

12-14-2015

## A Phenomenological Study of the Experiences of Parents of a Child or Children Diagnosed with Deafness

David Patrick Leach  
*University of South Carolina - Columbia*

Follow this and additional works at: <https://scholarcommons.sc.edu/etd>



Part of the [Education Commons](#)

---

### Recommended Citation

Leach, D. P.(2015). *A Phenomenological Study of the Experiences of Parents of a Child or Children Diagnosed with Deafness*. (Doctoral dissertation). Retrieved from <https://scholarcommons.sc.edu/etd/3264>

This Open Access Dissertation is brought to you by Scholar Commons. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of Scholar Commons. For more information, please contact [digres@mailbox.sc.edu](mailto:digres@mailbox.sc.edu).

A PHENOMENOLOGICAL STUDY OF THE EXPERIENCES OF PARENTS  
OF A CHILD OR CHILDREN DIAGNOSED WITH DEAFNESS

by

David Patrick Leach

Bachelor of Arts  
University of South Carolina, 1997

Master of Rehabilitation Counseling  
University of South Carolina, 2008

---

Submitted in Partial Fulfillment of the Requirements

For the Degree of Doctor of Philosophy in

Counselor Education

College of Education

University of South Carolina

2015

Accepted by:

Joshua Gold, Major Professor

Moody Crews, Committee Member

Kerry Lachance, Committee Member

Michael Walsh, Committee Member

Lacy Ford, Senior Vice Provost and Dean of Graduate Studies

© Copyright by David Patrick Leach, 2015  
All Rights Reserved.

## DEDICATION

This work is dedicated to the memory of Dr. Jerome Hanley.

## ACKNOWLEDGEMENTS

To God: Thank you for blessing me and allowing me to complete this research project. To Courtney, Bubs, and Bean: All of my love. You are my heart and my light. To Mom and Dad: Thank you for being and there and loving and supporting me since the beginning. To Dr. Gold: Thank you for your support and guidance these last four years. I have learned so much from our time together. To my Committee; Dr. Crews, Cr. Lachance, and Dr. Walsh: Thank you for investing in me and being a part of this journey. To Beginnings SC: Thank you for the opportunity to work