (c) results or outcomes expected to be achieved, (d) all EI services the child will receive, (e) in what setting the services will take place, (f) when and where the services will occur, (g) frequency of services, (h) who will pay for services, (i) name of the service coordinator, and (j) information regarding transition out of EI. It is critical to IFSP implementation that parents receive a full and detailed explanation of the plan followed by written consent before services can begin (Center for Parent Information Resources, 2014).

Important to note is the vast amount of literature cited in the areas of UNHS and EI and the lack of information available in scholarly journals regarding the pre-adolescent and adolescent population who are deaf or hard of hearing (Jamieson et al., 2011). In an effort to provide information regarding needs and supports to parents of school-age children who are either deaf or hard of hearing, Jamieson et al. (2011) embarked on a study that focused on 10- to 18-year-old elementary and adolescent students who were deaf or hard of hearing. The authors recognized that the family-centered approach of provision of services in EI is not typical practice when a child transitions to school age; rather, the typical approach practiced becomes child-centered. Parental concerns grow as a child grows, as a new transition brings on new parental concerns stemming from the child’s changing and growing needs. The authors also recognized that the literature regarding the school-age child who is deaf or hard of hearing is sparse in comparison to the amount of literature available regarding the EI population.

Education of the Hearing Impaired in the School-Age Years: The Law and the IEP

The field of education of the deaf and hard of hearing has a complex history built upon differing viewpoints, diverse communication methods, and diverse socio/cultural influences. The issue that began centuries ago of where and how to best educate children who are deaf or hard of hearing remains alive today. Professionals in the field of deafness may differ about how individuals who are deaf should communicate. Some educators lean toward a sign-language symbol system, whereas others uphold the oral tradition. These philosophical differences are at the center of this ongoing debate, adding to the confusion as parents make educational choices for their children (Luckner, n.d.; Moores, 2012; Quittner et al., 2010).

Hearing parents of children with hearing loss must consider many factors as they navigate the educational system and develop an understanding of the educational implications of hearing loss. The Commission on Education of the Deaf (COED) compiled a report in 1988 that detailed the less than acceptable status of education of the deaf in the United States. The COED made specific recommendations to the president and Congress regarding the educational needs of children with hearing impairment that focused on cognitive, emotional, linguistic, social, and academic development. The Americans with Disabilities Act (ADA) of 1990, as amended on January 1, 1990, protects students needing a special education. Section 504 of the ADA ensures that these students are not discriminated against because of their disabilities and that they are entitled to a public education that is equal to the education provided to their typically developing peers (Weber, 2010). In 1992 and 1994, the United States Department of Education (USDOE) released policy guidelines regarding how to guarantee a FAPE for all children classified as deaf or hard of hearing, followed by 1997 and 2004 amendments to the IDEA requiring educational programs for children classified as deaf or hard of hearing to examine language and communication needs of these children (National Association of the Deaf, 2014). The incorporation of these considerations into present education law has been an evolutionary process and a challenge to parents, schools, and IEP teams (Seaver & DesGeorges, 2004).

The Evolution of Special-Education Law

The late 1800s until the early 1900s were critical years in establishing America's outlook on the role of the school. The school was viewed as the place to learn right from wrong, attendance was mandated by law, and the school served students from diverse backgrounds. What resulted from the diversity of the population was the development of special classes for students who had needs that were different from those of the general population. Additionally, the initiation of administering intelligence tests and the awareness of student differences demonstrated to educators that individuals exhibited different needs (Shea & Bauer, 1997).

The educational outlook in America changed with the influence of World War II, the race to outer space, and the need for ramped-up education to preserve American ideals. The 1960s proved to be a time of increasing social upheaval and increased awareness toward special education. The social-systems perspective of special educators posited that the children were not responsible for failing—rather, it was the school that failed the children. It was from this point that the federal government took the initiative to develop laws to ensure the rights of those individuals with special needs (Shea & Bauer, 1997).

The Rehabilitation Act of 1973, specifically Section 504, was instrumental in establishing rights for individuals with disabilities in protection against discriminatory practices related to their disabilities. Section 504 implored any school receiving federal funding to adhere to the regulation of providing children with disabilities to an education equal to that of their typically developing peers (Weber, 2010).

The ADA of 1990, as amended on January 1, 1990, also protects students needing a special education. Section 504 and the ADA ensure that students are not discriminated against because of their disabilities and that they are entitled to a public education that is equal to the education provided to their typically developing peers. However, the educational rights of children were challenged in the courts, and rulings that went against the principles of Section 504 and ADA 1990 resulted. Hence, the ADA Amendments Act was passed in 2008 and became effective January 1, 2009, to further protects the rights for elementary- and secondary- school students with disabilities. This proactive moment by the federal government, which began in 1973 with the Rehabilitation Act, continued with the passage of EAHCA in 1975, which evolved into IDEIA 2004 (Weber, 2010).

On December 3, 2004, President George W. Bush signed the IDEIA of 2004 into law, the last iteration of EAHCA. The enactment of IDEIA (2004) under congressional authority ensured the rights of every child with a disability to receive a FAPE in the LRE (Jackson, 2010). Since IDEIA (2004) became law, it has gone through five iterations, which congress has overseen. What has remained steadfast is the commitment to parents that they have the legal right to full involvement and shared decision making concerning their children's special-education programs.

In 1992 and 1994, the USDOE released policy guidelines regarding how to guarantee a FAPE for all children classified as deaf or hard of hearing, followed by 1997 and 2004 amendments to the IDEA requiring educational programs for children classified as deaf or hard of hearing to examine language and communication needs of these children (National Association of the Deaf, 2014). The incorporation of these considerations into present education law has been an evolutionary process and a challenge to parents, schools, and IEP teams (Seaver & DesGeorges, 2004).

Federal Legislation Affecting Education: NCLB and IDEA

Two specific legislations that have been put into practice to help restructure educational practices, NCLB and IDEIA, contain philosophical differences that have been at the source of educator contention (see Table 1). When President Bush signed NCLB into law in 2002, he did so with purpose and good intentions. However, some educators have argued that NCLB has complicated and compromised the education of children with disabilities and deprived them of their right to an individualized education

(Owen, 2010).

Table 1

A Timeline of Special-Education History

1973	Rehabilitation Act of 1973 Section 504 of the Rehabilitation Act is enacted into statute
1975	P.L. 94-142 Education for All Handicapped Children Act (EAHCA) EAHCA mandates that all school districts educate students with disabilities, and school systems are mandated to include parents in decisions about their children's educations.
1990	The Americans with Disabilities Act (ADA) is enacted. ADA adds protection to parents and students with disabilities and adopts the Section 504 regulations as part of the ADA statute.
1990	P.L. 101-476 Individuals with Disabilities Education Act (IDEA) The EAHCA is amended and is now called the IDEA (Individuals with Disabilities Education Act). Parental rights are expanded.
1997	P.L. 105-17 Individual with Disabilities Education Act (IDEA) (1997) The IDEA is reauthorized with the addition of requirements mandated by IDEA '97, specific to parental input.
2001	No Child Left Behind (NCLB) NCLB holds schools accountable for students' academic success and ensures parental involvement in children's educations, as well as shared decision making.
2004	P.L. 108-446 Individuals with Disabilities Education Improvement Act (IDEIA) Signed into law on December 3, 2004. Changes to Part B of the Individuals with Disabilities Education Act (IDEIA 2004), effective July 1, 2005.

NCLB was structured to apply to all students with the "common expectations for all students for academic achievement" (Left, 2002). Although NCLB mandated the same requirements for all students, it recognized that students with disabilities needed "reasonable adaptations and accommodations" (Left, 2002, 20 U.S.C. §6311(b) [(3)] (C) [(ix)]). Also specified was that these accommodations align with accommodations and alternative assessments as supported by IDEIA (Owen, 2010). This, however, is where the disconnect and disapproval of NCLB requirements was contested by the tenets of IDEIA. To be alternately assessed, NCLB defined specific criteria regarding whether a student qualifies for alternate assessment. A child who cannot achieve proficiency on grade level and is deemed incapable of achieving grade level proficiency by the IEP team may be alternately assessed. What NCLB did was negate the unique nature of each student with a disability and the individualized programming needed for educational success. It opposed the promise that IDEIA (2004) made to "ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services" (20 U.S.C. § 14009[d]); Owen, 2010).

Although NCLB had drawn criticism (see Left, 2002), it also drew approval for its emphasis on parental involvement. NCLB (Left, 2002) defined parental involvement in Title IX under the General Provisions as follows:

> The term "parental involvement" means the participation of parents in regular, two way, and meaningful communication involving student academic learning and other school activities, including ensuring-(A) that parents play an integral role in assisting their child's learning; (B) that parents are encouraged to be actively involved in their child's education at school; (C) that parents are full partners in their child's education and are included, as appropriate in decision making and on advisory committees to assist in the education of their child; (D)

the carrying out of other activities, such as those described in section 1118.

Since IDEIA (2004) became law, and through its five iterations, six major principles were left basically the same since 1975: (a) zero reject, which is called the child-find system, that implores the schools to educate all children with disabilities, birth through 21 years; (b) nondiscriminatory identification and evaluation, which is known as protection in evaluation procedures; testing and evaluation procedures must be given in the child's native language, and identification and placement decisions must not be based on one test score; (c) FAPE; (d) LRE; (e) due-process safeguards, which schools must ensure in protecting the rights of parents and their children with disabilities, and (f) parent and student participation and shared decision making. Though each of these mainstays of IDEIA (2004) is critical to this discussion, the attention to increased parental involvement is the primary focus of this study.

IDEIA, FAPE, LRE, IEP: Implications for the Deaf or Hearing-Impaired Student

The provision of a FAPE based upon the unique needs of every child is the essence of IDEIA (2004). However, this very essence has been compromised because of the loose interpretations of FAPE and LRE, which have a direct effect on the formation and implementation of the IEP (Taormina-Weiss, 2012). The LRE mandates that children with disabilities be educated to the maximum extent appropriate with their typically developing peers (Yell, 2006). Though LRE does lean toward inclusionary practices, instances occur where placement with typically developing peers is inappropriate in meeting the students' needs (Taormina-Weiss, 2012). According to

IDEIA (2004), FAPE and LRE specify the following:

> To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and that special classes, separate schooling, or other removal of children with disabilities from the regular educational environment only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. (IDEA, 2004, § 1412)

McLeskey, Landers, Williamson, and Hoppey (2012) explored the controversial LRE mandate by examining how placements have changed within the past 20 years with regard to LRE. At the center of the LRE controversy is "the issue of balancing the extent to which students are educated in general education classrooms, on one hand, with an emphasis on student outcomes on program effectiveness, on the other" (McLeskey et al., 2012, p. 132). Their findings revealed that even in face of controversy there was a reported increase in placements in general education settings and a large decrease in pullout, separate classes, and separate schools. Such findings held not only for those students classified with mild disabilities but also students in major disabilities categories. McLeskey et al. (2012) wanted to clarify that their study was investigatory only, and the data they presented in their study were not reflective of personal bias.

Given the recommendations of the COED, it seems that the national trends in placement of children with disabilities does not align with the COED's recommended changes to how the federal government views education for the student who is deaf or hard of hearing. The interpretation of FAPE and LRE with regard to students with hearing impairment must take into account the critical educational needs of those students, especially with regard to their communication and language needs (Taormina-Weiss, 2012).

Following the COED's report, the U.S. Department of Education's Office of Special Education Programs (OSEP) published the "Deaf Students Education Services Policy Guidance Report." OSEP examined how FAPE was interpreted for students with significant hearing loss. OSEP's policy guidelines aimed to provide guidance for state and local agencies regarding FAPE for students who were deaf or hard of hearing. The considerations that must be taken into account when devising an IEP for a student who was deaf or hard of hearing as recommended by OSEP include, but were not limited to the following:

1. Communication needs and the child's and family's preferred mode of communication.
2. Linguistic needs.
3. Severity of hearing loss and potential for using residual hearing.
4. Academic level.
5. Social, emotional, cultural needs, including opportunities for peer interactions and communication. (Seaver, 2014, p. 2)

The "Deaf Students Education Services Policy Guidance Report" (as cited in Seaver, 2014) also suggested that the professionals who were responsible for the identification, evaluation, and needs assessments be conducted by educators who had expertise in the area of deafness, as well as a grasp of the educational planning needs of said population. As stated in the policy:

> Any setting, including a regular classroom, that prevents a child who is deaf from receiving an appropriate education that meets his or her needs, including communication needs, is not the LRE for that child. Placement decisions must be based on the child's IEP. Thus the consideration of LRE as a part of the placement decision must always be in the context of LRE in which appropriate services can be provided. Any setting that does not meet the communication and related needs of a child who is deaf, and therefore does not allow for the provision of FAPE, cannot be considered the LRE for that child. The provision of FAPE is paramount, and the individual placement determination about LRE is to be considered within the context of FAPE. (Seaver, 2014)

As an answer to these specific needs of students who are deaf or hearing impaired, the reauthorization of IDEA in 1997 acknowledged these specific language challenges, which remain as Section 614 of IDEIA (2004). The specific section states the following:

> Sec. 614 (3) Development of IEP; (B) Consideration of Special Factors. The IEP team shall (iv) Consider the communication needs of the child, and in the case of the child who is deaf or hard of hearing, consider the child's language and communication needs, opportunities for direct communications with peers and professional personnel in the child's language and communication mode, academic level, and full range of needs, including opportunities for direct

> instruction in the child’s language and communication mode; and (v) Consider whether the child requires assistive technology devices and services. (Seaver, 2014)

The Foundation of a Student’s Educational Program: The IEP

An IEP is “a written statement for each child with a disability that is developed, reviewed, and revised in a meeting accordance with 34 CFR 300.320 through 300.324” (U.S. Department of Education, 2006, p. 1). More than 6 million children ages 3–21 are entitled to IDEIA services across the United States (U.S. Department of Education, 2010). Critical to the IEP process and required by law is that each school must make every effort to accommodate the parents. In 2005, the U.S. Department of Education stated the following:

> To ensure parental participation, schools and agencies are mandated to show evidence of making meeting times and places as convenient as possible for parents, assuring that procedural safeguards are presented to and understood by parents, and providing a system to work out grievances and differences. (Trussel, Hammond, & Ingalls, 2008, p. 19)

According to IDEIA 2004, Section 1414(d)(1)(B), the IEP team includes the following: (a) the parents; (b) not fewer than one regular-education teacher of the child if the child is or may be participating in a general-education setting; (c) not fewer than one special-education teacher or not less than one special-education provider of the child; (d) a representative of the local education agency; (e) an individual who can interpret the instructional implications of evaluation results; (f) at the discretion of the parent or the agency, other individuals who have knowledge or special expertise regarding the child, including related services personnel as appropriate; and (g) whenever appropriate, the child with a disability (Wrightslaw, 2010).

According to the law, the IEP must include the following: (a) a statement of the child's present level of performance and functional performance; (b) a statement about annual educational goals; (c) special-education supports and services; (d) modifications and accommodations; (e) a statement regarding how the child's progress will be monitored; (f) a statement about individual accommodations necessary to measure academic achievement and functional performance on state and district-wide assessments; if the IEP team determines that alternate assessment is the choice for said child, the IEP must include a statement of why the alternative assessment is appropriate for the child; and (g) the projected commencement date for services, the modifications, and the frequency, location, and duration of those services and modifications (Center for Parent Information and Resources, 2010).

Parental Involvement in Special Education

Parenting a child who is receiving a special education can be a challenge to parents. As the information presented in this literature review makes evident, much information exists that the parents need to process to be adequately prepared to negotiate the special-education system. Parents can impart much information to the professionals working with their children, as parents can share pertinent information about their children's areas of strength and weakness, behavior issues, how they learn, and what types of educational methodologies have been successful (An & Hodge, 2013).

Federal law makers recognized the value of parental input by constructing and implementing regulations that mandate the inclusion of parents in their children's special education. The IDEIA as it is today continues to guarantee full participation for parents in all stages of their children's educational processes (An & Hodge, 2013; Bronfenbrenner, 1979; Comer & Haynes, 1991; Kibaara & Ndirangu, 2014; LaRocque et al., 2011; Yell et al., 2009). However, what is required and what is really happening does not meet the standard of practice the IDEIA intends (Fish, 2006, 2008; Haley, Hammond, Ingalls, & Marin, 2013; Jamieson et al., 2011; Reiman et al., 2010; Zeitlin & Curcic, 2013). Lawson, Sanders-Lawson, and McNeal (2012) stated:

> Coupled with a focus on compliance versus partnering with parents, the 1970s, 1980s and 1990s presented an era of research designed to address the federal mandates related to parent involvement, yet increased parent involvement did not translate into decision-making and governance roles for parents. (p. 43)

Although the federal government views parents as "critical partners" (Lawson et al., p. 43) in education, this remains an ambiguous and inconsistent practice in special-education forums.

Current research indicates that conflicting perceptions exist regarding implementation of IDEIA mandates, professional adherence to the law, and parental perceptions of involvement (Fish, 2006; 2008; Hornby & Lafaele, 2011). Parents and professionals have indicated the need for more parental involvement, yet parents indicate that schools are not providing successful opportunities for meaningful parental involvement and team collaboration (Calderon, 2000; Christle & Yell, 2010; Zeitlin &

Curcic, 2013). In addition, parents and educators differently perceive what constitutes effective and meaningful parental involvement (Walker, Wilkins, Dallaire, Sandler, & Hoover-Dempsey, 2005). Parents often feel excluded by education professionals and administrators during the development of the IEP. What is intended to be a collaborative process is now a process that leads to negative feelings among the parents (Lake & Billingsley, 2000; Ryndak, Orlando, Storch, Denney, & Huffman, 2011; Shelden, Angell, Stoner, & Roseland, 2010).

Parents have identified numerous barriers to effective collaboration and team building between parents and educators: (a) poor communication, (b) disregard for parental input, (c) lack of respect, (d) lack of trust, (e) use of educational jargon, (f) lack of familiarity with the special-education system, and (g) lack of attention to cultural diversity (Fish, 2006; Wolfe & Duran, 2013). Fish (2006) investigated parental perceptions of the IEP process and asked parents what positive changes the schools could implement to improve the IEP meeting. Parents indicated they wanted to feel like equal partners in decision making. More specifically, they wanted professional team members to be open to their input and exercise flexibility in decisions regarding their child's needs.

Fish (2006) emphasized, "Relations between educators and parents strengthened through increased awareness of student disabilities among educators in addition to parents becoming more knowledgeable of the IEP process" (p. 67).

Ingber and Dromi (2010) investigated the collaboration of parents of children with congenital, bilateral, sensorineural hearing loss averaging 53 months of age and parents participating in a family-centered program. The children had varying degrees of hearing loss with 4.2% having a mild hearing loss, 29.2% having a moderate hearing loss, 27.4% having a severe hearing loss, and 39.2% having a profound hearing loss. Both parents and professionals received different versions of a questionnaire, which revealed the common belief of supporting family-centered practices. Results also indicated the need to provide parents with a thorough understanding of educational procedures.

All too often, parents feel that schools focus on their children from a deficit perspective rather than a strengths perspective. Parents indicate feeling uncomfortable, embarrassed, and even intimidated by such exchanges (Lake & Billingsley, 2000; Ryndak et al., 2011). As Shelden et al. (2010) posited, when the parents and the educational team come from two opposing points of view, parents tend to lose trust in future exchanges with the education system. It is incumbent upon education professionals to establish trust with parents of children in the special-education system to build collaborative partnerships that are positive.

Wiart, Ray, Darrah, and Magill-Evans (2010) conducted a qualitative study to explore parental experiences with goal setting for their children with cerebral palsy. A thematic analysis of the data stressed the importance of the establishment of a trusting relationship between parents and teachers. In view of the need to share personal information openly with the staff that could affect parental participation in the educational process, parents felt that the establishment of trust was essential.

Parents of children with disabilities represent a wide range, from parents of children with severe disabilities of a more global nature to parents of children with disabilities requiring lower levels of intervention. The extent to which a parent participates in his or her child's education may be related to the degree of the disability. In addition, parents raising a child with a multifaceted disability, such as hearing loss, may have information and support to offer education professionals who have sufficient levels of knowledge about that disability but might not have the appropriate knowledge of IEP procedures to effectively impart this information (Fish, 2006; Ingber & Dromi, 2010).

Much of the existing literature suggests that school professionals do not offer parents the opportunity to become valued parts of shared decision making and seldom offer opportunities to dialogue about their children's educational issues (Brandon, Higgins, Pierce, Tandy, & Sileo, 2010; Spann et al., 2003). Parents have reported that during the IEP process they feel depersonalized as they sit in the extremely emotional atmosphere of an IEP meeting (Zeitlin & Curcic, 2013). As Trussel et al. (2008) posited, "special education has done a marginal job in accomplishing the ethical responsibility of including and informing parents at each level of the education process" (p. 20).

Failing to develop an understanding and equal partnership between the parents and the school is not only a breach of education law, but it is also a disservice to the student when research reveals the positive effect strong family/school partnerships have on students' success (Christenson, 1995; Epstein, 2001). Staples and Diliberto (2010) concluded the following:

> Building positive stakeholder relationships is essential for optimal success of a child. Increased collaboration between parents, teachers, administrators, and special education needs professionals fosters parent participation and involvement

> in a student's education and leads to a host of positive outcomes. (p. 8)

The ecological theory of human development Bronfenbrenner (1979) posited supports the critical nature of collaboration between parents, teachers, and administrators, in which he recognizes the importance of multiple contexts on a student's success in learning. Thus, it is his theory upon which I have built the conceptual framework for this study.

Although studies investigating parental experiences with the IEP process of students with various disabilities are plentiful in the literature, there is a lack of research investigating hearing parents' perspectives of the special-education process among school aged children with hearing loss.

Conceptual Framework

As indicated in educational research, the more parents are involved in their children's educations, the stronger the opportunity for positive academic outcomes. When schools create environments that encourage parental involvement, it is more likely the parents will become involved in their children's educations (Pomerantz, Moorman, & Cheung, 2012). EST creates the conceptual framework that supports the collaboration between school, home, and family (Bronfenbrenner, 1979). As Pomerantz et al. (2012) posited, and aligned with Bronfenbrenner's (1979) theory, family/school partnerships have the potential to provide the support and educational resources needed to assist positive educational outcomes.

Bronfenbrenner (1994, 2005) proposed that a child's development is affected by relationships both within and outside of the family unit. He identified four environments, or systems, that influence development: (a) the microsystem, (b) the mesosystem, (c) the exosystem, and (d) the macrosystem in his original model, and the fifth system, e) the chronosystem, in his bioecological model. The specific ecological contexts Bronfenbrenner (1979, 1994) conceptualized that are critical to this study are the microsystem and mesosystem. The *microsystem* consists of the home and family, which are central to a child's life. The relationship between these ecologies is conceptualized as the *mesosystem*, or the connections between two or more settings outside of the home and family, such as the school. Events that occur in one microsystem affect the other microsystems, which influence interactions in the mesosystem. Though the family is the "principal context in which human development takes place, it is but one of several settings in which developmental processes can and do occur" (Bronfenbrenner, 1986, p. 723). In his model, processes operating in different settings affect each other. As posited by Hepworth, Rooney, Rooney, Strom-Gottfried, and Larsen (2010),

> Each system is unique, varying in its characteristics and ways of interacting (e.g. no two individuals, families, groups, or neighborhoods are the same). As a consequence, people do not merely react to environmental forces. Rather, they act on their environments, thereby shaping the responses of other people, groups, institutions, and even the physical environment. (p. 15)

While conducting the literature review for this study, it was evident that many researchers investigating parental involvement in children's educations used Bronfenbrenner's (1979) EST as the conceptual framework for their study. I gave consideration to other theorists noted in studies regarding parental involvement in education while building the conceptual framework for this study; however, it was Bronfenbrenner's model that most adequately aligned with the problem, purpose, and research questions related to this study.

Bronfenbrenner's Theory as Modified by Other Theorists

Much of what has been postulated about parental involvement is based on Epstein's (1995) work. Her model is similar to Bronfenbrenner's (1979) in that she sees child development as occurring in spheres of overlapping context. Like Bronfenbrenner, she considers the family and school to be two of the most critical contexts. She agrees with Bronfenbrenner's position that the interactions among contexts could bear positive academic results for children. According to Epstein (2001), parents desire a more positive educational experience for their children and want to be involved in their educations. The ecological model affirms that parents and schools assume a bidirectional relationship by influencing each other and together have a strong effect on the child (Christenson, 1995). The ecological model suggests that educators and parents have a shared responsibility for the child's academic success. When the microsystems of parents and school are in disagreement, a disruption occurs in how the mesosystem functions, which can negatively affect the child (Bronfenbrenner, 1979; Christenson & Hirsch, 1998).

Epstein (2001) equates the connection between home, school, and the community to that of a bridge. In order for those bridges to be sturdy, educators and families have a responsibility to talk and work together to support positive outcomes in their children's educations. It is critical to study parental perceptions of the education process to build a better bridge to communication. Children require and deserve a coordination of efforts to support their educational success.

Summary

IDEIA (2004) mandated parental involvement in children's educations with a major emphasis on the planning and development of the IEP. Parents should be experiencing equal partnerships during IEP meetings; however, the facilitation of shared decision making in IEP meetings is filled with inconsistencies (Hornby & Lafaele, 2011). Parents often feel that education professionals do not value their input or give them equal weight in decision-making processes (Fish, 2006; Lake & Billingsley, 2000).

The special-education classifications targeted in this study were children who were deaf or hearing impaired only. The unique characteristics of hearing impairment add many layers of complexity to a child's educational programming. Each of the parents who participated in this study had experienced early newborn hearing screening, an initial diagnosis of hearing loss, entrance into early intervention, decisions regarding amplification needs and school-age educational placement. Once a child is fitted with appropriate amplification, there is a lifelong commitment to continued auditory monitoring and equipment maintenance. The educational team must acknowledge that the needs of the parents are ongoing. Therefore, the purpose of this study was justified.

Perceptions of parental involvement in IEP meetings from the parents themselves is critical if the special-education professionals are to embrace the tenets set forth by IDEIA (2004) and make parents equal members of the IEP team. Parents who are raising children with hearing impairments are facing challenges that may require a school lifetime within a special-education setting. If the education specialists are to give these children what they need to achieve academic success, the parents must be given the legally mandated opportunity to exercise their rights as equal partners in shared decision making regarding their children’s educational futures. Educators must become aware of parental attitudes and perceptions toward their involvement with the special-education process and realize that all parents come to the table with their own stories. Thus, by hearing the parental perspective through a comprehensive interview protocol in which the parents told their stories in their own words, education professionals can make the changes necessary for a more balanced partnership.

An exhaustive search of the literature revealed the lack of information regarding hearing parents raising children with hearing loss and their perceptions of special education and the IEP process. Thus, I intended to close the gap in the literature by investigating hearing parents of children with hearing loss and gaining their perspectives regarding the special-education process. This information can assist educators in fulfilling the needs of the parents as they try to gain equal partnership in their children’s educations. As it has been noted, successful parental involvement in their children’s education can lead to more positive outcomes for these children.

Chapter 3: Research Method

Introduction

The purpose of this study was to understand, describe, and explore the perceptions of hearing parents of children between the ages of 5 and 12 years who have hearing loss toward the education system and IEP process. In this study, the children had a classification of hearing impairment or deafness only, as indicated on their IEP. I identified (a) parent perceptions and experiences with the education system, (b) parent perceptions and experiences with the special-education process including the IEP process, and (c) the types of educational and emotional support parents need from the special-education providers. Though researchers had conducted numerous studies with regard to parental perceptions of the special education and IEP planning process of children with various disabilities, a lack of research existed regarding investigating hearing parents raising a child with a hearing loss (MacKichan & Harkins, 2013).

Chapter 2 included a review of clinical information basic to the understanding of deafness, types and degrees of hearing loss, hearing aids and cochlear implants, as well as information about early hearing identification and early intervention. I also provided a historical review of special-education law, the IEP and parental involvement, and Bronfenbrenner’s ecological systems theory.

I used the phenomenological research method to glean a rich and deep understanding of these parents’ perspectives. Phenomenology provided the tools to delve into the lives of those individuals studied, and the structure to interpret the individuals’ experiences (Moustakas, 1994).

This chapter includes the method that guided this study, with descriptions of the research design and approach, an explanation of the rationale for the selection of the research method, the setting and participant sample, a description of the process used to collect and analyze the data, and the interview procedure. Also described in this chapter are the role I took as the researcher, ethical concerns related to participant confidentiality, protection of participants, protection of data, and issues of trustworthiness.

Research Design and Rationale

The four research questions in this study follow:

1. How do hearing parents of children between the ages of 5 and 12 years who have a hearing loss only describe their experiences with the educational system?
2. How do hearing parents of children between the ages of 5 and 12 years who have hearing loss only perceive their experiences with the special-education process as their children proceed through the education system?
3. What patterns of coping do hearing parents of children between the ages of 5 and 12 years who have hearing loss only identify as most helpful in managing the stress related to their experiences with the educational system?
4. What do hearing parents of children with hearing loss only want professionals in the special-education school system to know?

Because the purpose of this study was aligned with phenomenology, a qualitative phenomenological approach was appropriate. The following qualitative designs were considered but were inadequate for the purposes of this study.

Grounded theory, which Glaser and Strauss (1967) originated, is similar to phenomenology in that both have emergent strategies, beginning with data collection through interviewing. However, the purpose of grounded theory is to develop theory about the phenomena that are studied, as opposed to phenomenology, which strives to capture the essence of the experiences of individuals. The generation of a hypothesis, the basic principle of grounded theory, was not compatible with the purpose of this study.

Yin (2009), a highly regarded researcher in the tradition of case-study research, defined the *case study* as “an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident” (p. 18). Case-study researchers commonly attempt to answer *how* or *why* questions in an attempt to reveal a phenomenon through in-depth study using a variety of data-collection methods, such as surveys, interviews, diaries, documentation review, observation, or collection of objects.

I rejected the case-study method because I was seeking a deeper understanding of everyday experiences rather than the how or why. I also considered a narrative approach; however, narrative inquiry did not satisfactorily align with the focus of this study. The definition of narrative research as recognized by educational researchers Clandinin and Connelly (2000) emphasized the importance of the partnership between the researcher and participants as the participant tells the story of his or her life.

As Clandinin and Connelly (2000) posited, narrative inquiry is a way of understanding experiences through the participants’ words, which are constructed into stories. One key difference between the two methodologies is that narrative analysis focuses on the chronology of individuals' lives and how their life experiences have led to their current states, whereas phenomenology assesses how people viewed or view their lives and past experiences in their lives. Though the focus of both approaches is on a first-person description of an individual's experiences, the phenomenological researcher seeks to understand the essence of the individual's experience with the intent to generalize, and the focus of narrative methodology is on the individual's life without the intent to generalize.

Role of the Researcher

Prior to undertaking this research, I had served as a speech and language pathologist and audiologist for the past 35 years, and had been employed by New York State for 23 of those 35 years. I had the opportunity to work with many students who attended programs for the hearing impaired while I served as their related service provider or preschool collaborative classroom teacher. Several of the participants in this study were known to me, but I had not had contact with them for at least 5 years or more; and guarantee I had no power over them.

Morse, Barrett, Mayan, Olson, and Spiers (2002) stated that the "research is only as good as the investigator" (p. 17). I knew that the quality of information that I would glean through the interview process was directly related to my own skill as the interviewer, and I paid attention to every stage of research. This included gathering, organizing, and analyzing the information gleaned from the words and perceptions of my participants.

As Patton (2002) stated, the advantages of the unstructured interview compensate for the challenges. Some of the challenges that face the interviewer are being comfortable with the interview format and guarding against one’s preconceptions and biases. To manage bias, I embraced the principles of epoch and bracketing (Hatch, 2002; Husserl, 1970, Moustakas, 1994).

The process of bracketing bias assists the researcher in eliminating prejudices, feelings, viewpoints, or assumptions concerning the phenomenon under investigation (Creswell, 2007). The questions I asked during the interview were open-ended and information-seeking. My ethical responsibility was to ensure fair representation of the parents’ words and stories. According to Moustakas (1994), it is fundamental for the researcher to bracket preconceived to perceive the participants’ stories with a fresh perspective. Gearing (2004) suggested that the researcher engage in a process of reflective bracketing throughout the entire study, not only at the commencement of the study. By doing so, the researcher remains consciously aware of any prior personal preconceptions about the phenomena of study.

Methodology

I based my decision to use a qualitative approach on my research topic and the intent of the study. Patton (2002) stated that a qualitative researcher using a phenomenological approach engages in a “study of essences . . . one that focuses on descriptions of what people experience and how it is that they experience what they experience” (pp. 106–107). Therefore, as the stories are told, the study will unfold as it progresses (Marshall & Rossman, 2011; Miles & Huberman, 1994). To accomplish the goal of collecting the richest data, I conducted in-depth interviews with the individuals who had lived the experience or phenomenon of raising children with hearing loss. By giving voice to these individuals, I became immersed in a face-to-face experience of studying the essence of the phenomenon.

Adherence to the belief in the value of the participants' own words and own perceptions as a reflection of their reality is the philosophy upon which phenomenology is based (Hatch, 2002; Husserl, 1970). Husserl posited, "The ability to bring everyday events into consciousness allows the researcher to develop an unprejudiced view of the world and explore their rational interconnection" (p. 43). The phenomenological tradition encourages these personal stories.

After considering both a quantitative and qualitative study, I rejected quantitative research because the goal was to discover experiences, events, and situations the individuals lived and told in their own words, as opposed to a study testing a hypothesis and reporting data in the form of precise measurements. In this qualitative study, on the other hand, I was the instrument that "illuminate[d] the phenomenon in terms of its members and meanings, and then arrive at an understanding of the essence of the experiences" (Husserl, 1970, p. 49).

Participant Selection Logic

According to Moustakas (1994), selecting participants who have experienced the phenomenon and who have an interest and willingness to give time and energy to complete the necessary interviews is essential to the selection process. Phenomenology is designed to secure depth and breadth of the participants' perceptions; thus, the goal is not to secure a large sample but to secure a sufficient sample that will garner insight into the phenomenon of study. In addition, the purpose of phenomenology is not in generalizability but in transferability.

Researchers have suggested that purposeful intensity sampling of eight to 12 information-rich cases is suitable for the purposes of a phenomenological study (Mason, 2010). To locate information-rich cases, I used snowball, or chain sampling (Mason, 2010; Patton, 2002). Lincoln and Guba (1985) recommended that a purposeful sample size should be determined by the amount of information to be obtained. The researchers posited, "If the purpose is to maximize information, the sampling is terminated when no new information is forthcoming from new sampling units; thus, redundancy is the primary criterion" (Lincoln & Guba, 1985, p. 202). Patton suggested that qualitative sampling designs "specify minimum samples based on expected reasonable coverage of the phenomenon" (p. 246). Strauss and Corbin (1998) referred to this redundancy as the concept of saturation. The researchers posited that the emphasis of saturation should be with reaching the point where more information becomes "counterproductive" and does not necessarily add anything to the overall story, model, theory, or framework (Strauss & Corbin, 1998, p. 136).

Criteria for participation in this study were clearly stated in the initial notice of the intent to conduct a phenomenological study, the informed consent, and the initial data form the parent participants fill out. Only those parents meeting the following criteria were selected for the study: (a) both parents must have had normal hearing and (b) a child who was classified as hearing impaired or deaf only as defined by IDEIA and had an IEP, and (c) the child needed to have been currently between the ages of 5 and 12 years.

With those numbers serving as a guideline for the present study, the sample size for this study consisted of 10 hearing parents from 10 families raising a child who was deaf or hearing impaired only and in the 5- to 12-year-old age range. As Patton (2002) stated, “The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/ analytical capabilities of the researcher than with sample size” (p. 245).

I recruited participants from two counties on Long Island, NY. Currently, 125 school districts are located on Long Island. I contacted two New York state-certified private practitioners who were dually certified as speech and language pathologists and teachers of the deaf specializing in auditory rehabilitation with students classified as deaf or hard of hearing. These individuals agreed to disseminate invitations and research packets to their clients for the purpose of recruiting participants for this study. These practitioners did not know which of their clients participated in the study, as prospective participants returned completed forms to me in an appropriately addressed and stamped envelope. Each participant was assured of anonymity and confidentiality of records, and all participants self-identified that they meet the criteria established for this study.

I chose those families who met the criteria for selection on a first-come, first-served basis. I sent an e-mail to families who responded after the required sample size had been met stating that they were not selected for the first round of interviews but that they would be contacted at a later date if their participation in the study had been needed.

Instrumentation

Prior to commencing the research study, I obtained Institutional Review Board (IRB) approval from Walden University (#09-03-15-0229760). I prepared one large research packet for the private practitioner, which contained smaller packets for the parents. The parent packets consisted of (a) informed consent forms (see Appendix A), and (c) initial data forms (see Appendix B). The packets also included a self-addressed stamped envelope for prospective participants to return the forms. Because I did not expect all families to respond, research packets were distributed to more families than are required for the sample. My goal was to send out 30 packets.

To answer the research questions, I conducted one interview with each hearing parent of a child between the ages of 5 and 12 with hearing loss only. I offered the participants the option of telephone or Skype interviews in the event that participants were uncomfortable with in-person, face-to-face interviews.

I used an interview protocol to guide my questions during each interview (See Appendix D). I wrote the interview protocol, which was created to align with the research questions and conceptual framework. A guiding question was followed by open-ended probing questions to generate rich descriptive data from the participants (Hatch, 2002). Table 2 illustrates the relationship between the research questions and the interview questions.

Table 2

Research Questions and Data-Collection Instrument

Research questions	Interview questions
RQ 1: How do hearing parents of children between the ages of 5 and 12 with hearing loss only describe their experiences with the educational system?	**IQ 1: (Warm-up)** At what age did your child enter the educational system? a. What was your child’s initial special-education diagnosis (classification)?
	IQ 2: Have you received information that assisted you in making educationally based decisions for your child, and if so, what type of information did you receive?
	IQ 3: Tell me what, if anything, your educational team could have done differently to provide you with the assistance you needed.
RQ 2: How do hearing parents of children between the ages of 5 and 12 with hearing loss only perceive their experiences with the special-education process as their children proceed through the educational system?	**IQ 1:** If you are willing to tell me, would you please describe the contents of your child’s IEP? I especially would like to know what you think of the IEP process. **(Probes)** a. What is your child’s current special-education classification? b. How do you feel about the IEP? c. How have your feelings toward the process changed over time? d. How many IEP conferences have you attended, either in person or by telephone? e. How do you perceive the nature of your parental involvement at an IEP meeting?
	IQ 2: If you could change anything about the IEP process, what would you change?
	IQ 3: What is the focus of your child’s present educational program? a. How does the school’s focus align with your vision of what you want

	for your child educationally? b. How are your child's audiological needs represented on the IEP? **IQ 4:** As you contemplate your child's IEP meeting for the upcoming school year, what changes, if any, do you foresee? If so, can you tell me what they are? **IQ 5:** Please describe what parental involvement in the IEP process means to you. **IQ 6:** Please describe what parent-teacher collaboration means to you. **IQ 7:** If anything, what would discourage you from participating in an IEP meeting? **IQ 8:** Please share a personal experience of when you tried to improve collaboration with professionals during the IEP process.
RQ 3: What patterns of coping do hearing parents of children between the ages of 5 and 12 with hearing loss only identify as most helpful in managing the stress related to their experiences with the educational system?	**IQ 1:** Which parts of the IEP process were more stressful than others? **IQ 2:** What kinds of coping skills, if any, helped you manage stress during those times?
RQ 4: What do hearing parents of children with hearing loss only want professionals in the special-education system to know?	**IQ 1:** If you could sit down with the professionals in the special-education system and tell them anything you wanted about your experiences as a parent of a child in the special-education system, what would you tell them? **IQ 2:** Can you tell me what you would change, if anything, about your interactions with the professionals you came in contact with?

Procedures for Recruitment, Participation, and Data Collection

The purpose of the qualitative research interview is to describe and understand the meaning of what the interviewees say (Kvale, 1996). The unstructured interview gives the interviewer the flexibility to probe for information and follow the direction of the interviewee's flow of words on an individual basis (Patton, 2002). I informed the participants of the importance of participating in more than one interview, if necessary, to extract the essence of their experiences and tell their stories in the most accurate and meaningful way possible. I reviewed the interview process with each participant. The length of each interview was discussed prior to commencement of the interview and was flexible as long as I and the interviewee agreed upon it. In addition, I informed the interviewee that he or she had the right to ask to stop the interview process at any time and for any reason.

The interviews took place in a mutually agreed upon locale that was comfortable for the interviewees. I digitally recorded each interview to accurately capture and transcribe the interviewees' responses. I used a pad and paper to write down notes during the interview process. All data collected from the interviews, including recordings and notes, will be kept under lock and key and will remain with me for 5 years after completion of the study, according to IRB guidelines. I took care to ensure the confidentiality of participants' responses by providing each participant with a unique pseudonym, such as Participant 1.

I made provisions for a follow-up plan to ensure the recruitment of additional participants if necessary. The original individuals who disseminated recruitment packets would proceed with an additional round of recruitment following the guidelines of the initial recruitment. Upon their exit, I provided the participants with a debriefing form that included information that summarized the purpose of the study, the reason for their participation, contact information for the researcher and university personnel in the case of questions or additional concerns, and a sincere thank-you in appreciation of their time and valued information.

Data Analysis Plan

Kvale (1996) emphasized the importance of establishing a comfortable and safe interview situation in which the participant feels confident to engage in mutual conversation. I had the responsibility to come into the interview prepared with a question guide and the understanding that the more spontaneous the interview, the more animated the process. I crafted all the interview queries from the research questions (See Appendix D to view the interview question guide).

The researcher must enter a study with the ability to “bracket” any personal experiences, biases, or prejudgments, allowing the participants to have a mutual conversation without being influenced by the researcher. I used an inductive approach to data analysis and followed the analytical steps Hatch (2002) suggested:

1. Initial read through of the data and identify frames of analysis.
2. Define categories (or domains) that have been found within the frames of analysis.
3. Identify relevant domains and assign them codes. Irrelevant domains are set aside.

4. Reread to determine if the domains identified in step three are well grounded in the data.
5. Scrutinize the resultant domains for relationships within or between them, using inductive reasoning to interpret how the data fits together.
6. Complete analysis within the domains.
7. Search for themes across the domains.
8. Present the findings. (pp. 162–179)

The data the qualitative interview generated was "voluminous" (Patton, 2002, p. 440). The task of organizing the data was both critical and time consuming. How one organizes data should ensure close and comfortable immersion with the data. Qualitative-data analysis involves coding, either by hand, by computer-assisted software programs, or a combination of the two. Creswell (2013) explained the following:

> The process used for qualitative data analysis is the same for hand coding or using a computer: the inquirer identifies a text segment or image segment, assigns a code label, searches through the data base for all segments that have the same code label, and develops a printout of these text segments for the code. In this process, the researcher, not the computer program, does the coding and categorizing. (p. 201)

As Hatch (2002) posited, each researcher has a personal style that is reflected in how we conduct ourselves throughout our research. I transferred the transcribed data to NVivo (version 11). Researchers can use NVivo, advanced computer-assisted qualitative analysis software, to organize the data into themes and patterns and link codes.

Issues of Trustworthiness

Lincoln and Guba (1985) argued that trustworthiness of a qualitative-research study is critical when assessing its value. Lincoln and Guba outlined four criteria for measuring trustworthiness of data: (a) credibility, which refers to confidence in the truth of the findings; (b) transferability, which shows that the findings can be applied in other contexts; (c) dependability, which means that the findings are consistent and can be repeated; and (d) confirmability, which refers to the researcher maintaining a neutral position, in which bias has been addressed and the participants generate the findings of the study.

For qualitative researchers to achieve credibility of findings, Lincoln and Guba (1985) posited a series of strategies, three of which include prolonged engagement, peer debriefing, and member checking. From initial contact, I was available to answer questions, address concerns, and provide information about the study. I conducted one interview with each participant. All these actions assisted in the building of trust and positive rapport with the participants through prolonged engagement. I sought the assistance of an uninvolved colleague to act as a peer to debrief and uncover any biases or statements that seem unreasonable or misguided. This person was a duly certified speech and language pathologist and teacher of the deaf. Member checking, as Lincoln and Guba posited, is the most critical of techniques for establishing credibility. This involves obtaining participants' feedback as to the truthfulness and accuracy of data, categories that emerged from the data, and an opportunity to correct errors. I employed member checks for this study.

In terms of transferability, I used a participant sample who provided thick descriptions of their experiences with the phenomenon. Through these dense descriptions I gathered “sufficient information about the context in which an inquiry was carried out so that anyone else interested in transferability has a base of information” (Lincoln & Guba, 1985, pp. 124–125). Further, dependability, which is related to consistency of findings, is established when another professional unrelated to the study is asked to examine all the data and assess it for fairness, accuracy, and uniformity.

Finally, generating an audit trail is an essential component to adding organization to a study that produces copious amounts of information. I created such a trail that detailed the steps I used in this study.

Ethical Procedures

The researcher has the responsibility of protecting the rights of the participants. I took all necessary steps to ensure the rights of the research participants and, as noted earlier, received approval of the IRB at Walden University. I also adhered to the three ethical principles of beneficence, justice, and respect for persons outlined in the so-called Belmont Report (1979). Participation in this study was completely voluntary, and all participants were asked to review and sign an informed consent document (see Appendix B) prior to commencing any involvement in the study. Each participant was assured of confidentiality of records, the right of refusal, and any potential risks and benefits associated with participation in the study. I carefully reviewed all collected data with each participant to ensure accuracy. In addition, the participants received information regarding dissemination of the results (Seidman, 2006). All participants who elected to be in the study remained in the study.

Summary

This chapter included a review of several qualitative approaches considered for this study including a detailed description of the phenomenological approach chosen for this study. A phenomenological research method provided me with the suitable tools to explore the lives of the participants in this study and the structure to interpret their experiences. A purposeful intensity sample of 10 hearing parents from 10 families raising children with hearing loss only was used. Data collection consisted of a questionnaire to identify basic demographic information and one, one-on-one unstructured interview. I analyzed the data using the inductive approach to data analysis Hatch (2002) suggested.

Chapter 3 also includes rationales for setting and participant sample, an explanation of the interview procedure, the researcher's role, procedures for ensuring participant confidentiality, ethical concerns related to participant confidentiality, protection of participants, protection of data, and issues of trustworthiness. In Chapter 4, I present the results of the study, and in Chapter 5, I present a discussion and conclusion of the results. I offer recommendations for action and for further research, as well as the potential for implementing positive social change.

Chapter 4: Results

Introduction

In recent decades, public education has been affected by the No Child Left Behind Act, standardized testing, and Common Core Standards, as well as numerous federal and state-level budget cuts. As a result, educational leaders have struggled to balance these limitations against the mandatory individualized education process to meet the needs of children with learning or other disabilities, as mandated by the IDEA and IDEIA. With specialized education typically requiring more financial and professional resources, the implementation of standardized education and budget cuts have made it more difficult for special education providers to meet the needs of all children.

Given that context, the purpose of this phenomenological research study was to understand, describe, and explore the perceptions of hearing parents of children with hearing impairment, between the ages of 5 and 12 years, toward the education system and the IEP process. A phenomenological approach enables a researcher to produce detailed information surrounding life experiences—in this case, experiences with the special education system (Denzin & Lincoln, 1994). Quoted excerpts are shared to ensure accuracy of the analysis and provide information from various perspectives. The research questions follow:

Research Question 1. How do hearing parents of children between the ages of 5 and 12 years who only have hearing loss describe their experiences with the educational system?

Research Question 2. How do hearing parents of children between the ages of 5 and 12 years who only have hearing loss perceive their experiences with the special-education process as their children proceed through the education system?

Research Question 3. What patterns of coping do hearing parents of children between the ages of 5 and 12 years who only have hearing loss identify as most helpful in managing the stress related to their experiences with the educational system?

Research Question 4. What do hearing parents of children who only have hearing loss want professionals in the special-education school system to know?

In this chapter, the setting and participants are described, along with data collection procedures and the process used for the data analysis. The procedures included a detailed explanation of the discovery of the emerging patterns and themes. Evidence of trustworthiness is presented, along with the key findings obtained from the 10 in-depth interviews.

Setting

This study took place on Long Island, New York. Long Island is divided into two counties and 125 school districts. The participant sample for this study came from 10 school districts from one of the two counties. All 10 participants preferred to meet in their homes; interviews were conducted sitting either at a kitchen or dining room table with adequate privacy and few distractions. All parents described themselves as active in their child's special education and IEP process and had had experience with early diagnosis and EI for their child with hearing loss.

Demographics

Without hearing loss themselves, seven mothers and three fathers from 10 families participated. Each parent had a child between the ages of 5 and 12 years with a hearing loss. The family structure varied, with three parents having one child, and seven parents having two or more children. During the interviews, parents discussed their child who had a diagnosis of deaf or hearing impaired. All 10 children received an early diagnosis of hearing loss and entrance into EI between 3 and 24 months of age. Two had been diagnosed as profoundly deaf; out of the remaining eight children with hearing impairment, five were identified as moderate to severe, one was diagnosed as moderate, and two were diagnosed as mild-moderate. Six interviewees reported using a combination of hearing aids and FM systems; two interviewees reported using hearing aids only, and two described using a combination of cochlear implants together with FM systems to enhance their child's hearing (see Table 3). Each participant is described below. To ensure confidentiality, all names are pseudonymous.

Ann was a wife and the mother of two sons. Her oldest son, an 11-year-old boy, was diagnosed as having a mild to moderate bilateral sensorineural hearing loss of an unknown origin. She also had another younger child who was born with normal hearing. Her son currently wore bilateral hearing aids, and, according to his IEP, did not require the use of an FM system at this time. Her son's initial entry into the special education system occurred when he was 2.5 years of age. It was at this time he was enrolled into the early intervention program under the New York State special education system. His present educational placement was in a district-based general education seventh-grade classroom setting where he received support services from a teacher of the deaf. Ann recalled that she was quite overwhelmed when she first received the diagnosis but really didn't feel stressed. "In general, we weren't stressed about it; it was just a matter of finding, calling the right people. . . . We only had one kid at the time, so it wasn't like that overwhelming."

Grace was a wife and the mother of a 6-year-old boy who was diagnosed as having a moderately severe bilateral sensorineural hearing loss of unknown origin. Her son, an only child, was aided with bilateral hearing aids. Grace's recollection was that her son began early intervention services in January, making him approximately 9 months of age. Grace reported that her initial experiences with the ENT and audiologist who diagnosed her son were kind of "find your own way figure it out. Someone had given me the name of three places—it might have been [X, Y, and Z] were your three options for early intervention. . . . There were no guidelines." She also reported feeling completely overwhelmed.

> I felt like they had no concept of how to work with someone who had just been diagnosed. . . . Not that it would ever be pleasant, but it wasn't comforting or, you know, "Here's some pamphlets, call early intervention." It was awful.

Grace reported that once her son was enrolled in early intervention and the decision was made to go to [X] for early intervention services. "It was great. It was just finding the right place." His present educational placement was in a first-grade district-based general education program where he receives support services from a teacher of the deaf and speech and language pathologist.

Lena and her husband were raising four children on Long Island, two boys and two girls. Her oldest son, who was 12 years old, was diagnosed as having a bilateral moderately severe sensorineural hearing loss of unknown origin. Their youngest daughter was also diagnosed with a moderately severe bilateral sensorineural hearing loss and several co-morbidity issues. Lena met the criteria for participation with regard to her son, as his diagnosis was reported as hearing loss only and an initial hearing screening fail.

Lena's story was interesting in that she believed the hospital misdiagnosed her son's hearing loss. After initially failing his newborn hearing screening, he passed a rescreen. Follow-up testing revealed a bilateral moderately severe sensorineural hearing loss, affirming the initial screening fail. As a 12-year-old, Lena's son was in a district-based general education setting benefitting from the use of his bilateral hearing aids and an FM auditory system and receives support services from a teacher of the deaf.

Scott's 12-year-old son was diagnosed at birth with a bilateral moderately severe hearing loss with an unknown etiology. Scott's son was enrolled in a district-based general education setting

> Scott: My wife keeps me up to date. Look, I have to be honest with you. I haven't, I knew he had meetings and stuff, but she really handled it. Look, I haven't gone to one meeting. She tells me, Oh, we have a meeting and this is what we are going to ask for. It works.

Denise was married with three children. Her oldest child, a girl, was diagnosed at birth with a moderate bilateral sensorineural hearing loss of unknown etiology. Her two younger children are of normal hearing status. Denise reported that the audiologist who diagnosed her daughter recommended that they look into the early intervention program at [X] and get her aided. She received her hearing aids, which early intervention financed, at 3.5 months of age:

> Ironically, we started early intervention when she was about three months and they did all their initial evaluations. You know the teacher came, the special education teacher, and I don’t know how you really evaluate a 3-month-old who can’t really sit up, but they do.

Initial services were minimal, with a parent trainer and speech therapist coming to the house two times in a 6-month period. Upon the suggestion of the audiologist, Denise contacted a state-funded early intervention program. Denise’s daughter was approximately 8 months of age when she began to attend the program with other children with hearing loss. Now 7 years old, Denise’s daughter was enrolled in a district-based general education elementary school, where she continues to be bilaterally aided and uses an FM auditory training system throughout her instructional day. She also received support services from a teacher of the deaf.

Mark was the father of a 10-year old boy who was diagnosed with a moderate to severe bilateral sensorineural hearing loss. Mark reported his son to have enlarged vestibular aqueducts, the cause of his son’s hearing loss. Mark said,

> I am still very worried because even though he is doing very well now and his hearing every year tests to be very stable. . . . I am hoping, keeping my fingers crossed that his hearing does not grow worse. So I am still paying attention every

> day when he approached a puberty state for that, because I know that will be a second time that his hearing can go bad.

Mark’s son wore bilateral hearing aids, and used an FM system during his instructional day as represented on his IEP. His son was a fifth grader in a general education public school classroom receiving support services from a teacher of the deaf and speech teacher.

Rose’s son was diagnosed with a moderate to severe bilateral hearing loss. Rose reported that the initial introduction into early intervention was not a quick process. She reported that it took early intervention 6 months to get back to her after her initial contact. A series of evaluations and referrals was completed when her son was 2 years of age. Early intervention purchased bilateral hearing aids for her son and provided teacher of the deaf and speech and language services. Rose reported that the audiologist played a critical role in helping her get the educational services that were needed for her son. Her son was a fifth grader who attended a district-based general education public school. He was bilaterally aided and wore an FM unit during his instructional day. Rose reported that she thought her son received teacher of the deaf services three times a week for one hour, and speech and language therapy services three times a week for 30 minutes.

Lisa’s 7½-year old-son was diagnosed with a bilateral profound sensorineural hearing loss. “Once all the testing was done and everything happened,” she said, “we were in contact with early intervention. Everything happened so fast. They actually gave me the name of the doctor who ended up doing his cochlear implants.” Lisa’s son was simultaneously implanted with implants in both ears at the age of 11 months. Lisa’s son was in first grade in a district-based general education setting and used a compatible FM system with his implants during the instructional day. He received speech services four times a week, both in small group and individually. Lisa was not sure of the exact numbers. In addition, he received support services five times a week for 45 minutes from a teacher of the deaf and counseling once a week

Dan was a husband and the father of three boys. His middle boy, who was 7 years old, was diagnosed with a bilateral profound sensorineural hearing loss and was advised that the earlier his son receive bilateral cochlear implants the better. Dan's son received both his implants simultaneously before his first birthday. Dan's son was in first grade in a district-based general education setting. Dan could not recall all of the details of his son's IEP.

> I do know he's pulled out. He does have, I don't know if it's one-on-one speech or if that was last year. I can't recall. Or, if it's in a group. But one-on one speech and small group speech is probably good for him.

Ellie was a wife and mother of an 8-year-old girl who was diagnosed with a moderate-severe bilateral sensorineural hearing loss at birth. She was an only child. Ellie reported that there had been discussion about cochlear implants, but she was not sure if that was the choice they want to make for their daughter. Ellie reported that her daughter began receiving early intervention services at 4 months of age, and also received hearing aids at that time. The daughter currently wore bilateral hearing aids and used an FM system during her instructional day. She was in a district-based general education second-grade class.

Table 3

Child's Degree of Hearing Loss and Amplification Used

Characteristic	*n*
Child's diagnosis	
Profound	2
Moderate-severe	5
Moderate	1
Mild-moderate	2
Amplification used	
Hearing aid & FM	6
Hearing aid only	2
Cochlear implants & FM	2

Data Collection

As noted in Chapter 3, after approval of the proposal by the IRB, I contacted two individual stakeholders to disseminate 30 recruitment packets on my behalf to prospective participants. The recruitment packet consisted of two forms. The first form was the informed consent, which listed the criteria for participating and stated that participation was strictly voluntary and data collection would be completely confidential. The second form was an initial data form (Appendix A) to be filled out by the parent. As stated, if the participants met the criteria for the study, they would be considered on a first-come, first-served basis. A total of 16 parents responded to the initial mailing. Of those 16 parents, three did not meet the criteria for participation in the study and were sent an e-mail thanking them for their interest. In another e-mail sent to the three parents who responded after the required sample was met, I explained they were not selected for the first round of interviews but they would be contacted at a late date if their participation in the study was needed. Interview times were established with the 10 eligible participants. Prior to beginning the interviews, I explained the parameters of the study, answered any questions about the study, and gave out a copy of their consent form. At their request, the interviews took place in the homes of the participants. Most of the interviews lasted between 45-60 minutes, with one interview lasting 69 minutes. The interviews were audio-recorded, and I transcribed them. Each participant had final approval of the transcript to ensure accuracy (see Appendix E). All interview recordings were stored on a flash drive, which I stored in a locked safe box.

Data Analysis

My initial responsibility to my research was to manage bias by engaging in the principles of epoch and bracketing (Hatch, 2002; Husserl; 1970; Moustakas, 1994). Thus, prior to and during my data analysis, I remained consciously aware of any personal preconceptions about the phenomena of study. The data were then analyzed using the inductive approach and analytical steps suggested by Hatch (2002).

I transcribed each interview by listening to the digital recordings several times and word-processed them verbatim. Next, I reread the transcribed manuscripts while listening to the digitally recorded interviews to ensure accuracy of the initial transcriptions and making any needed changes. I printed out a hard copy of each participant’s transcribed interview, which was then placed in an appropriate color-coded folder. The pseudonym for each participant was written on the tab of each folder for easy identification. These transcripts and other documents pertinent to the study such as identifying information, letters of informed consent, and initial data forms were also stored in each folder and kept in my home office in a locked file cabinet.

I immersed myself in the data by reading and re-reading the transcribed interviews before beginning any type of hand coding. The initial steps to inductive analysis begin with organizing the raw data and identifying frames of analysis. As I re-read the transcriptions, I made notations in the text, defined categories and domains found in the frames of analysis, and assigned them codes. These codes can be found in Appendix E. I reread the text to determine if the domains were well-grounded in the data, and I searched for themes across the domains. In essence, I grouped the data, reducing the number of categories by combining similar headings into broader categories. I used NVivo to assist with coding and analysis (Creswell, 2013).

Following the initial coding, these codes were organized into categories that addressed the four research questions:

1. How do hearing parents of children between the ages of 5 and 12 years who only have hearing loss describe their experiences with the educational system?
2. How do hearing parents of children between the ages of 5 and 12 years who only have hearing loss perceive their experiences with the special-education process as their children proceed through the education system?
3. What patterns of coping do hearing parents of children between the ages of

5 and 12 years who only have hearing loss identify as most helpful in managing the stress related to their experiences with the educational system?

4. What do hearing parents of children who only have hearing loss want professionals in the special-education school system to know?

From this information, I formed analyzed thematic categories to identify relationships among the codes, and then I used inductive reasoning to identify and understand the "how and what components of the research questions better" (Cottrell & McKenzie, 2011, p. 228). Next, themes were identified by connecting the thematic categories or labels to reveal deeper insights from the data, as Hatch (2002) recommended.

Themes

Five themes developed during the data analysis (see Tables 4–8). The first theme developed was the need for more parental assistance surrounding the first IEP meeting. The second theme was the need for greater knowledge of hearing loss among special education professionals, as well as being more attentive to parental concerns. The third theme reflected the need for compassionate communication, and the fourth reflected the importance of parents serving as an advocate for their child in a struggle over the right amount and type of services. The fifth and final theme pointed to increased comfort with meeting protocol and expectations as a result of becoming more familiar with the IEP process.

Table 4

Coding Samples in Access to Information Category

Theme	Codes	Sample associated text fragment(s)
Information overload	Too much at once	"I know the teachers [and the] audiologist thought they were being helpful, but . . . sometimes they were just boom, boom, boom, do this, do that and that's it."
	No guidelines	"There [were] no guidelines or book…and you're getting hit at all different ways"
Not enough information	Sought information independently	But we put the effort in to make sure we got what we needed or we understood before and after the meeting.
	Lack of information	I think somehow they have to better educate the parents to the process before going through it.
	Sought information independently	I was or I was able to derive what each role was based on the handouts that they provided at the meeting
	Lack of information affects meetings	So my involvement in the meeting is kind of muted because I'm learning this information during the meeting.
	Confusing acronyms	There were a lot of acronyms that I was not aware of. There were job titles I wasn't aware of.
Business-like and political nature of the process	Impersonal	It is not personal. It is like a mill. So many people go through this
	Businesslike/ impersonal	I think what I felt was or what I thought at that time was it was all about money.
	Unclear and political	The politics of it … I don't know if they are forthcoming

Table 5

Coding Samples in Mix of Emotions Category

Theme	Codes	Sample associated text fragment(s)
Lost or confused	Unsure of self	"A lot of not knowing." "I am sitting here telling you I was very knowledgeable, I thought I had all the knowledge, but I didn't."
	Unclear	"It wasn't made very clear."
Fear	Gut response	I was sick to my stomach.
	Fear of unknown	We were scared. We didn't know what was going to happen.
	Shock / fear	That was really shocking. We were really scared.
	Unsure of self	Then the more you think about it the more you question yourself.
Upset	Feel unheard.	I don't know if they even hear what I'm saying. They are nice and all, but they talk *at* you.
	Frustrated.	Frustrated. I felt they dismiss it (hearing loss).
	Uncomfortable.	I really didn't feel comfortable.
Satisfaction	Happy with process	It just progressed great everything fell into place perfectly. I thought the process was fantastic once it was in play.
	Happy with teacher	Yes, loved her.
	Happy with education	Once I got there, I wouldn't have changed anything the education was great there.
	Happy with teachers and services	The services, the teachers, that wasn't an issue at all.

Table 6

Coding Samples in Perceptions of SE Process-Over-Time Category

Theme	Code	Sample associated text fragments
Struggle to maintain appropriate services	Struggle	There is mental anguish as a parent of a 'tween. It is a hard time. Hearing impairment is only part of it."
Parent becoming more comfortable with the process	Restricted services	You know as they grow things change. You know in middle school I think they just try to cut it (services) so sharply that it could be a detriment to the child… you don't know what restrictions especially when they go to a new school and now I have to deal with new people and you're not sure who they are or how they feel about things."
	Discussing services with school	When you go to that meeting apparently most of them have already spoke and it's just kind of like a formality that you have to sit there and once you get to that point they are really much more receptive and agreeable to services."
	More comfortable	I feel more comfortable now.
		I have gotten more comfortable with what the situation is.
	Improving	It is a very good system compared to before.
	Declining stress	[Stress] declined because we kind of knew all along that we would get what we wanted.
Lack of knowledge about the process among professionals	Don't understand	I felt that they dismiss it as a very minor little thing and they don't understand why he would need so much help.
	Lack of knowledge	They were not knowledgeable [about the needs of children with hearing loss] because it's just not that common among kids.
	No training.	There are just not that many children with hearing aids which is great but then you get them and no one's really trained.
	Lack of staff	There's no dedicated person.
Educator-parent communication, collaboration, and involvement	Communication	I talk to the teacher of the deaf more than I do to the classroom teacher.
	Collaboration	They are always so supportive, and they know what (my child) needs
	Involvement	He still did great because he had the teacher of the deaf and they always knew to put him in the front of the class
		Her teacher of the deaf is almost like her confidant, she loves her. They have such a great relationship which makes me happy

Table 7

Coding Samples in Coping with Stress Category

Theme	Codes	Sample associated text fragments
Social support	Spouse support	I really am lucky because my husband handles stress better than I do.
	Peer support	Meetings, speakers [helped]… Talking to other parents helped… Asking a lot of questions helped.
	Professional support	A lot of the coping in the beginning was really like we went to places like in [name of place] who did a bunch of presentations. I have a very good relationship with the teacher of the deaf.
Emotional release	Yelling	Um yelling, I'm a yeller. Not necessarily at people, but I'll hang up the phone and I'll start screaming
	Crying	Crying, I shut down and kind of get into a not so good place.
Being an advocate for your child with hearing loss	Tact when advocating	You cannot go in there and say 'my child deserves more than any other child… You have to say my child deserves exactly the same chance as every other child in that school.
	Parent role as advocate	Your role is to just give them a fair shake. Like you said, look it's not that you want to make sure they get as much as they can; it's just making sure that their impairment isn't hindering them in whatever assistance they need is to put them on a level playing field.
	Advocate by collaborating	There are teachers there who have been in the classroom… I can only tell them this is what I see at home… Putting those two things together, we can really figure out what his needs really are.
	Parent role as advocate	I'm an advocate.
Being a parent of a child with a hearing loss	Stress of being parent	I need to know if he's ignoring me or if he can't hear me.
	Stress with condition	We don't know why he has a hearing loss. Um so I'm always terrified it's going to get worse.
	Child needs more attention	Not only financially but energy-wise, you really need to spend more attention to the children with disability. I hate to say it, but, it takes a lot of work sometimes.

Table 8

Coding Samples in Reflections for Professionals and Opportunities to Change Category

Theme	Codes	Sample associated text fragment(s)
More compassionate communication	Less businesslike	Make it more comfortable. I know they have to take care of business, like I said, but, I am a parent, and my daughter is not a business, she is a person.
	Impersonal	Many teachers [act] like they're on autopilot.
	Lack compassion	They speak to you about your child from their weaknesses instead of about their strengths. It's rare. They don't have much of a bedside manner.
	Make parents comfortable	[Professionals] should explain things to them [the parents], and let them know, hey, we are going to take care of that child.
More attentive to parental concerns	Parents have important knowledge	Nothing compares to the parents who actually have to deal with the children day to day…
	Take parent feedback into account	It is a little bit more about what the tests show, but it really is the parent that really knows their child.
	Take parental feedback into account	I want them to care about what I have to say
Suggestions for assistance to prepare parents for the first meeting	Difficult to access information	But when you're meeting a parent for the first time it's not just about getting the services.
	Unorganized first meeting	I still find that there is really no one place that you will be able to find all these resources easily.
	Need step by step directions	[Professionals] just throw all of this information at you…
	Need step by step directions	[It's important] to tell you what you need to do, and 'this is going to happen.'
	Need closer direction	I [needed] a list. There was so much to read through, and I just had a really hard time doing that.
		A buddy system [would be helpful].

Evidence of Trustworthiness

I conducted one interview with each of the 10 interview participants. To assess the trustworthiness of this research, and to anticipate problems that need to be addressed during the research process, the following four criteria of trustworthiness are addressed as set forth by Lincoln and Guba (1985): credibility, transferability, confirmability, and dependability (authenticity was later added as a fifth criterion, and is also established for this research). First, I chose to focus on 10 information-rich cases determined through the amount of "issues of central importance to the purpose of the research," with previous scholars suggesting that eight to 12 cases would be sufficient for a phenomenological study (Markula & Silk, 2011, p. 114; Mason, 2010). I also used snowball/chain sampling to recruit members from the appropriate population (Mason, 2010). Participating families with children with hearing loss were clients of two dually-certified New York teachers of the deaf /speech and language pathologists who specialize in auditory rehabilitation.

Credibility

To ensure credibility in this research study, I asked open-ended questions during the interviews and ensured accuracy by comparing transcriptions of the audio recording to the audio recording itself. I also verified quotes with the interview participants to ensure accurate representation through member checking, meaning the responses of the participants were restated; I asked the interviewees to check and correct any inconsistencies or errors. The truth of the data, or the accurate representation of the interview participants (Polit & Beck, 2012), was improved by taking these measures. I also used the strategies of epoch and bracketing throughout the research process to be more aware of my own biases and assumptions (Gearing, 2004; Hatch, 2002; Husserl, 1970; Moustakas, 1994), and then to control them (Creswell, 2007) to approach the phenomenon under investigation with a neutral viewpoint. In adherence to epoch, I made journal notations of all reflections (see Appendix H), preconceived notions, biases, and possible issues of conflict that should be removed along the process and addressed further in the analysis (Polit & Beck, 2008, p. 228). I was well guarded in maintaining neutrality when parents revealed situations that occurred during their experiences that challenged or confirmed a personal belief or position. Data saturation, as well as in-depth understanding of the phenomenon and appropriate sampling, was achieved through repeatedly reviewing the transcripts until no new themes arose (Lowes & Hulatt, 2006). Finally, congruence was established through the alignment between the research question (experiences of parents with hearing loss) and the methodology (phenomenological, in-depth interviews). Such characteristic implies a more credible research study (Birks & Mills, 2015). The data analysis is organized below by research question to support the congruence of the data collection with the analysis of the information (Birks & Mills, 2015).

Transferability

Although my research represents just one case study, I took measures to make the results of this study more transferable. Transferability is defined as being able to apply research findings to other populations or settings (Houghton, Casey, Shaw, & Murphy, 2013; Polit & Beck, 2012). To make these results more applicable to other people and places, I described the demographics of the participants, the setting in which this study took place, and individual descriptions of each research participant. This information makes it easier for individuals who read this report to decide whether the results of this study would be relevant or similar under different conditions or using different groups of participants. I also enhanced transferability by providing thick and information-rich descriptions of the data to better understand the responses of the participants and the formed themes, enabling readers to decide for themselves if these results might be transferable to their own contexts.

Dependability

A dependable study must be consistent and accurate (Lincoln & Guba, 1985). To ensure the dependability of this study, I enlisted the aid of an external researcher to conduct an independent audit of my method and the results of my research. The dependability audit is a technique whereby an independent auditor appraises the researcher’s activities as specified in the audit trail.

Confirmability

I assured confirmability by checking quotes with research participants, as well as providing many in-text quotations of interviewees, to represent their perceptions and experiences as expressed in their own words and to refrain from obscuring their meaning through my own biases (Polit & Beck, 2012; Tobin & Begley, 2004). Many quotations are also included to provide support for the selection of the themes as reflected in interviews.

Results

In the previous section, I outlined the trustworthiness of this research by analyzing the following components: credibility, dependability, transferability, confirmability, and authenticity. In this section, I will describe the key findings or themes of this research. The analysis and support of these results are organized based on each research question.

Initial Communication With Early Intervention

Experiences with the early intervention process were common among the parents. Although the focus of this study was not on the early intervention process and experiences with the system, seven of the 10 parents referred to their initial experiences with EI and the effect its providers had on their initiation into the special education system and beyond. Overall experiences with early intervention were reported as positive, with evidence of occasional pitfalls in the system.

> Denise: Ironically, we started early intervention when she was about three months and they did all their evaluations. . . . The audiologist at [X Hospital] sent me to [X School]. She gave me the name of the psychologist. You have to go there. . . . We went there, I met with the psychologist, I signed up and we started at the young age. [My daughter was] maybe 7 months, 8 months. When she was 9 months we did start getting speech therapy services through early intervention.

> Mark: I really think that EI at that point had done a good job because of that person handling the case… I believe that EI actually they have a good

system in assisting parents but it is the guideline to determine whether children qualified for that type of assistance is what blocking us.

Once all the testing was done and everything had happened, we were in contact with early intervention. I think the person I spoke to was [Name]. She had called me one night and told me about the [X School] program. I think within a week or so we went to the program. They actually gave me the name of the doctor who ended up doing his cochlear implants. Really, that is where I got all of the information in the beginning.

Ellie: So, we got a lot of information from EI and we kind of listened to them. I had to trust someone, and my audiologist said they were good.

Three of the parents experienced frustration with getting to early intervention. Rose said it seemed that the initial agency she contacted did not expedite the process, and took 6 months to get back to her to evaluate her son. So, she and her husband decided to seek a second agency, which Rose reported managed to rush everything through the process. Once they were successfully enrolled in the system, their experiences were overwhelmingly positive.

Grace: Well, once I got into the educational system at (school) it was great. It was just finding the right place. It was just the information before I got to (school), it was tough. Once I got there, I wouldn’t have changed anything in the education, was great there. The services, the teachers, that wasn’t an issue at all.

Ann: I thought the process was fantastic once it was in play. If I recall back, um,

> the teacher that first came to the house was like a speech support person and was just like a General Ed. She was just not the right because she didn’t have any background in hearing loss or anything like that, so she then directed us toward [X School]. It wasn’t a direct connection, but it wasn’t a long time in between—it was a fast process once we found out where we needed to go.

Every parent participant had the common experience of early intervention. Although their comments were not included in the data analysis, their perceptions about the process were shared, with an overwhelming positive perspective of their experiences. This section was included to inform the reader of the experiences the parents have had even before their child enters school. These past experiences may influence parental attitudes towards their subsequent experiences with the education system and IEP process.

Research Question 1

How do hearing parents of children between the ages of 5 and 12 who only have hearing loss describe their experiences with the educational system?

The Initial IEP Meeting

Six of the 10 interviewees experienced negative feelings associated with the first IEP meeting, especially feeling overwhelmed, nervous, or confused leading up to and at the initial meeting. Lena provided some feedback on her initial IEP meeting:

> Lena: The IEP at the beginning I think sets the, a big footprint of how well they will adjust as they get older. The very beginning. You don’t know how it’s

really going to work when you first walk in there your stress level is so high you almost feel like you are going to faint.

Lisa: It was just very nerve-wracking. Are we doing this right? Is he going to be okay? Is this going to work? I think at first I was kind of very anxious. I did not really know. What does he need? I do not know what a child with hearing loss [needs] and he cannot tell me. You do not know what to expect. You do not know what they are going to give him. Is that the right thing? It is always constant second guessing.

Ellie: The first time we had our meeting, and we went, we were kind of . . . well, I was sick to my stomach. I felt like I was, I don’t know. We were scared. We didn’t know what was going to happen, or who we were going to talk to. I remember walking in and like, gee, I remember I felt kind of little. Do you understand? I really didn’t feel comfortable.

Scott: You have to learn all this new lingo. . . . I think part of that is that you’re faced with the reality that your son or daughter is faced with, impacted by a disability and right now you’re trying to make sure what to do.

Dan: I probably could have pushed a little harder to provide more input. But a lot of it was that they seemed to sit in these meetings. They know what the meeting is all about. We had no idea really. So a lot of it was just listening to them talk back and forth and negotiate what was going to happen. The first meeting, it was a fight. At the initial meeting they had their perspective

> on what they wanted to do with our son. We had ours and we were far apart.

Feelings of uncertainty, anxiety, stress, and the unknown were words used to describe how the majority of parents felt about their initial IEP meetings. One parent reported that their initial IEP meeting was stressful but the outcome was positive. Another parent, Ann, whose child was aged 1, reported their meeting as being nothing but positive: “We are in a really good district when we started with the IEP, everything was positive. We never got turned down, we always got what we wanted and needed.”

Access to Information

During their introduction into the education system, all parents received information about their child’s future. This information included what types of classroom educational options were available, as well as the type and amount of support services that were available to their child. While all parents had to acquaint themselves with this crucial information, some had much to say about the nature of the delivery methods. Some thought the information was delivered in an overwhelming way, while others said they never received enough information. Still others suggested that they were content with the way that they received this information, and did not encounter any hardships with learning about the procedures that would be necessary for their child’s progression through the education system.

Information overload. Four participants (40%) suggested their experience with the education system was overwhelming, citing a barrage of information that they found barely manageable. Ellie said, “I know the teachers [and the] audiologist thought they were being helpful, but . . . sometimes they were just boom, boom, boom, do this, do that. and that's it." Grace recalled, "There [were] no guidelines or book . . . and you're getting hit at all different ways." In their interviews Scott and Mark echoed this experience.

Not enough information. Although four participants had a poor experience with an overwhelming amount of information, four others said they did not receive enough information to feel comfortable at some point. Grace and Scott suffered from an information overload in some instances but felt underinformed at other points. In addition, Rose and Dan experienced a lack of sufficient information during their child's progress through the education system.

Business-like and political nature of the process. Five of the 10 interviewees mentioned being "talked at" by professionals regarding their child's educational needs in an impersonal, business-like way. Ann said, "It is not personal. It is like a mill. So many people go through this." Dan recalled, "I think what I felt was or what I thought at that time was it was all about money. And they don't want to pay for that, right. I think they had a financial obligation." According to Scott, "The politics of it . . . I don't know if they are forthcoming. They don't say, 'Here these are the things you are going to potentially get.' You kind of get [what you get] not knowing [you may be entitled to other services]." Others agreed with Scott's outlook:

> Grace: I guess like everything else . . . it's political. The whole business part of it these meetings were very stressful. Is he going to get the services? Is he not

going to get the services? Do I have to fight for it? You know, everyone tells you [that] you have to fight for what you want.

Ellie: In the beginning I felt . . . well, um, can I say this, unwelcome[d]. It is like, they are nice and all, but they talk at you. And you know, it's like they are a business. But this is my kid, and she is important. I want you to know my kid, and they really don't. Sometimes these people in the meetings have their own ideas, and it's like they already know, but they don't. I know my daughter. She is more than just tests.

Interview participants seemed to connect the business-like and political nature of special education meetings with feelings of stress, noting that they were unfamiliar with the process and what to expect.

Research Question 2

How do hearing parents of children between the ages of 5 and 12 who only have hearing loss perceive their experiences with the special education process as their child proceeds through the special education system?

A Mix of Emotions

Many participants found themselves having a mix of emotions during their experience with a child progressing through the special education system. The most commonly perceived emotions among these parents were the feelings of being lost, confused, upset, or happy with the process after the child had been satisfactorily placed and their concerns had been addressed.

Feeling lost or confused. The feeling of being lost or confused during the process was the most commonly cited, with seven of the 10 participants indicating they perceived the experience as confusing or they felt lost at some point. These respondents included Ann, Grace, Scott, Denise, Mark, Rose, and Ellie. Ellie recalled, “A lot of not knowing.” Even after receiving some preliminary information, Ellie still felt confused, noting that she had received so much information all at once. Denise had been unaware that her child would receive a teacher of the deaf at school, rather than speech services only. “It wasn’t made very clear.” She argued that, “I am sitting here telling you I was very knowledgeable. I thought I had all the knowledge. But I didn’t.”

Being fearful. Four participants—Denise, Mark, Lisa, and Ellie—recalled feeling fearful during the process. Denise alluded to her fear prior to her child’s initial school-age IEP meeting. She was pregnant with twins at the time:

> I was so emotional being super pregnant and going through this transition exactly at that time, I was in my transition meeting crying and telling them you know I am sorry I am so emotional, but I need to know for sure that everything is going to be okay.

Denise revealed she was unaware that her child would be receiving teacher of the deaf services, but felt that she would have been much more at ease if she had that information. Lena noted how she felt less trust toward the system without this information and would have benefitted from a more streamlined source of information. She was reluctant to “blindly take what [professionals] say” without some secondary source of information.

Feeling upset. Denise, Mark, Lisa, and Ellie indicated that they were upset at some point in the experience. Ellie was unhappy with the way she was treated during meetings, where some IEP team members would write things down instead of looking at her when she was speaking. "I don't know if they even hear what I'm saying," she remembered. "They are nice and all, but they talk at you."

Feeling satisfaction. Though participants tended to feel a mix of emotions during the process, after their children were able to fully integrate into the system, five were satisfied with the system in one way or another. Ann, Grace, Denise, Rose, and Lisa all experienced satisfaction. These parents referenced their agencies, teachers, or in some cases the process itself when discussing their satisfaction.

Perceptions of the Special Education Process Over Time

Several parents found themselves grappling with the changing emotional needs of their child as they grew into their middle school/junior high school years. Although these parents may have expressed increased comfort with the IEP process because of their familiarity with what to expect at these meetings, they now struggled with the individual needs of their children as they entered the higher grades and what constituted appropriate services. Parents mentioned the lack of knowledge of special education professionals regarding hearing impairment, including the technical aspects relating to hearing aids, FM systems, and cochlear implants. Many of the parents expressed the importance of ongoing communication and collaboration with their child's educators.

The struggle to maintain appropriate services. Several of the parents whose children were entering the so-called 'tween and middle school years indicated that their current experiences and concerns with IEP meetings and outcomes have changed, especially when related to the struggle to establish and maintain the appropriate amount and type of services central to their child's experience. "There is mental anguish as a parent of a 'tween," Ann said. "It is a hard time. Hearing impairment is only part of it."

Lena, the parent who said the first meeting was the one that sets the footprint for the future, spoke about her concerns now that her child was in junior high:

> You know, as they grow, things change. In middle school I think they just try to cut it (services) so sharply that it could be a detriment to the child. You still get nervous when you go because as they get older you don't know what restrictions, especially when they go to a new school, and now I have to deal with new people, and you're not sure who they are or how they feel about things.

Scott also expressed concern about his son's entrance into middle school and the adjustments that go along with it.

> I think we're concerned. There is a big adjustment with just going to middle school. So you want to separate the extra stuff from the hearing deficit stuff, versus just everything a kid goes through.

Parental understanding and satisfaction with the outcomes of the IEP process seemed to have increased as parents experienced subsequent IEP meetings, although some parents still went into meetings feeling anxious. According to Denise, "I think the process was fantastic once it was in play."

> Lena: When you go to that meeting, apparently most of them have already spoke, and it's just kind of like a formality that you have to sit there. And once you

get to that point they are really much more receptive and agreeable to services.

Lisa: For us, I am very happy with it. The school is great. . . . It is a disability they cannot deny. Really it was just figuring out what a child who cannot express what he needs. As the years go by it has changed. He is getting older. He is speaking up for himself, but I think it has been pretty easy with him.

Lisa, although pleased with her IEP meeting experiences and the interactions with the professionals, did report feeling anxious about her son's changing needs with regard to educational placement and class size. Her perception about a one size fits all philosophy to education was her only complaint and an obvious concern. "Every kid is different, and you cannot fit everybody into that. I think the only complaint I would have is that they think every kid should just fit into this model that we have."

Another parent, Ann, whose experiences with the educational system and IEP process were positive with regard to the district's responsiveness to her child's needs, expressed her concerns regarding yearly placement of her child. She spoke about the limited slots in classrooms, and the yearly concern she had over whether the district would be prompt in completing evaluations to ensure her child would have a place in an appropriate classroom setting. "You are powerless waiting for a district. You don't know what behind the scenes are."

The overall struggle to establish or maintain the appropriate amount and type of services can correspond to a change in a child's performance. Five parents described the services over time to be consistent, while the other half described changes in the process-over-time. Scott explained how it is frustrating to observe and experience each school year the lack of effort to incorporate more innovative methods to help the children learn: "I hate saying it, you're almost like it's expected. . . . This is what I did in seventh grade; this is what you're getting in eighth grade. It's almost like a formula. . . . To say this is what we [parents and children] get, this is what we need." Denise expressed her satisfaction with her child's program, "She'll always have access to [services]. . . . What she gets now is teacher of the deaf services. Her teacher of the deaf is amazing and she's a friend of mine, and to know that she will have her straight through her years in school is the biggest relief for me." Parents explained how the teachers and even the services have not changed over the past few years:

> Rose: I think pretty much all of the people that we met in kindergarten, they have been all similar, very similar except the classroom teachers, because his speech therapist has been with him almost for the four or five years. . . . So, very much the same, very much the same. I do not think it is that different from the beginning."
>
> Lisa: It changes year to year. . . . I do not know if much would change on his IEP between now and next year. Next year he will be going to a different school, so I do not know if they would change anything right off the bat.

Grace and Ellie described their struggles with providers in trying to establish the right amount and type of services for their children.

> Ellie: She does have trouble pronouncing things. They say she should get speech only two times a week. What? I know this is wrong. My husband and I know that is not right. We don’t want other kids making fun of her.

Five participants described a change in services over time. For example, Ellie described her child being weaned off of services due to her progress. Anne described children getting lost in the process, whether by not receiving the appropriate amount or type of services needed: “Kids can get lost in the process, specifically for kids with hearing loss.” Grace explained that her child used to receive more treatments and services but over time, less attention was given and individual service declined as well. The concern comes from the hindrance in the progress of her child. Grace recalled that the special education professional said:

> “I think we can cut it back, he’s reading [well].” I’m not so quick to cut it back. I don’t want to cut it back. I’m like, “He is doing this fantastic because he’s had these services.” I don’t want to cut it back to see if he regresses and then play catch up. . . . Even his speech services—he used to get individualized [services] twice a week, and now he gets individual [services] once and a group [service] once [per week].

Describing how her child’s progress precipitated a decrease in services, Denise said, “When she was in kindergarten and first grade it was partially push in and partially pull out. Um, this year they are only doing pull out.” Rose felt that although the services were overall the same, there were slight differences, from classroom teachers to “whoever is conducting the meeting changes over time [change] a little bit.”

Mark had a more positive perception of cutting back services:

> I personally do not think I am very happy with how things work out because I am the one to believe that gradually when he starts to receive less it really is good news. When your child needs to receive more [*laughs*] it is actually not that of good news.

This struggle to achieve the appropriate amount and type of services is central to interview participants' experiences as parents of children with hearing impairment. The next category discussed refers to a positive change that occurs over time.

Parents becoming more comfortable with the process. Of the 10 participants, five mentioned becoming more comfortable as they became more accustomed to what to expect and how the process works. Denise explained, "I mean, I have gotten more comfortable with what the situation is" over time.

> Mark: In the beginning of the year they will reach out to you, tell you what is going on. It is a very good system compared to before, the first year when the school was engaged with just a speech therapist provider they are more passive. . . . I do not think so far I see any—the process is very consistent so the parents will know what is expected. That is a good thing. I think that will remain the same until he reaches high school.

Compared to interviewees' perceptions of the initial meeting following diagnosis, the perceptions of the special education process-over-time are increasingly positive.

Dan explained that over time stress levels "declined because we kind of knew all along that we would get what we wanted." Rose also explained how familiarity with what to expect, as well as being comfortable with the special education process, makes meetings go more smoothly:

> Whoever we have in the meeting, we get to know each other better. And so when we go there, it is very much it is like a conversation of how [child's name] is doing. And we see his classroom teachers every day. So, very much we are okay. . . . It feels like a breeze. It is just they know what we want. We know whatever they put down on the IEP that is what we expect, so, that is it.

A lack of knowledge of hearing loss among special education professionals. Four of the 10 participants mentioned the lack of knowledge regarding specific needs of children with hearing loss in schools. For example, two parents described being responsible for trouble shooting problems with their children's hearing aids, sometimes without a professional in the building to quickly fix such issues. According to Lena, "I felt that they dismiss it as a very minor little thing and they don't understand why he would need so much help."

> Grace: They were not knowledgeable [about the needs of children with hearing loss] because it's just not that common among kids. . . . There are just not that many children with hearing aids, which is great, but then you get them and no one's really trained. There's no dedicated person [to troubleshoot problems with amplification].

Rose described her experience struggling with issues with the hearing aid and FM system during an entire school year because of a lack of knowledge within the IEP staff. She recalled a situation where two separate entities, including the school and a separate contractor, who were attempting to fix her child's hearing aids. Neither of the two could identify the problem, because only one entity worked with the hearing aid, and the other assessed the FM system. "The contractor came in with the audiologist and checked the FM system, and then [said] the FM has no problems," she recounted. Simultaneously, the school was unable to find a problem with the hearing aids. After nearly a year of little to no feedback, the two began to work together and were finally able to identify the problem by checking the two pieces of equipment together. After about two hours of examining the equipment, the contractor and audiologist concluded that his hearing aid was in need of maintenance. Because the two entities lacked comprehensive knowledge, they were unable to identify the problem until the contractor and audiologist were forced to work together. The main issue, Rose thought, was that there was no system in place to bring these two entities together and collaborate a full skill set and sufficient knowledge.

> Grace: [Members of the IEP team] were not knowledgeable because [hearing loss] it is just not that common among kids. . . . I don't think the system understands how nerve wracking that is for a parent to have to go in [and] have a teacher use an FM that they've never been trained on. They don't get enough training on it. . . . I just think it is they are more used to dealing with OT, PT, autism. Autism is more common now. [Hearing loss] is just not one of those things that is not very out there.

Dan, whose son wore bilateral cochlear implants, expressed his concerns from his experiences with the special education system: "I thought they lacked qualified professionals who know how to work with people who have cochlear implants." Not only did parents who participated in this study identify the need for more knowledge of hearing impairment in schools, but they also discussed their struggle to establish and/or maintain the appropriate amount of services.

Educator-parent communication, collaboration, and involvement. Many of the parents in this study expressed their reliance on the feedback and communication with their child's teacher of the deaf and speech therapist, and less interaction with the general education teacher. Ellie said, "I talk to the teacher of the deaf more than I do to the classroom teacher. I also talk to the speech teacher a lot. They are always so supportive, and they know what (my child) needs." Denise spoke about the positive interactions that occurred between her daughter and her teacher of the deaf:

> Her teacher of the deaf is almost like her confidant, she loves her. They have such a great relationship which makes me happy. She kind of pulls a lot out of her. In the context of teaching, learning, and stuff like that.

Grace spoke about her feelings toward the teachers of the deaf who she came in contact with during her son's education, and reflected back to his preschool years when he had a dedicated teacher of the deaf at all times. "He still did great because he had the teacher of the deaf and they always knew to put him in the front of the class." Now that her son is in a general education classroom with no dedicated teacher of the deaf, Grace admitted:

> Would I love a dedicated teacher of the deaf in every school, audiologist, yes. Would it make my life easier knowing that there's someone there not just for that

> 45 minutes or an hour? Because what happens when she leaves? What if the FM stops working?

As noted by Lisa, the teacher of the deaf played a major role in problem solving and trouble shooting her son's FM system.

All of the parents noted the importance of positive collaboration between themselves and the school. Ann described a successful collaboration experience with her son's sixth grade teacher, who happened to be the only male teacher in the school. She shared how much her son liked his teacher, and why she liked this teacher. "He talked about his strengths and not his weaknesses. That kind of teacher is positive, and he always called to talk about and tell me things."

Other parents shared various experiences of parent-teacher collaboration and offered their opinions. Scott expressed how the collaboration between parent and teacher was much easier in the earlier grades, but now that his child is in middle school they have more concerns. Several of the parents emphasized the importance of being on the same team and working together.

As discussed in this section, not only do parents become more familiar and comfortable with the special education process-over-time; the struggle to establish and maintain the appropriate amount and type of services is central to their experience. Parents also mentioned a lack of knowledge among special education professionals on the unique needs of children with hearing impairment, including technical aspects relating to the maintenance of hearing aids, FM systems, and cochlear implants. Parents pointed to the importance of parent-teacher communication, and specifically, with the TOD and speech therapist working with their child.

The next section is focused on the third research question, relating to effective coping habits in the maintenance of stress.

Research Question 3

What patterns of coping do hearing parents of children between the ages of 5 and 12 who only have hearing loss identify as most helpful in managing the stress related to their experiences with the educational system?

Patterns of Coping in Managing Stress

To provide a framework for parents' coping strategies, I asked participants about which aspects of their experience with the educational system presented the most stress. Five of the 10 parents thought not knowing what was going to happen in the future was a large contributor to their stress. Parents identified social support, an emotional release, and resolving the problem as successful coping strategies. Social support included positive relationships with special education professionals, the support of a significant other, attending meetings, and talking with friends and family. Parents identified their role as being primary advocate for their child as one of their most successful coping strategies.

Social support. Nine out of 10 interview participants described social support as important to coping with stress associated with being a parent of a child with hearing loss, and stress associated with the resultant IEP process. Although participants described different sources of support, from a teacher of the deaf to other parents to a significant other, the similarity was the source of social support. “I really am lucky,” Ellie said, “because my husband handles stress better than I do. He kind of gets me to talk about things. Lena explained that attending “meetings, speakers [helped]. Talking to other parents helped. Asking a lot of questions helped.”

> Scott: A lot of the coping in the beginning was really like we went to places like in [name of place], who did a bunch of presentations.
>
> Denise: I still had my support people from [name of organization], you know (name of person? She was like my personal therapist. We would sit on my couch and we would talk about I don’t even know what, that was a big help. . . . But without that one-on-one help from the people in (school), I really would have been in the dark. . . . I have a very good relationship with the teacher of the deaf. . . . We’ve had a new audiologist that we switched to who has been very helpful.
>
> Lisa: The people who had him—his teachers—were amazing. They just made us feel like we were doing the right thing and he was going to be okay.

One of the strengths of the special education system outlined by interview participants was the helpfulness and positive attitude of many of the professionals who worked with the children of the parent participants, with nine out of 10 interview participants noting this during the interview process. Out of the nine interviewees who found special education professionals to be helpful and positive in their interactions, eight of them specifically mentioned an audiologist or teacher of the deaf to be a particularly useful source of knowledge and support.

When asked about how he copes with stress, Mark described the importance of parents sticking together and not blaming each other:

> Work with your partner/your spouse; share a common goal. There are always disputes even now in how to raise a child with disability. Like I am more conservative. My wife is more [of an] optimist. . . . It is very important that the family members . . . come to compromise in discussions.

Rose referred to a family member who has hearing loss to gain insight into what her child is going through:

> Because his cousin has hearing loss as well, I did talk to him sometimes about how he feels, how he goes through life, stuff like that. So, it is kind of like getting experience from him to kind of apply on (my child) but not exactly on (my child), but kind of know maybe he will go through something like this later in life when his school when something might happen to him like this. . . . Whatever we do not know or I do not know, I probably ask him. He is probably the best resource now about things.

Other interviewees described the importance of parent groups, presentations and meetings where individuals and professionals who deal with hearing loss gather to discuss resources and provide support for one another.

> Rose: We go to the parent group. They do have people; they have the audiologist and other parents that have kids older than [child's name]. So, whatever they experience, then they kind of talk and then I know. Now, because he is

> older now, if I go to the meeting, I actually give information to other parents that need help.

Emotional release. Three parents described simply releasing emotions as a source of stress release—for example, yelling and crying. "I'm a yeller," Grace said. "Not necessarily at people, but I'll hang up the phone and I'll start screaming."

Lena admitted, "I yelled at my husband a lot."

Resolving the problem. One participant described taking steps to resolve their concerns as being helpful in releasing stress. Researching a specific issue and meeting with teachers to address concerns were mentioned as examples. Grace realized she does not "de-stress until I know it's resolved to my benefit."

Being an advocate for your child with hearing loss. Nine participants described what it means to be the parent of a child who needs special education services due to hearing impairment. Other parents focused on what it means to advocate for their child with hearing loss, and the role of parent-teacher collaboration. Lena described how she found an effective approach for advocating for services for children with hearing impairment:

> You cannot go in there and say, "My child deserves more than any other child," because as soon as you say the word *more* they have shut down. You have to say my child deserves exactly the same chance as every other child in that school.

Lena also explained that being a parent of a child with hearing loss "means research, it means making sure everyone knows who you are, it means asking questions. You can't settle. I think it's extremely important for the parents to be there."

> Scott: Your role [as a parent] is to just give them a fair shake. Like you said, look it's not that you want to make sure they get as much as they can; it's just making sure that their impairment isn't hindering them in whatever assistance they need is to put them on a level playing field.

Lisa also emphasized the importance not only of being an advocate for her child, but also the value of effective collaboration between parents and teachers:

> There are teachers there who have been in the classroom. They can say how [child's name] is in school, how he is in the class, and how he navigates that environment. I cannot do that. I can only tell them this is what I see at home. They say this is what it is at school. Putting those two things together, we can really figure out what his needs really are. I mean I do not think you could do one without the other.

Dan summarized his perceptions of being a parent of a child with hearing loss, corroborating similar concerns from interview participants in this section: "I'm a father. I'm an advocate. Sometimes I'm a policeman. It's all about providing guidance."

Being a Parent of a Child With a Hearing Loss

Some parents focused on the specific challenges and experiences involved in raising a child with hearing loss. Grace admitted how it was terrifying to think about the future condition of the child: "I need to know if he's ignoring me or if he can't hear me. And that the part that terrifies me. . . . We don't know why he has a hearing loss. So I'm always terrified it's going to get worse."

> Mark: Not only financially but energy-wise, you really need to spend more attention to the children with disability. In this case for [child's name], as I said, every day I observe. I have to pay close attention to his learning.

Mark said that as a parent of a child with hearing impairment he spends 60% of his time as an advocate, "20% as support, and 20% as a researcher. Because you also need to do a lot of research."

Ellie described how she had no idea at first of the responsibility she was about to take on upon hearing the condition of her child:

> Wow . . . what does it mean? It means I have, um, a very big responsibility to my child. I hate to say it, but, it takes a lot of work sometimes. And, other times it doesn't. I have to be her ears sometimes, really a lot of the times. When it is really noisy it is hard for her to hear, even when she has her hearing aids on.

The last research question addresses areas of improvement for the special education system, as reflected in interviews.

Research Question 4

What do hearing parents of children who only have hearing loss want professionals in the special-education system to know?

Reflections for Professionals and Opportunities for Change

When discussing what they would like professionals to know, parents cited the confusion they faced with regard to the IEP and the initial IEP meeting, as well as individual concerns related to their child. The parents identified the need for (a) more compassionate communication, (b) being more attentive to parental concerns, and (c) greater parental assistance and support surrounding the first IEP meeting.

More compassionate communication. Five participants voiced a need for more compassionate communication with parents, especially during the first meeting, when parents are feeling most vulnerable. Simply understanding that parents are experiencing this problem for the first time and need reassurance is vital in making parents feel secure in the process. Ellie suggested, "Make it more comfortable. I know they have to take care of business, like I said, but, I am a parent, and my daughter is not a business. She is a person." Anne complained how teachers can sometimes be insensitive toward their actions and feelings: "So many teachers are robotic like they are on autopilot, and they speak to you about your child from their weaknesses instead of about their strengths. It's rare. They don't have much of a bedside manner."

> Scott: It's just a part of work for [the special education professionals]. But when you're meeting a parent for the first time it's not just about getting the services. You're emotionally, your son or daughter has a disability and treat that person like, they're scared, my son or daughter what we were afraid with (child's name) when he went into kindergarten and first grade we were afraid, was he going to be able to keep up? [The teachers/ special education professionals should] explain things to them [the parents], and let them know, hey, we are going to take care of that child.

Interviewees suggested that other than being more compassionate in their communication, special education professionals could also do a better job of listening to and incorporating parental concerns.

More attentive to parental concerns. Four participants urged professionals to listen more to the concerns of the parents with their children's hearing loss, explaining that although special education professionals have training, parents know their children the best out of anyone.

> Mark: Just because somebody is very knowledgeable in a field they can only offer you what they learned from their work experience, from their reading and studying. Nothing compares to the parents who actually have to deal with the children day to day. . . . When [it] comes to teachers and parents collaborating, it is two parties working together to achieve the same common goal.

Grace wanted to justify that "it is a little bit more about what the tests show, but it really is the parent that really knows their child." Ellie admitted that she wanted the teachers to be more compassionate of their needs and feelings: "I want them to care about her and this sounds selfish, but I want them to care about what I have to say." Finally, Grace said, "I feel like they probably do not take so much of what the parent wants into consideration." This concern reflected the idea that within the highly diverse and individualized field of special education, parents are the ones who are most familiar with the specific, unique needs of their children, which includes hearing loss.

Suggestions for more assistance to prepare parents for the first meeting. Ann, Grace, Lena, Denise, Mark, Dan, and Ellie suggested that parents should be given some form of guidance through the process and during the initial meeting to decide upon special education services for their children. Dan thought that he would have been much better prepared if he had been provided all of the IEP information upfront before entering the process. While Mark also noted this need, he also thought that it would be difficult to give every parent what they need using some similar format. He compared this provision of information to a car salesman's responsibilities teaching a buyer about a car:

> You cannot rely on a system and sit there and expect a white glove service that they will know exactly what you want. As simple as you won a car, you cannot just expect that you bring a car to a dealer and they will immediately tell you all the things that you need. The dealer needs to know what you want.

Though Mark thought the main responsibility was on the parents, he believed the information should also be more accessible, noting, "I still find that there is really no one place that you will be able to find all these resources easily." Lena suggested that information such as this could be disseminated through a class setting. She saw this option as a forum for parents to discuss and ask questions of the professionals, while receiving this information in an organized manner.

Grace responded, "[Professionals] just throw all of this information at you" and indicated she felt that information was received without any orderly manner. "You take it home and you try to sort it out and go through it by yourself, but you can't possibly."

Ann also suggested how important it is "to tell you what you need to do, and, 'This is going to happen,'" providing details from start to finish.

Though these parents felt the need for some form of guidance, their suggestions were vague and nebulous. Ellie broke this trend, making specific requests pertinent to her needs and the shortcomings of the system. She identified herself as a "list maker." In describing herself in this way, she highlighted her personal need for organized guidance. Ellie continued her recommendations: "I wish they would have given me a list. There was so much to read through, and I just had a really hard time doing that." She thought that she would benefit if professionals "would just tell you, 'Do this first, do this second.'" Ellie also recalled receiving lists of people to contact but not knowing who they were or what they did. Lena also requested specific guidelines.

Interview participants mentioned a desire for a personal advocate/guide, particularly at the beginning of the special education process. Describing her unease surrounding the first meeting, Ellie recalled being nervous, scared, and uncomfortable because she did not know what to expect. Lena suggested a variation of the idea of a parent advocate, explaining that if "you had a mentor [that explained] this is what you need to expect, like if you had a buddy system," it would be helpful for the parents.

Ann elaborated upon a particular population that may need extra support during the onset of the special education process:

> I feel bad for parents that do not speak English as their first language. They don't know how to advocate for themselves. . . . [It would be useful] to have smart advocates for the parents so we are prepared for the initial meeting. So they can

> guide the parents and give them good questions to ask. It should be an option to have the advocates read the child's case before the meeting and say, these are the three most important things that you should ask at the meeting. . . . [Early intervention] parents need resources. . . . [It's] important to tell you what you need to do and this is going to happen.
>
> Scott: It would almost be [better] if you had a mentor [or a] buddy system . . . before it starts, things like the common core tests, it would be nice like if the year before. . . . The organization says, "Hey we're going to have these meetings, [and] you're welcome to [attend] any meetings to explain."

The parents in this study reflected on their own experiences with the education system in addressing their needs. Some parents were more specific to how the education system could be improved to better serve them, while other parents reported the weaknesses within the system without providing solutions.

Summary

The results from this study shed light on the unique parental experiences of children with hearing loss, particularly those involving experiences with the special education system. This chapter included descriptions of the setting and demographics, including a rich description of the parent participants in this study. The data collection procedures, steps to data analysis, and evidence of trustworthiness were described. Finally, the results section contains detailed and information-rich data in response to the four research questions formulated for this study.

Research Question 1 focused on how parents describe their experiences with the educational system. Upon experiencing their initial IEP meeting, parents commented about the business-like and political nature of the meetings. Interviewees also expressed their dissatisfaction with overwhelming amounts of information and paperwork presented during the first meeting.

In terms of how parents perceive their experiences with the special education process-over-time, participants reported becoming more familiar and comfortable with the special education process-over-time, and described their struggle to establish and maintain the appropriate amount and type of services as central to their experience. Interviewees also mentioned the lack of knowledge by special education professionals regarding hearing impairment, including the technical aspects relating to amplification. When asked about ways to manage stress associated with their experiences with the special education process, parents mentioned the use of social support, emotional release, and positive resolution of the problem.

In answer to the final research question, parents of children with hearing loss offered four insights they wanted to impart to special education professionals: (a) more compassionate communication, (b) being more attendant to parental concerns, (c), greater knowledge of implications of hearing loss among students classified as deaf or hard of hearing within the schools, and (d) more parental support and assistance surrounding the first special education meeting following the initial diagnosis.

In Chapter 5, I discuss the results in more detail and analyze the findings in light of previous literature to provide a meaningful discussion of the data. The interpretation of the findings, limitations of the study, recommendations, and implications that arise out of these research results are discussed as a part of the data analysis in Chapter 5.

Chapter 5: Discussion

Introduction

The purpose of this phenomenological study was to understand, describe, and explore the perceptions of hearing parents toward the education system and IEP process of a child between the ages of 5 and 12 years with hearing loss only. Given that the participants in the study had children in elementary through middle school, my research extends this knowledge to parents of students who had progressed further through the special education system, which revealed the more experienced insights of parents over time (Berndsen & Luckner, 2012; Day & Brice, 2013; Hintermaier, 2010; Kobosko, 2011, 2012; Szymanski et al., 2013). These experiences are beneficial for finding ways the individualized special education process can be improved to meet the needs of children with hearing loss.

The key findings of this study include the following: (a) a need for more parental assistance surrounding the first meeting due to reports that this first meeting is overwhelming, with voluminous amounts of information involved, (b) due to reports that there is a lack of information of hearing loss among special education professionals, better training and support, as well as more concern for parents, (c) the need for compassionate communication (because parents feel overwhelmed at the first meeting, and interviewees note the importance of social support in coping with stress), (d) the importance of parents serving as an advocate for their child in the struggle over the right amount and type of services, and (e) that parents reported feeling more comfortable over time as a result of becoming more familiar with what to expect (reflecting their familiarity with the business/political nature of the special education process).

Chapter 5 includes a presentation of the data analysis and interpretation of the findings, followed by the limitations, recommendations for positive social change, and implications. The chapter concludes with the summary and conclusion.

Interpretation of Findings

Because of the lack of research on perceptions of hearing parents of children with hearing loss regarding the IEP process (MacKichan & Harkins, 2013), I focused on the unique experiences of parents of children with hearing loss, particularly in relation to the special education system. As a result, this research adds to the existing special education literature the unique perspectives of parents with children having a hearing loss. The insights contribute to knowledge of the ways in which the special education process can be improved, particularly for children with hearing loss. The focus of my research was unusual in its exploration of the elementary and middle school years. Thus, this section ties my research into what is already in the research literature.

The first finding of this research is the need for more parental assistance surrounding the first IEP meeting. Past literature has established parents are flooded with a plethora of new information pertaining to hearing impairment and its effect on academic, social, and emotional development (Antia et al., 2011; Baker, 2012; Meadow-Orlans et al., 2003). Bosteels et al. (2012) conducted a study in Belgium similar to this one, using in-person interviews with hearing parents of children with hearing loss (N = 10). Bosteels et al. also found that parents reported being overwhelmed by the amount of information and instructions on how to work with their child, and the effects those experiences had on their attitudes toward professionals who were imparting the information.

Echoing previous research, half of the current interview participants reported difficulty with initial testing for hearing loss, a critical time for diagnosis to prevent developmental and speech delays. Previous researchers focused primarily on early intervention and cochlear implants (Sass-Lehrer, 2012; Young & Tattersall, 2007). Reflecting a need for professionals to better incorporate parental concerns, the current finding is supported by past research showing that when parents are involved in their children's education, the children are likely to have strong academic performance (Bogenschneider & Johnson, 2004).

The second finding is that to improve the lack of knowledge of hearing loss among special education professionals, better training and support are needed, as well as more attention on parental concerns. The literature suggests the lack of knowledge of hearing loss is common among special education professionals (Fish, 2006; Ingber & Dromi, 2010). The current findings extend existing literature regarding specific ways in which parents of children in the special education process can enhance the understanding of special education professionals in relation to their child's specific condition and needs (An & Hodge, 2013; Fish, 2006; Ingber & Dromi, 2010). Parents with children who are hearing impaired can contribute technical knowledge to teachers regarding auditory devices. An and Hodge (2013) stated, "Parents can impart much information to the professionals working with their children, [including] their children's areas of strength and weakness, behavior issues, how they learn, and what types of educational methodologies have been successful" (p.148). Previous research on parental perceptions of the special education process in terms of team collaboration has shown the limited number of available opportunities for meaningful involvement for parents of children in special education (Calderon, 2000; Christle & Yell, 2010; Zeitlin & Curcic, 2013).

The third finding suggests there is a need for more compassionate communication between educators and parents. Interviewees reported being overwhelmed at such meetings, particularly in the beginning of their involvement in the special education process. In addition, social support is reported by interview participants to be the most effective and commonly used strategy for coping with stress. Previous research has established that during and following the initial diagnosis, parents of children with hearing impairment experience a variety of emotions, including fear, shock, confusion, depression, frustration, anger, and guilt (Kurtzer-White & Luterman, 2003; Yoshinago-Itano & de Uzcategui, 2001). Parents experience these emotions on an individual basis and for varying amounts of time and intensity (Whittingham et al., 2013). Specifically mentioned was frustration when educators approach the needs of a child from their deficits rather than their strengths, echoing findings from previous research, in which these types of exchanges were associated with parents feeling uncomfortable and embarrassed (Lake & Billingsley, 2000; Ryndak et al., 2011).

Eichenstein (2014) discussed the unique emotional experiences of parents who have children with disabilities and advocated for greater attention to parents' well-being. Corroborating previous research suggesting parents can feel depersonalized during the

IEP process (Zeitlin & Curcic, 2013), the participants in this study perceived the special education process as being business-like and political. In addition to dealing with and managing their own emotions relating to their child’s needs and the special education process, parents must learn to comfort their child when necessary (Shea & Bauer, 1997). Other scholars have noted the importance of a trustful relationship between the family of the child with a disability and educational professionals in setting goals for the child (Wiart et al., 2010). Specific barriers identified in past research to effect improved collaboration between family and educators, and supported in this research, include the following: (a) poor communication, (b) technical jargon, (c) the failure to effectively incorporate parental concerns, and (d) the initial lack of familiarity with the education process for children with disabilities (Fish, 2006; Wolfe & Duran, 2013).

Reflecting the importance of social support in coping with stress, which was another finding of this research, the existing literature has linked parental resilience and positive attitudes in response to a diagnosis of deafness to strong systems of social support and other coping mechanisms (Calderon & Greenberg, 2000; Plotkin et al., 2013; Quittner et al., 2010). Previous research supports the need to provide additional social, emotional support, and informational services and resources for parents of children with hearing impairment (Jamieson et al., 2011; Luterman, 2004; Zaidman-Zait, 2008).

The fourth finding revealed the important role parents play as advocate for their child, as well as the struggle with special education professionals over the right amount and type of services, which are central to the experiences of parents of children with hearing impairment. This sentiment may also extend to parents of children with other types of disabilities. Results showed that the parental role of an advocate begins once a child is diagnosed. Previous researchers have shown the need to identify hearing impairment as early as possible to prevent developmental and speech delays (Arehart & Yoshinaga-Itano, 1999; Butler, 2012; Holte et al., 2012; Matthijs et al., 2012; Patel & Feldman, 2011). Complicating the parent's role as an advocate for their child, previous researchers have found that parents of children in special education often report feeling that their input is not valued, and that they are not equal partners in the decision making process that will affect their child's educational opportunities and outcomes (Fish, 2006; Lake & Billingsley, 2000).

The fifth finding of this research was that parents of children with hearing loss tended to feel more comfortable with the special education process over time, perhaps because of increasing familiarity with what to expect (including the business/political nature of the special education process). Although this result is not surprising, given that there is a lack of research on parents of children with hearing loss, this new finding extends the knowledge of the interactions between parents and teachers within the special education system. Future researchers could extend this knowledge by measuring more specific instances and processes to detangle specific positive and negative experiences and turning points along the special education process. It would also be useful to extend this analysis into the first year following high school graduation to expand knowledge into the early post-high school years of children with hearing loss.

Conceptual Framework

Bronfenbrenner's (1994, 2005) EST of human development brings an understanding to the important role parents play in their children’s educations and serves as the conceptual framework for this study. This framework visually consists of four levels of concentric circles, beginning with the innermost, smallest circle (the microsystem, or immediate relationships between the child and family members or the child and educational professionals). The next-smallest circle is the mesosystem, or the interaction between family and school professionals that all effect the child. The second-largest circle is the exosystem, or systems that the child does not interact with directly but still effect him or her, like the greater community, local governance, and parental place of employment. Finally, the largest circle is the macrosystem. Although the most distant influence on the child, the macrosystem can have a large effect on his or her life. Governmental actions and policy, the economy, wars, and religious and cultural values are all a part of the larger macrosystem within which the child develops. Scholars have previously noted the importance of the microsystem and mesosystem upon the child, and the strong effect the school and parents have on the child (Turnbull et al., 2011). Therefore, this research focused most closely on those systems.

Although the quality of interactions between children and their family, as well as between children and their educational providers (the mesosystem), are vital to student success and development, these efforts can be magnified if the family and school work in tandem to help the child. Several participants mentioned the importance of collaboration between parents and the special education professionals, which is a textbook example of the mesosystem. Working against educational providers who have different goals can not only be stressful for the parent; it makes the achievement of goals for the furtherance of child progress more difficult to attain. Since atypical development is associated with impaired functioning (Johnson, 1994), there must be a smooth and comfortable collaboration between parents and teachers to achieve consistency within the mesosystem.

Further, the specific needs of children with hearing impairment make this smooth collaboration more technical, with interviewees noting a lack of ability to work with auditory equipment within the education system. The exosystem corresponds to local and state-level governing policies, as well as the school district's budget. The macrosystem in the case of this research includes the application of educational policies, including the shift toward standardized testing (e.g., the No Child Left Behind Act) as well as legislation enacted to protect the educational opportunities of children with disabilities (e.g., the IDEA and the IDEIA), among other legislative influences. The adjusted conceptual framework shown in Figure 1 reflects the findings of my research.

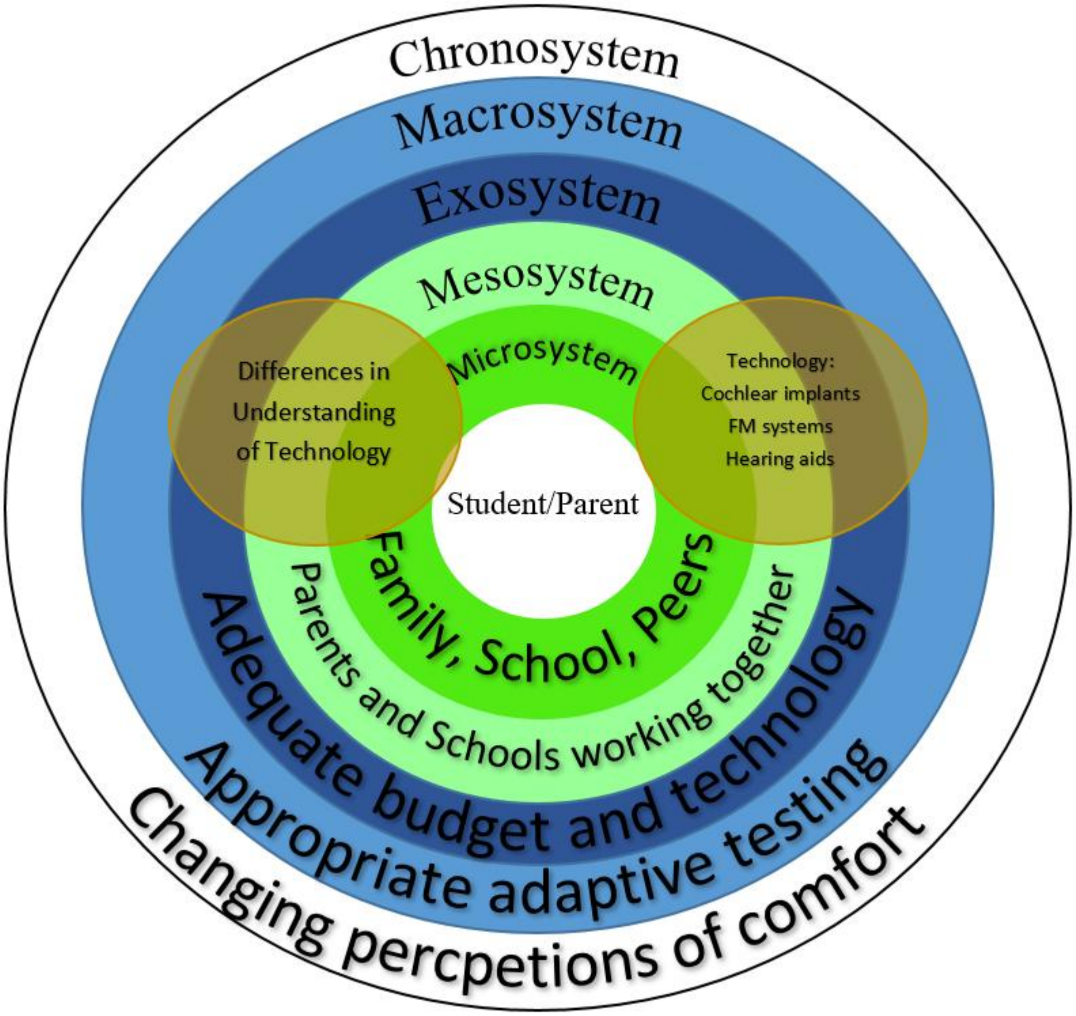

Figure 1. Adjusted conceptual framework with elements from the results of this study.

Limitations of Study

The differences among participants based upon the degree of hearing loss were not measured. The parents who participated in this study happen to be actively involved in their children's special education process. Less involved parents may experience additional barriers (for example, deaf parents or parents who are not native English speakers). Thus, their involvement might be more difficult, and they might have had different experiences and needs that those interviewed in this study. In future research on the special education experiences of parents of children with hearing loss, it would be useful to find a more diverse sample of parents, including those from a variety of cultural backgrounds and levels of socioeconomic status, reflecting different levels of involvement with their children.

Although I worked to establish positive rapport and trust with interview participants, I assumed that participants' descriptions of their experiences would be accurate. It is difficult to know if an experience was distorted during the interview, or if interviewees omitted information. Another limitation of this study was the relatively small sample size and a lack of diversity (all from Long Island, NY), although scholars have deemed eight to 12 in-depth interviews sufficient for phenomenological research seeking to explore a phenomenon in detail (Mason, 2010). To minimize my own biases as a professional participant in IEP meetings, I included audit trails, ensured accurate representation of information (e.g., quotes), and bracketed the information (Creswell, 2007).

Recommendations

Recommendations for Future Research

The present study was designed to contribute to the literature on parental perceptions of the special education process. Although challenges remain, the specific needs of children with hearing loss could be better incorporated within the education system upon reflection on parental viewpoints. Regarding contributions to research methodology and empirical implications, future researchers should encourage interview participants to bring copies of IEPs and other helpful educational documents to provide specific information and details surrounding their experience.

Previous researchers have shown that special education professionals are often unfamiliar with the needs of children with hearing loss (Berndsen & Luckner, 2012; Szymanski et al., 2013), and parents tend to be most familiar with their children's needs. Learning from the experiences of parents of children with hearing loss within the special education system could point to areas in which the improvement of education services for children with hearing impairment are needed.

Participants in this study came from a small suburban area outside of New York City, which has a higher standard of special education services and acceptance of individuals with disabilities than can be found in other countries. Adding the perspectives of normally hearing parents of children from different parts of the United States and other countries, particularly developing and poverty-stricken nations, would benefit educators attempting to improve educational practices. If this study were to take place in one of these other locations, the results could differ based on macrosystem influences (e.g., different governance, culture, religion, etc.). It would also be important to study how special education services interact with the school environment and peer social support to complement special education services.

A more diverse sample of research participants, including parents who are less involved with their children's education, could expand knowledge of the experiences of parents of children with hearing loss. This research could also be repeated for children who are blind or who have been diagnosed with a particular disability that requires assistive devices. Rather than interviewing parents, researchers could measure the perceptions of the special education professionals on children with hearing impairment

Recommendations for Action

In line with the findings of this research, the following five recommendations correspond to each research question: (a) provide more parental assistance for the first meeting; (b) improve training on the amplification options used by children with hearing impairment, and better incorporation of the concerns of parents; (c) aim for more compassionate communication and social support for the parents; (d) become familiar with the special education process increases parents' comfort; and (e) make it easier for parents to be effective advocates for their children.

The recommendations for action for this research are aimed at special education professionals and policy makers. This research corroborated previous literature in finding that special education professionals are sometimes unfamiliar with the unique needs of children with hearing impairment (Fish, 2006; Ingber & Dromi, 2010). To address the needs of hearing-impaired youth, educators should be better trained on hearing aids, FM systems, and cochlear implants, as well as how to troubleshoot them efficiently (so that the child does not miss out on learning material due to audio device malfunctioning) by a qualified professional. Schools should also have an individual available whose responsibility it is to manage technical aspects of hearing impairment, as well as parental support. Nine of the 10 interviewees in this study repeatedly mentioned the helpfulness of audiologists and teachers of the deaf, both in terms of their positive parental social support and their knowledge of unique challenges specific to children with hearing impairment.

These findings are relevant for individuals who contribute to the construction of special education policy as well. To promote society-wide and policy-level change, insights from the experiences of parents of children with hearing loss should be incorporated to provide equal opportunities for children with hearing loss. For example, a parental advocate involved in educational meetings could be included in proposed legislation to encourage parental support for children early on, which is vital to healthy child development.

This research is also useful for parents of children with hearing loss who are new to the special education system. It is comforting and valuable to learn from the experiences of those individuals who have already advanced through the special education process with their children. These findings could lead to changes in the way that special education professionals approach hearing loss, relate to parents, and advocate for advanced training on the various types of auditory equipment worn by students. This research can also lead to changes in the way parental concerns are viewed by educators, as well as the way special education professionals perceive, respond to, and approach parents who are often overwhelmed, stressed, and upset about the first IEP meeting. When parents raise their voice or get angry during a meeting, professionals could try to empathize with the parent rather than feel defensive or attacked.

In summary, the findings suggest a need for more training and technical support for parents of children with hearing impairment, more compassionate communication with parents, and strengthened sources of social support for parents. The results also indicate additional parental assistance and support surrounding the first meetings and transitions for children, as well as a buddy system for parents to partner with and mentor each other. Resources should be provided for more effective parental advocacy through not only social support groups but additional information and better incorporation of parental concerns in IEP.

Implications for Positive Social Change

The findings may contribute to positive social change by increasing the awareness of both general and special educators of the need to change current practices surrounding the IEP meeting and special education process in meeting the needs of the parents. The parents' stories have shed light on the challenges, weaknesses, and strengths of the IEP meeting and special education process, which, when shared with the professional community, may influence educators to communicate with parents in a manner that is more empathetic, less business-like, and more collaborative.

Children with hearing loss present unique educational considerations requiring specific instructional methodologies regarding their hearing loss and amplification needs. These findings clarify questions educators have regarding the importance of amplification, and the need to increase teachers' and administrators' knowledge and comfort level when working with a child with a hearing loss. There is no question that the needs of parents having a child with a hearing loss in the special education system are often overlooked due to a lack of communication between themselves and the educational professionals responsible for their child's education. When the education professionals listen to the parents and learn from their perspective, there will be an increase in their awareness to existing problems, and attempts to modify existing practices that will promote successful outcomes for the student with hearing loss.

Conclusion

The purpose of this phenomenological study was to understand, describe, and explore the perceptions of hearing parents of children with hearing impairment, between the ages of 5 and 12 years, toward the educational system and the IEP process. The main findings of this research, derived from 10 in-person interviews with the parents of children with hearing impairment, include the following:

1. More parental assistance should be provided about the initial special education meetings to encourage and enable parent involvement.
2. Special education teachers would benefit with technical training on auditory devices and troubleshooting for hearing impaired students, which would allay parental concerns regarding in-school amplification.
3. A friendly relationship should be encouraged between the parents and the special education professionals, as well as more compassionate communication.
4. Increasing parents’ familiarity with the special education process would enable them to feel more comfortable and be able to advocate effectively for their children.

Regarding the theoretical implications of this research, the findings support the concept of the mesosystem in its critical importance and strong influence on children. To lead to a most effective intervention, the school and family should work together to encourage a friendly, cohesive relationship with similar goals (Bronfenbrenner, 1979). The warm and effective collaboration of parents and teachers is vital to child development. Bronfenbrenner (1979) emphasized the importance of different influences from the microsystem (e.g., family, teachers, and neighbors) in not only their individual influence but their combination, as a vital influence on child development. This emphasis on smooth and effective collaboration between familial and educational influences is supported by the existing literature that supports the important influence of parent involvement in education. Future researchers should encourage interviewees to bring copies of IEPs and other educational documents to provide specific information and details surrounding their experience. A larger and more diverse sample would also contribute to the literature.

Bronfenbrenner's (1979) EST suggests that the family unit, the school, and the community are all a part of the microsystem/mesosystem and are influential in the child's educational outcomes. Therefore, it follows that positive collaboration and relationships between parents and education professionals (effective collaboration within the mesosystem) are vital to child progress.

Ample literature has suggested parental involvement is linked with higher educational outcomes for students (Zeitlin & Curcic, 2013). Likewise, the results of this study suggest there is a need for more training of special education professionals on hearing aids, cochlear implants, and FM systems, as well as with troubleshooting the auditory equipment for common problems. Another contribution of this research is better understanding of the change in parental perceptions of the special education process-over-time, because most previous research focused on early intervention and education. Increasing familiarity with the process-over-time, as well as the development of positive relationships with special education professionals, may contribute to interviewees' reports of feeling increasingly comfortable with the process as they gained knowledge through experience with prior meetings. This knowledge can help to guide interventions to increase collaboration between families of children with disabilities and education professionals by illuminating the unique experiences of parents of children with hearing loss. Adopting the recommendations from this research will enable a more cohesive, positive collaboration effort between parents and special education professionals to improve the mesosystem (Bronfenbrenner, 1979).

As I reflect on this dissertation journey, I am taken back to my initial college work in speech and theater, far different from education of the deaf, speech pathology, or audiology. I loved the theater, but somehow I knew that I was travelling down the wrong path. I fell in love with the beauty of sign language, which to me was an extension of my theatrical side. I changed colleges, enrolled in a program rich in the communication sciences, and became immersed in the world of education of the deaf and hearing impaired. My initial introduction into this field of study was powerful, and thus began my passion. I do wonder, however, if it began with my experiences as a teenager when I babysat for a family who had three children, the youngest of whom was diagnosed with a bilateral profound hearing loss.

As I traveled through my career, I had the opportunity to work with a diverse population of parents of children with hearing loss. When I became a parent, my senses were heightened in terms of listening to the parents as they shared their experiences with me, both positive and negative. I began to observe my colleagues as they interacted with parents when we sat in team meetings. These observations brought me to realize how powerful was the connection between parent and professional.

With each step I took through this dissertation process, I increased my understanding of the parental journey and the essence of parents' experience. Listening to the parents' words and putting them down on paper for others to read will, I hope, implore the professional community to take heed and increase their understanding of that journey.

References

American Speech-Language-Hearing Association. (2008). *Prevalence and incidence of hearing loss in children*. Retrieved from http://www.asha.org/public/ hearing/disorders/children.htm

American Speech-Language-Hearing Association. (2011a). *The audiogram.* Retrieved from http://www.asha.org/public/hearing/Audiogram/

American Speech-Language-Hearing Association. (2011b). *Type, degree, and configuration of hearing loss.* Retrieved from http://www.asha.org/uploadedFiles/AIS-Hearing-Loss-Types-Degree-Configuration.pdf

American Speech-Language-Hearing Association. (2013). *How we hear.* Retrieved from www.asha.org/public/hearing/How-We-Hear

An, J., & Hodge, S. (2013). Exploring the meaning of parental involvement in physical education for students with developmental disabilities. *Adapted Physical Activity Quarterly, 29*(2), 147–163.

Antia, S. D., Jones, P., Luckner, J., Kreimeyer, K. H., & Reed, S. (2011). Social outcomes of students who are deaf and hard of hearing in general education classrooms. *Exceptional Children, 77*(4), 489–504.

Arehart, K. H., & Yoshinaga-Itano,C. (1999). The role of educators of the deaf in the early identification of hearing loss. *American Annals of the Deaf, 144*, 19–23.

Bagdi, A., & Vacca, J. (2005). Supporting early childhood social-emotional well being: The building blocks for early learning and school success. *Early Childhood*

Education Journal, 33(3), 145–150. doi:10.1007/s10643-005-0038-y

Baker, L. M. (2012). Conquering the unknown: Exploring the options. *International Journal of Disability, Development & Education, 59*(2), 209–213. doi:10.1080/1034912X.2012.676442

Belmont Report. (1979). *The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research*. Retrieved http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html

Berndsen, M., & Luckner, J. (2012). Supporting students who are deaf or hard of hearing in general education classrooms: A Washington state case study. *Communication Disorders Quarterly, 33*(2), 111–118. doi:10.1177/1525740110384398

Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide.* Thousand Oaks, CA: Sage.

Birnbaum, S. (2013). *Helping is healing.* Retrieved from http://www.nymetroparents.com

Bogenschneider, K., & Johnson, C. (2004, February). *Family involvement in education: How important is it? What can legislators do?* Retrieved from http://www.familyimpactseminars.org/fia_brchapter_20c02.pdf

Bosteels, S., Van Hove, G., & Vandenbroeck, M. (2012). The roller-coaster of experiences: Becoming the parent of a deaf child. *Disability & Society, 27*(7), 983–996. doi:10.1080/09687599.2012.705059

Brandon, R. R., Higgins, K., Pierce, T., Tandy, R., & Sileo, N. (2010). An exploration of the alienation experienced by African American parents from their children's educational environment. *Remedial and Special Education, 31*(3), 208–222.

doi:10.1177/0741932509338350

Bronfenbrenner, U. (1974). Is early intervention effective? *Teachers College Record, 76*(2), 279–303. Retrieved from http://files.eric.ed.gov/fulltext/ED093501.pdf

Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology, 22*(6), 723. doi:10/1037/0012-1649.22.6.723

Bronfenbrenner, U. (1994). Ecological models of human development. In T. Husten & T. N. Postlethwaite (Eds.), *International encyclopedia of education* (2nd ed., Vol. 3, pp. 1643–1647). New York, NY: Elsevier Science.

Bronfenbrenner, U. (2005). *Making human beings human: Bioecological perspectives on human development*. Thousand Oaks, CA: Sage.

Butler, I. (2012). Identification and management of childhood hearing loss. *CME: Continuing Medical Education, 30*(9), 314–317.

Calderon, R. (2000). Parental involvement in deaf children's education programs as a predictor of child's language, early reading, and social-emotional development. *Journal of Deaf Studies and Deaf Education, 5*(2), 140–155. doi:10.1093/deafed/5.2.140

Calderon, R., Bargones, J., & Sidman, S. (1998). Characteristics of hearing families and their young deaf and hard of hearing children: Early intervention follow-up. *American Annals of the Deaf, 43*, 347–362. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/9842062

Calderon, R., & Greenberg, M. (2000). Challenges to parents and professionals in promoting socioemotional development in deaf children. In P. E. Spencer, C. J. Erting, & M. Marschark (Eds.), *The deaf child in the family and at school* (pp. 167-190). Mahwah, NJ: Lawrence Erlbaum.

Calderon, R., & Low, S. (1998). Early social-emotional, language, and academic development in children with hearing loss: Families with and without fathers. *American Annals of the Deaf*, *143*(3), 225–234. doi:10.1353/aad.2012.0115

Carney, A., & Moeller, M. (1998). Treatment efficacy: Hearing loss in children. *Journal of Speech, Language, and Hearing Research*, *41*(1), S61–S84. doi:10.1353/aad.2012.0115

Center for Parent Information and Resources. (2010). *Contents of the IEP.* Retrieved from http://www.parentcenterhub.org/repository/iepcontents/

Center for Parent Information and Resources. (2014). *Writing the IFSP for your child.* Retrieved from http://www.parentscenterhub.org/repository/ifsp/#what

Center for Public Education. (2009). *Special education: History of IDEA.* Retrieved from http://www.centerforpubliceducation.org

Centers for Disease Control and Prevention. (2010). *Early hearing detection & intervention (EHDI) program: EHDI basics*. Retrieved from www.cdc.gov

Christle, C. A., & Yell, M. L. (2010). Individualized education programs: Legal requirements and research findings. *Exceptionality, 18*(3), 109–123. doi:10.1080/09362835.2010.491740

Christenson, S. L. (1995). Best practices in supporting home-school collaboration. In A. Thomas, & J. Grimes (Eds.), *Best practices in school psychology-III* (pp. 253–267). Washington, DC: National Association of School Psychologists.

Christenson, S. L., & Hirsch, J. A. (1998). Facilitating partnerships and conflict resolution between families and schools. In K. C. Stoiber, & T. R. Kratochwill (Eds.), *Handbook of group intervention for children and families* (pp. 307-344). Needham Heights, MA: Allyn & Bacon.

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco, CA: Jossey-Bass.

Clark, J. G. (1981). Uses and abuses of hearing loss classification. *Asha*, *23*, 493–500. Retrieved from http://www.asha.org/public/hearing/Degree-of-Hearing-Loss /

Cochran, M. (1992). Parent empowerment: Developing a conceptual framework. *Family Science Review*, *5*(1 & 2), 3-21. doi:10.1007/s10826-010-9405-4

Comer, J., & Haynes, N. (1991). Parent involvement in schools: An ecological approach. *Elementary School Journal*, *91*(3), 271. doi:10.1086/461654

Cottrell, R.R., & McKenzie. (2011). *Health promotion & education research methods* (2nd ed.). Boston, MA: Jones & Bartlett.

Creswell, J. (2007). *Research design: Qualitative, quantitative, and mixed methods approaches: Choosing among five approaches* (2nd ed.). Los Angeles, CA: Sage.

Creswell, J. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (3rd ed.). Los Angeles, CA: Sage.

Day, L. A., & Brice, P. (2013). Development and initial validation of a questionnaire to measure hearing parents’ perceptions of health care professionals’ advice. *Journal of Deaf Studies and Deaf Education*, *18*(1), 123–137. doi:10.1093/deafed/ens041

Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of qualitative research.* Newbury Park, CA: Sage.

Dunst, C. (2000). Revisiting “Rethinking early intervention.” *Topics in Early Childhood Special Education*, *20*(2), 95–104. doi:10.1177/027112140002000205

Dunst, C. (2007). Early intervention with infants and toddlers with developmental disabilities. In S. L. Odom, R. Horner, M. Snell, & J. Blacher (Eds.), *Handbook of developmental disabilities* (pp. 531–551). New York, NY: Guilford.

Dunst, C. (2010). Parapatric speciation in the evolution of early intervention for infants and toddlers with disabilities and their families. *Topics in Early Childhood Special Education*, *31*(4), 208–215. doi:10.1177/0271121411426904

Education.com. (2009). *Individualized education program.* Retrieved from http://www.education.com/reference/article/individualized-education-program-iep1/

Eichenstein, R. (2014). *Managing your emotions after your child’s special needs diagnosis.* Available from http://www.nymetroparents.com

English, K. (2005). Get ready for the next big thing in audiologic counseling. *The Hearing Journal*, *58*(7), 10–15. doi:10.1097/01.HJ.0000286416.66547.47

English, K. (2010). *Facing hearing loss in our children: The emotional impact*. Retrieved from http://professionals.cochlearamericas.com

Epstein, J. L. (1985). Home and school connections in schools of the future: Implications of research on parent involvement. *Peabody Journal of Education*, *62*(2), 18-41. doi:10.1080/01619568509538471

Epstein, J. L. (1995). School/family/community partnerships: Caring for the children we share. *Phi Delta Kappan*, *76*(9), 701. doi:10.1177/003172171009200326

Epstein, J. (2001) Building bridges of home, school, and community: The importance of design. *Journal of Education for Students Placed at Risk, 6*(1 & 2), 161–168, doi:10.1207/S15327671ESPR0601-2_10

Evans, H. (2008). *Technological early intervention tools for families of children with hearing loss: Parental learning preferences*. Baltimore, MD: ProQuest.

Feher-Prout, T. (1996). Stress and coping in families with deaf children. *Journal of Deaf Studies and Deaf Education*, *3,* 155–166. doi:10.1093/oxfordjournals.deafed.a014291

Fish, W. (2006). Perceptions of parents of students with autism towards the IEP meeting: A case study of one family support group chapter. *Education-Indianapolis Then Chula Vista*, *127*(1), 56. Retrieved from http://home.sandiego.edu/~joi.spencer/EDUC%20500%20SPR%202007/autismarticle.pdf

Fish, W. (2008). The IEP meeting: Perceptions of parents of students who receive special education services. *Preventing School Failure*, *53*(1), 8–14. doi:10.3200/PSFL.53.1.8-14

Gallaudet Research Institute. (2011, April). *State summary report of data from the 2009-*

10 annual survey of deaf and hard of hearing children and youth. Washington, DC: GRI, Gallaudet University. Retrieved from http://research.gallaudet.edu

Gallaudet University. (2014). *Placement considerations.* Retrieved from http://www.gallaudet.edu/clerc_center/information_and_resources/info_to_go/educate_children_%283_to_21%29/placement_issues/placement_considerations.html

Garguilo, R. (2012). *Special education in contemporary society: An introduction to exceptionality.* Thousand Oaks, CA: Sage.

Gearing, E. (2004) Bracketing in research: A typology. *Qualitative Health Research, 14*(10), 1429–1452. doi:10.1177/1049732304270394

Gilliver, M., Ching, T. Y., & Sjahalam-King, J. (2013). When expectation meets experience: Parents' recollections of and experiences with a child diagnosed with hearing loss soon after birth. *International Journal of Audiology, 52*(S2), S10–S16. doi:10.3109/14992027.2013.825051

Glaser, B., & Strauss, A**.** *(1967). The discovery of grounded theory: Strategies for qualitative research.* Chicago, IL: Aldine.

Government Accountability Office. (2011). *Deaf and hard of hearing children: Federal support for developing language and literacy*. Retrieved from http://www.gao.gov/products/GAO-11-357

Gracey, K. (2003). Current concepts in universal newborn hearing screening and early hearing detection and intervention programs. *Advances in Neonatal Care, 3*(6), 308–317. doi:10.1016/j.adnc.2003.09.007

Haley, M., Hammond, H., Ingalls, L., & Marín, M. R. (2013). Parental reactions to the special education individual education program process: Looking through the lens of grief. *Improving Schools, 16*(3), 232-243. doi:10.1177/1365480213505180

Hatch, J. A. (2002). *Doing qualitative research in education settings*. Albany: State University of New York Press.

Hepworth, D., Rooney, R., Rooney, G. D., Strom-Gottfried, K., & Larsen, J. A. (2009). *Direct social work practice: Theory and skills*. Boston, MA: Cengage Learning.

Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *Journal of Deaf Studies and Deaf Education*, *11*(4), 493–513. doi:10.1093/deafeden1005

Holte, L., Walker, E., Oleson, J., Spratford, M., Moeller, M., Roush, P., . . . Tomblin, J. (2012). Factors influencing follow-up to newborn hearing screening for infants who are hard of hearing. *American Journal of Audiology*, *21*(2), 163–174. doi:10.1044/1059-0889

Hoque, Z. (2006). *Methodological issues in accounting research: Theories, methods and issues*. London, England: Spiramus Press.

Hornby, G., & Lafaele, R. (2011). Barriers to parental involvement in education: An explanatory model. *Educational Review, 63*(1), 37–52. doi:10.1080/00131911.2010.488049

Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher*, *20*(4), 12-17. doi:10.7748/nr2013.03.20.4.12.e326

Houston, K., Bradham, T. S., Munoz, K. F., & Guignard, G. (2011). Newborn hearing screening: An analysis of current practices. *Volta Review*, *111*(2), 109–120. doi:10.1590/S0034-72992009000200013

Huang, Y., Kellett, U., & St. John, W. (2010). Cerebral palsy: Experiences of mothers after learning their child's diagnosis. *Journal of Advanced Nursing*, *66*(6), 1213–1221. doi:10.1111/j.1365-2648.2010.05270.x

Husserl, E. (1970). *Logical investigations.* New York, NY: Humanities Press.

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Individuals with Disabilities Education Improvement Act, 20 U.S.C. § 1400 (2004).

Ingber, S., & Dromi, E. (2010). Actual versus desired family-centered practice in early intervention for children with hearing loss. *Journal of Deaf Studies and Deaf Education*, *15*(1), 59-71. doi:10.1093/deafed/enp025

Jackson, C. (2010). The individuals with disabilities education act and its impact on the deaf community. *Stanford Journal of Civil Rights & Civil Liberties*, *6*(2), 355–390. doi:10.14507/epaa.v22n13.2010

Jackson, C. (2011). Family supports and resources for parents of children who are deaf or hard of hearing. *American Annals of the Deaf*, *156*(4), 343–362. doi:0.1353/aad.2011.0038

Jackson, C. W., Wegner, J. R., & Turnbull, A. P. (2010). Family quality of life following early identification of deafness. *Language, Speech, and Hearing Services in Schools*, *41*(2), 194–205. doi:10.1044/0161-1461(2009/07-0093).

Jamieson, J., Zaidman-Zait, A., & Poon, B. (2011). Family support needs as perceived by parents of preadolescents and adolescents who are deaf or hard of hearing.

Deafness & Education International, *13*(3), 110–130. doi:10.1179/1557069X11Y.0000000005

Janesick, V. (2011). *Stretching exercises for qualitative researchers* (3rd ed.). Los Angeles, CA: Sage.

Johnson, G. M. (1994). An ecological framework for conceptualizing educational risk. *Urban Education*, *29*(1), 34–49. doi:10.1177/0042085994029001004

Joint Committee on Infant Hearing. (*2008). History of the Joint Committee on Infant Hearing*. Retrieved from http://www.jcih.org

Kibaara, T., & Ndirangu, L. (2014). Parental involvement in their children's academic achievement in public secondary schools: A case of Kieni-West Sub-County, Nyeri County-Kenya. *International Journal of Education and Research*, *11*(2), 411–424. Retrieved from http://www.ijern.com/journal/2014/November-2014/33.pdf

Kobosko, J. (2011). Parenting a deaf child-how hearing parents cope with the stress of having deaf children. *Journal of Hearing Science*, *1*(3). Retrieved from http:// http://www.journalofhearingscience.com/download/index/idArt/882157

Koch, T. (2006), Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing, 53,* 91–100. doi:10.1111/j.1365-2648.2006.03681.x

Kurtzer-White, E., & Luterman, D. (2003). Families and children with hearing loss: Grief and coping. *Mental Retardation and Developmental Disabilities Research Reviews, 9,* 232–235. doi:10.1002/mrdd.10085

Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*.

Thousand Oaks, CA: Sage.

Lake, J., & Billingsley, B. (2000). An analysis of factors that contribute to parent–school conflict in special education. *Remedial and Special Education*, *21*(4), 240–251. doi:10.1177/074193250002100407

LaRocque, M., Kleiman, I., & Darling, S. M. (2011). Parental involvement: The missing link in school achievement. *Preventing School Failure, 55*(3), 115–122. doi:10.1080/10459880903472876

Lawson, G., Sanders-Lawson, E., & McNeal, L. (2012). Understanding parental involvement in American public education. *International Journal of Humanities and Social Science*, *2*(19), 1–10. Retrieved from http://www.ijhssnet.com

Left, N. C. (2002). Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled. *Public Law*, *107*(110), 107. Retrieved from https://bulk.resource.org/gpo.gov/laws/107/publ110.107.pdf

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

Lowes, L., & Hulatt, I. (2006). *Involving service users in health and social care research.* New York, NY: Taylor & Francis.

Luckner, J. L. (n.d.). *Issues in education of students who are deaf or hard of hearing*. Retrieved from http://www.unco.edu/cebs/sped/faculty/luckner.html

Luterman, D. (2004). Counseling families of children with hearing loss and special needs. *The Volta Review, 104*(4), 215–220. Retrieved from http://www.agbell.org/TheVoltaReview/

Luterman, D. (2006). *Children with hearing loss: A family guide: Practical counseling* *for today's parents of children with hearing loss*. Sedona, AZ: Auricle.

Luterman, D. (2009). *Counseling persons with communication disorders and their families*. Austin, TX: ProEd.

MacKichan, M., & Harkins, M. (2013). Inclusive education: Perceptions of parents of children with special needs of the individual program planning process. *Electronic Journal for Inclusive Education*, *1*(3), 1–28. Retrieved from http://corescholar.libraries.wright.edu/ejie/vol3/iss1/7

Madell, J., & Flexer, C. (2008). *Pediatric audiology: Diagnosis, technology, and management*. New York, NY: Thieme.

Mapp, I. (2004). *Essential readings on stress and coping among parents of deaf and hearing-impaired children*. New York, NY: Gordian Knot.

Markula, P., & Silk, M. (2011). *Qualitative research for physical culture*. Palgrave, England: Macmillan.

Marschark, M., Young, A., & Lukomski, J., (2002). Perspectives on inclusion. *Journal of Deaf Studies and Education*, *7*(3), 187–188. Retrieved from http://jdsde.oxfordjournals.org/content/7/3/187.full.pdf

Marshall, C., & Rossman, G. (2011). *Designing qualitative research* (5th ed.). Thousand Oaks, CA: Sage.

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *11*(3). Retrieved from http://www.qualitativeresearch.net

Matthijs, L., Loots, G., Mouvet, K., Van Herreweghe, M., Hardonk, S., Van Hove, G.,

. . . Leigh, G. (2012). First information parents receive after UNHS detection of their baby's hearing loss. *Journal of Deaf Studies and Deaf Education*, *17*(4), 387–401. doi:10.1093/deafed/ens020

McGrath, A. P., Vohr, B., & O'Neil, C. A. (2010). Newborn hearing assessment in 2010. *Medicine & Health Rhode Island*, *93*(5), 142–144. Retrieved from http://www.rimed.org/rimedicaljournal-archives.asp

McLeskey, J., Landers, E., Williamson, P., & Hoppey, D. (2012). Are we moving toward educating students with disabilities in less restrictive settings? *The Journal of Special Education*, *46*(3), 131–140. doi:10.1177/0022466910376670

Meadow-Orlans, K. P. & Mertens, D. M. & Sass-Lehrer, M. A. (2003). *Parents and their deaf children: The early years.* Washington, DC: Gallaudet University Press.

Meinzen-Derr, J., Lim, L. H., Choo, D. I., Buyniski, S., & Wiley, S. (2008). Pediatric hearing impairment caregiver experience: impact of duration of hearing loss on parental stress. *International Journal of Pediatric Otorhinolaryngology*, *72*(11), 1693-1703. doi:10.1016/j.ijporl.2008.08.005

Miles, M., & Huberman, A. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.

Moeller, M. P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics*, *106*(3), e43. doi:10.1542/peds.106.3.e43)

Moeller, M., P., Carr, G., Seaver, L., Stredler-Brown, & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and*

Deaf Education, *18(4),* 429–446. doi:10.1093/deafed/ent034

Moores, D. (2012). *The history of language and communication issues in deaf education*. Retrieved from http://www.oxfordhandbooks.com

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, *1*(2), 13–22. doi: 10.1177/160940690200100202

Moses, K. (1987, Spring). *The impact of childhood disability: The parent's struggle.* Retrieved from http://www.faculty.sfasu.edu/munromicha/munro515/moses_art.pdf

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: Sage.

Mueller, T. G., Singer, G. S., & Draper, L. M. (2008). Reducing parental dissatisfaction with special education in two school districts: Implementing conflict prevention and alternative dispute resolution. *Journal of Educational & Psychological Consultation*, *18*(3), 191-233. doi:10.1080/10474410701864339

Muse, C., Harrison, J., Yoshinaga-Itano, C., Grimes, A., Brookhouser, P. E., Epstein, S.,.. . Martin, B. (2013). Supplement to the JCIH 2007 position statement: Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Pediatrics*, *131*(4), e1324–e1349. doi:10.1542/peds.2013-0008

National Association of the Deaf. (2014). *Bill of rights for deaf and hard of hearing children.* Retrieved from http://nad.org/issues/education/k-12/bill-of-rights

National Center for Hearing Assessment and Management. (2012). *Newborn hearing* *screening*. Retrieved from http://www.infanthearing.org/screening/

National Institute of Health Development Program. (1993). Early identification of hearing impairment in infants and young children. *National Institutes of Health Consensus Development Conference Statement*, *1*(11), 1–24. Retrieved from http://consensus.nih.gov/1993/1993HearingInfantsChildren092html.htm

National Resource Center on ADHD: A Program of CHADD. (2015*). Educational issues: Educational rights*. Retrieved from http://www.help4adhd.org/en/education/rights

Nelson, L., Bradham, T., & Houston, K. (2011). The EHDI an early intervention connection. *The Volta Review 111*(2), 133–149. Retrieved from http:// http://eric.ed.gov/?id=EJ966470

Northern, J., & Downs, M. (2014). *Hearing in children* (6th ed.). San Diego, CA: Plural.

NYSED.gov. (2014). *Special education: Individuals with disabilities education improvement act 2004*. Retrieved from http://www.p12.nysed.gov/specialed/idea

Owen, A. (2010). Leaving behind a good idea: How No Child Left Behind fails to incorporate the individualized spirit of the IDEA. *The George Washington Law Review*, *78*(2), 405–437. Retrieved from http://heinonline.org/HOL/LandingPage?handle=hein.journals/gwlr78&div=18&id=&page=

Patel, H., & Feldman, M. (2011). Universal newborn hearing screening. *Pediatrics & Child Health*, *16*(5), 301. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3114997/

Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Plotkin, R, Brice, P., & Reesman, J. (2013). It is not just stress: Parent personality in raising a deaf child. *Journal of Deaf Studies and Deaf Education*, *19*(3), 347-357. doi:10.1093/deafed/ent057

Polit, D. F., & Beck, C. T. (2008). *Nursing research: Generating and assessing evidence for nursing practice*. Philadelphia, PA: Lippincott Williams & Wilkins.

Polit, D. F., & Beck, C. T. (2012). *Essentials of nursing research: Appraising evidence for nursing practice.* Philadelphia, PA: Wolters Kluwer Health/Lippincott, Williams, & Wilkerson.

Pomerantz, E., Moorman, E., & Cheung, C. (2012). Individual differences and cultural and contextual factors. In K. Harris, S. Graham, T. Urdan, S. Graham, J. Royer, & M. Zeidner (Eds.), *APA Educational Psychology Handbook*, *2*, 417–440. doi:10.1093/deafed/ent057

Quittner, A., Barker, D., Cruz, I., Snell, C., Grimley, M., & Botteri, M. (2010). Parenting stress among parents of deaf and hearing children: Association with language delays and behavior problems. *Parenting*, *10*, 136–155. doi:10.1037/0022-3514.59.6.1266

Rehm, R. S., Fisher, L. T., Fuentes-Afflick, E., & Chesla, C. A. (2013). Parental advocacy styles for special education students during the transition to adulthood. *Qualitative Health Research, 23* (10), 1377-87. doi:10.1177/1049732313505915

Reiman, J. W., Beck, L., Coppola, T., & Engiles, A. (2010). *Parents' experiences with* *the IEP process: Considerations for improving practice.* Retrieved from http://files.eric.ed.gov/fulltext/ED512611.pdf

Rice, G., & Lenihan, S. (2005). Early intervention in auditory/oral deaf education: Parent and professional perspectives. *Volta Review*, *105*(1), 73–96. Retrieved from ERIC database.

Ross, D.S., Gaffney, M., Green, D., Holstrum, W.J. (2008): Prevalence and effects. *Seminars in Hearing*, *29*(2), 141-148. doi:10.1177/1084713807306241

Rous, B., Hallam, R., Harbin, G., McCormick, K., & Jung, L. A. (2007). The transition process for young children with disabilities: A conceptual framework. *Infants & Young Children*, *20*(2), 135–148. doi:10.1016/j.ecresq.2010.11.00110.1016/j.ecresq.2010.11.001

Ryndak, D. L., Orlando, A. M., Storch, J. F., Denney, M. K., & Huffman, J. (2011). A mother’s perceptions of her ongoing advocacy efforts for her son with significant disabilities: Her twelve-year journey. *International Journal of Whole Schooling*, *7*(2), 74–91. Retrieved from http://files.eric.ed.gov/fulltext/EJ961502.pdf

Sass-Lehrer, M. (2012). Early intervention for children birth to 3: Families, communities, and communication. *A Resource Guide for Early Hearing Detection and Intervention*, *9*(1). Retrieved from http://www.infanthearing.org

Seaver, L. (2014). *Deaf is different: Educational impacts and cultural perspectives.* Retrieved from http://www.handsandvoices.org/ articles/education/law/different.html

Seaver, L., & DesGeorges, J. (2004). Special education law: A new IDEA for students who are deaf and hard of hearing. In R. Roesser & M. Downs (Eds), *Auditory disorders in children* (4th ed., pp. 9-24). New York, NY: Thieme Medical.

Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences* (3rd ed.). New York, NY: Teachers College.

Shea, T. M., & Bauer, A. M. (1997). *An introduction to special education: A social systems perspective* (2nd ed.). Madison, WI: Brown and Benchmark.

Shelden, D. L., Angell, M. E., Stoner, J. B., & Roseland, B. D. (2010). School principals' influence on trust: Perspectives of mothers of children with disabilities. *Journal of Educational Research, 103*(3), 159–170. doi:10.1080/00220670903382921

Shemesh, R. (2013). Hearing impairment: Definitions, assessment and management. In J. H. Stone, & M. Blouin (Eds.), *International encyclopedia of rehabilitation*. Retrieved from http://cirrie.buffalo.edu/encyclopedia/en/article/272/

Spann, S. J., Kohler, F. W., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism & Other Developmental Disabilities, 18*(4), 228–237. doi:10.1177/10883576030180040401

Special Education News. (30 March, 2015). *FAPE: Free appropriate public education.* Retrieved from http://www.specialednews.com/special-education-dictionary/fape---free-appropriate-public-education.htm

Staples, K., & Diliberto, A. (2010). Guidelines for successful parent involvement: Working with parents of students with disabilities. *TEACHING Exceptional Children*, *42*(6), 58–63. doi:10.1177/004005991004200607

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.

Szymanski, C., Lutz, L., Shahan, C., & Gala, N. (2013). *Critical needs of students who are deaf or hard of hearing: A public input summary.* Retrieved from http://files.eric.ed.gov/fulltext/ED543356.pdf

Taormina-Weiss, W. (2012). *Children who are deaf and hard of hearing: IDEA and section 504.* Retrieved from http://www.disabled-world.com/disability/education/section-504.php

Tobin, G., & Begley, C. (2004), Methodological rigour within a qualitative framework. *Journal of Advanced Nursing, 48,* 388–396. doi:10.1111/j.13652648.2004.03207.x

Trussel, R. P., Hammond, H., & Ingalls, L. (2008). Ethical practices and parental in rural special education. *Rural Special Education Quarterly*, *27*(1/2), 19. doi:10.117/1053451209338396

Turnbull, A., & Turnbull, R. (1990). *Families, professionals, and exceptionality: A special partnership* (2nd ed.). Columbus, OH: Merrill.

Turnbull, A., Turnbull, R. Erwin, E., Soodak, L., & Shogren, K. A. (2011). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust*. Upper Saddle River, NJ: Pearson.

United States Department of Education. (2005). *Deaf students education services guidance report*. Retrieved from http://www2.ed.gov/about/offices/list/ocr/docs/hq9806.html

United States Department of Education. (2006). *Individualized education program.* Retrieved from http://www2.ed.gov/policy/speced/guid/idea/modelform-iep.pdf

United States Department of Education. (2014). *Topic: Individualized education program (IDEA)*. Retrieved from http://idea.ed.gov/explore/view/p/,root,dynamic,TopicalBrief,10

Villeneuve, M., Chatenoud, C., Hutchinson, N. L., Minnes, P., Perry, A., Dionne, C., & . . . Weiss, J. (2013). The experience of parents as their children with developmental disabilities transition from early intervention to kindergarten. *Canadian Journal of Education, 36*(1), 4–43. http://dx.doi.org/10.3109/09638288.2014.996674

Walker, J. T., Wilkins, A. S., Dallaire, J. R., Sandler, H. M., & Hoover-Dempsey, K. V. (2005). Parental involvement: Model revision through scale development. *Elementary School Journal*, *106*(2), 85–104. doi:10.1080/03004279.2015.1059870.

Weber, M. C. (2010). *A new look at section 504 and the ADA in special education cases.* Retrieved from https://apps.americanbar.org/litigation/committees/childrights/content/articles/summer2011-section-504-ada-idea.html

White, K., Forsman, I., Eichwlad, J., & Munoz, K. (2010). The evolution of early hearing detection and intervention programs in the United States. *Seminars in Perinatology, 3*(2), 170-179. doi:10/1033/j.semperi.2009.12.009

Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013). Predictors of psychological adjustment, experienced parenting burden and chronic sorrow symptoms in parents of children with cerebral palsy. *Child: Care, Health and Development*, *39*(3), 366-373. doi:10.1111/j.1365-2214.2012.01396.x

Wiart, L., Ray, L., Darrah, J., & Magill-Evans, J. (2010). Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. *Disability & Rehabilitation*, *32*(3), 248-258. doi:10.3109/09638280903095890

Wolfe, K., & Durán, L. (2013). Culturally and linguistically diverse parents’ perceptions of the IEP process. *Multiple Voices for Ethnically Diverse Exceptional Learners*, *13*(2), 4–18. doi:10.1177/1540796914544548

Wright, P. W. D., & Wright, P. D. W. (2010). *Wrightslaw: Special education law.* Hartfield, VA: Harbor House Law Press.

Wrightslaw. (2010). *IDEA 2004: IEP team members & IEP team attendance.* Retrieved from http://www.wrightslaw.com/idea/art/iep.team.members.htm

Xu, Y., & Filler, J. (2008). Facilitating family involvement and support for inclusive education. *The School Community Journal*, *18*(2), 53–71. Retrieved from http://www.adi.org/journal/fw08/xufillerfall2008.pdf

Yell, M. L. (2006). *The law and special education*. Upper Saddle River, NJ: Merrill.

Yell, M. L., Ryan, J. B., Rozalski, M. E., & Katsiyannis, A. (2009). The U.S. Supreme Court and special education: 2005 to 2007. *Teaching Exceptional Children*, *41*(3), 68–75. Retrieved from https://www.researchgate.net/publication/28799808_The_US_Supreme_Court_and_Special_Education_2005_to_2007

Yin, R. K. (2009). *Case study research: Design and methods* (4th ed.). Thousand Oaks, CA: Sage.

Yoshinago-Itano, C. (2000). Successful outcomes for deaf and hard of hearing children. *Seminar in Hearing, 21*(4), 309–326. doi:10.1055/s-2000-13462

Yoshinago-Itano, C., & de Uzcategui, A. (2001). Early identification and social-emotional factors of children with hearing loss and children screened for hearing loss. In E. Kurtzer-White, & D. Luterman (Eds.), *Early Childhood Deafness* (pp. 13-28). Timonium, MD: York.

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

Zaidman-Zait, A. (2008). Everyday problems and stress faced by parents of children with cochlear implants. *Rehabilitation Psychology, 53*(2), 139-152. doi:10.1037/0090-5550.53.2.139

Zeitlin, V., & Curcic, S. (2013). Parental voices on individualized education programs: "Oh, IEP meeting tomorrow? Rum tonight!" *Disability and Society, 29*(3), 373–387. doi:10.1080/09687599.2013.776493

Appendix A: Informed Consent

Informed Consent

You are invited to take part in a research study of *Hearing Parents of Children With Hearing Loss: Perceptions of the IEP Process.*

- I am inviting normally hearing mothers and fathers of children diagnosed with hearing loss to be in the study.
- Your child must be between the ages of 5 and 12, who attends one of the schools located within the two counties on Long Island.
- Your child must be receiving special-education services because he or she has been identified as having hearing loss only, classified as hearing impaired or deaf as indicated on their IEP.
- If two parents are responding, each individual should sign a consent form; as each participant will be interviewed individually.
- This form is part of a process called *informed consent*, which allows you to understand this study before deciding whether to take part.
- A researcher named Robin Stegman, a doctoral student at Walden University, is conducting this study.

Background Information

The purpose of this study is to give mothers and fathers of children diagnosed with hearing loss a chance to share their everyday experiences. Another purpose of the study is to give fathers and mothers the opportunity to inform educators of their experiences, which will enable educators to gain further insight into the perspective of parents of children with hearing loss.

Procedures

If you agree to be in this study, you will be asked to:

- Fill out an initial form that asks for identifying information, such as age of your child, type of hearing loss, degree of hearing loss, hearing aid or cochlear implant user or both, and age of initial diagnosis.
- Partake in one to three audio recorded open-ended interviews in a naturalistic setting of your choice. Each interview will last for 45 minutes. Thus, the minimum time commitment requested of each participant for the interview process is 45 minutes and the maximum 2 hours and 15 minutes.
- Meet to go over data collected in a naturalistic setting of your choice for a length of time that is suitable for you. Or you may choose to review the data collected and respond by

e-mail or phone.

Voluntary Nature of the Study

This study is voluntary. Everyone will respect your decision as to whether or not you choose to be in the study. No one at _____________ will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time. You may skip any step or question that you do not desire to address.

Risks of Being in the Study

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as fatigue, stress, or becoming upset. Being in this study will not cause physical harm.

Payment

Participants will receive no payment, thank you gifts, or reimbursements for their participation in this study.

Privacy

Any information you provide will be kept confidential. I will not use your personal information for any purposes outside of this research project. Also, I will not include your name or anything else that could identify you in the study reports. Data will be kept secure in a locked box in an undisclosed location, known only to me. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via telephone at 516-286-4211 or via e-mail at Robin.stegman@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-612-312-1210. Walden University's approval number for this study is __________ and it expires on _____________.

Statement of Consent

I have read the above information, and I feel I understand the study well enough to make a decision about my involvement. By signing below I understand that I am agreeing to the terms described above. **The researcher will give you a copy of the signed form to keep.**

Please be advised that:

- A self-addressed stamped envelope has been enclosed so you can return the signed consent form and completed survey to me.

Printed Name of Participant _________________Date of Consent__________
Participant's Signature____

Researcher's Signature____

Appendix B: Initial Data Form

First Name________________________________ **First initial of last name**____
Participant #_____ (researcher's use only)
Pseudonym assigned: _________________________________(researcher's use only)

PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOURSELF

My parenting status is:

Mother _____ Father _____

Total number of children you parent _____

Total number of children you parent who have been identified as having a hearing loss _____

MY CONTACT INFORMATION IS:

Phone: (cell) _____________________ **(home)** ___________________

E-mail ___________________________________

Home address ____

____

PLEASE ANSWER THE FOLLOWING QUESTION ABOUT YOUR CHILD WHO HAS HEARING LOSS

Date of birth: ________________

Age of initial diagnosis of hearing loss: ___________

My child was identified with hearing loss before leaving the hospital through a newborn hearing screening program: Yes _____ No _____

Present age: _________________

Sex: Male_____ Female _____

My child's hearing loss is in:

One Ear _____ Both Ears _____

What is the degree of your child's hearing loss?

Mild (26-40dB) _____

Moderate (41-55dB) _____

Moderately severe (56-70dB) _____

Severe (71-90dB) _____

Profound (91+db) _____

My child wears:

One hearing aid ____

Two hearing aids ____

One cochlear implant ____

Two cochlear implants ____

One cochlear implant and one hearing aid ____

Bone conduction hearing aid ____

My child does not wear any amplification ____

Appendix C: Interview Question Guide

Research Questions	**Interview Questions**
RQ 1 1. How do hearing parents of children between the ages of 5 and 12 with hearing loss only describe their experiences with the educational system?	IQ 1 (**Warm-up**) At what age did your child enter the educational system? a. What was your child's initial special-education diagnosis (classification)? IQ 2 Have you received information that assisted you in making educationally based decisions for your child, and if so, what type of information did you receive? IQ 3 Tell me what, if anything, your educational team could have done differently to provide you with the assistance you needed.

RQ 2 1. How do hearing parents of children between the ages of 5 and 12 with hearing loss only perceive their experiences with the special-education process as their child proceeds through the education system?	IQ 1 1. If you are willing to tell me, would you please describe the contents of your child’s IEP? I especially would like to know what you think of the IEP process. **(Probes)** a. What is your child’s current special education classification? b. How do you feel about the IEP? c. How have your feelings toward the process changed over time? d. How many IEP conferences have you attended, either in person or by phone? e. How do you perceive the nature of your parental involvement at an IEP conference? IQ 2 If you could change anything about the IEP process, what would you change?

	IQ 3 What is the focus of your child’s present educational program? a) How does the school’s focus align with your vision of what you want for your child educationally? b) How are your child’s audiological needs represented on the IEP?
	IQ 4 As you contemplate your child’s IEP meeting for the upcoming school year, what changes, if any, do you foresee? If any, can you tell me what they are?
	IQ 5 Please describe what parental involvement in the IEP process means to you.
	IQ 6 Please describe what parent–teacher collaboration means to you.
RQ 3 What patterns of coping do hearing	IQ 7

parents of children between the ages of 5 and12 with hearing loss only identify as most helpful in managing the stress related to their experiences with the educational system?	If anything, what would discourage you from participating in an IEP meeting? IQ 8 Please share a personal experience when you tried to improve collaboration with professionals during the IEP process.
RQ 4 What do hearing parents of children with hearing loss only want professionals in the special-education system to know?	IQ 1 Which parts of the IEP process were more stressful than others? IQ 2 What kinds of coping skills, if any, helped you manage your stress during those times?

	IQ 1 If you could sit down with the professionals in the special-education system and tell them anything you wanted about your experiences as a parent of a child in the special-education system, what would you tell them? IQ2 Can you tell me what you would change, if anything, about your interactions with the professionals you came in contact with?

Appendix D: Member Checking E-mail

Date
Dear XXXXXXX,

Thank you for meeting with me in an extended interview and for sharing your experiences as a parent of a child who has hearing loss. I appreciate your willingness to share your unique and personal thoughts, feelings, events, and situations. I have attached a transcript of your interview. Would you please review the entire document? Be sure to ask yourself if this interview has captured your experience of having a child identified with having hearing loss. After reviewing the transcript of the interview, if you feel that your answers did not reflect what you really wanted to convey, please feel free to alter your comments in the left column of the transcript to better reflect your meaning and experience(s). If you prefer, we can arrange to meet again and record your additions or corrections or speak on the telephone. Please do not edit for grammatical corrections. The way you told your story is what is critical.

When you have reviewed the verbatim transcript and have had an opportunity to make changes and additions, please e-mail the corrected transcript back to me at robin.stegman@waldenu.edu. If I do not hear from you after 7 days, I will assume you are satisfied with the transcript. I have greatly valued your participation in this research study and your willingness to share your experiences. If you have questions or concerns, do not hesitate to contact me by e-mail or phone at robin.stegman@waldenu.edu or 516-286-4211. I hope your experience contributing to this study was a pleasant one.

With warm regards,
Robin Stegman

Appendix E: Initial Codes Anticipated from Qualitative Analysis

Number	Initial Code	Abbreviation
1	Common areas	CA
2	Coping skills	CS
3	Emotional response/reactions	ER
4	Successful collaboration	SuC
5	Negative interactions	NegI
6	Educator strengths	EdS
7	Educator weaknesses	EdW
8	Emotional support	ESup
19	Mother stressors	MSt
10	Father stressors	FSt
11	Significant events	SigE
12	Father’s experience	FE
13	Mother’s experiences	ME
14	Professionals suggestions	ProSug

Appendix F: Codes Used to Code Data

Number	Initial Code	Abbreviation
1	Access to information	AC
2	Coping with Stress	CWS
3	Emotional response/reactions	ER
4	Collaboration/Communication	CC
5	Information	INF
6	Information overload	IO
7	Lack of information	LOI
8	Satisfaction	SAT
9	Lack of Knowledge	LOK
10	Advocate	ADV
11	Needs	ND
12	Parental Concerns	PC
13	Parent of Child with Hearing Loss	PCHL
14	Upset	U
15	Fear	F
16	Confused	CON
17	Business-like nature	BN
18	Struggle	STR
19	Comfortable	COMF
20	Social Support	SS

Appendix G: Audit Trail

Hearing Parents of Children with Hearing Loss: Perceptions of the IEP Process

The audit trail outlines the steps I have taken to collect and analyze data for this phenomenological research study.

Collection of Data

Participants

A. Immediately after Walden IRB approval was received (9/3/15) the individuals who agreed to disseminate the recruitment packets to prospective participants were contacted.

B. Individuals came to my home to pick up recruitment packets on 9/4/15. I reiterated that their sole responsibility was to disseminate research packets.

C. I received either emails, phone calls, or the signed consent and initial data questionnaire forms from 13 individuals who were interested in participating in this study. As discussed in my proposal, if the participants met the criteria for the study they would be considered on a first come first served basis. Collection of the signed informed consent and initial data questionnaire was completed by 9/29/15. 10 individuals met the criteria for participation in the study.

D. The 10 participants were contacted the week of 10/1/15 to set up interview times.

E. Interviews were completed by 10/25/15.

F. The participants' transcripts were emailed to them for their approval or changes as needed. The revised transcripts were sent back to the participants for their final approval.

G. Interviewees approved their transcriptions by 11/4/15.

H. Data analysis commenced immediately after the transcriptions were completed.

The following is a list of participants and the date they completed their interviews:

Participant	Completion of Interview
Parent 1	10/03/2015
Parent 2	10/04/2015
Parent 3	10/11/2015
Parent 4	10/11/2015
Parent 5	10/12/2015
Parent 6	10/18/2015
Parent 7	10/18/2015
Parent 8	10/24/2015
Parent 9	10/24/2015
Parent 10	10/25/2015

Appendix H: Epoche Journal

According to Moustakas (1994), “In the Epoche, the everyday understandings, judgements, and knowings are set aside, and the phenomena are revisited, visually, naively, in a wide-open sense, from the vantage point of a pure or transcendental ego” (p.33). In practicing the point of view of epoche, the researcher must separate the participant’s information gleaned from the interview process from their own judgments and personal biases. This is essential, said Moustakas, “in order to allow things, people, and events to be seen as if for the first time” (p.85).

My responsibility as the researcher was to identify situations that could color my perceptions and/or understanding of the participants’ experience and findings of my research study. I entered the study with 35 years of professional experience with children having varying degrees of hearing loss and the following beliefs based on those experiences.

- I found many professionals in attendance at IEP meetings with poor interpersonal communication skills which were displeasing to me.
- Many IEP meeting members did not treat the parents with the respect they deserved.
- More often than not, IEP team members had a lack of knowledge about hearing loss and instrumentation.

My past experiences and judgment formation had the potential to interfere with my ability to suspend judgment and empathize with the parents. As a practicing professional, I tended to side on the favor of parents due to the impersonal and sometimes condescending nature of IEP team members. As such, epoche was an ongoing practice so as to “identify the data in pure form, uncontaminated by extraneous intrusions” (Patton, 2002, p. 485). Excerpts have been taken from my journal to illustrate the process.

10/3/15 My first interview is complete. I had to remember that each participant is an individual with individual needs, and individual responses. While I expected my questions to evoke lots of words, when they didn’t come, I tried to frame my follow-ups to elicit more of a response. I remained cognizant to the fact that I should not pressure or seek more than the participant was willing to give…and to just move on. I reminded myself that follow-up interviews were an available option if I did not get ample information. All in all I felt this went well. I did not have an urge to contribute with my own verbal noise. I found that I had to listen intently, and there really was no room or place for my stuff.

10/3/15 OK the transcribing experience…ugh. Did not have a good time initially, until I really worked out the process. I didn’t want the process to overtake my remembering the interview, the interviewee, and the events that occurred. Didn’t think it would take so long to do.

10/11/15 Today’s interview posed a nice challenge for me. My interviewee asked me if I knew (TOD name) and if I ever worked with her. I was taken back a step and did answer that I knew of her. I didn’t think there was any harm in that, and honesty seemed to be the best policy. I did softly head her back into the direction of the interview with a follow up that kept us on track, and kept my thoughts or words out of the conversation. I also had to maintain neutrality, especially my facial expressions, as she imparted a story that left a bad taste in my mouth…kind of a personal pet peeve of mine too! I did remain quite aware of her emotions as she told the story, and knew I had to keep mine at bay. This was a good test for me as an interviewer doing research. I reflected on some of the exercises I had to do for my qualitative research class, and kept all of those rules of interviewing in the front of my mind.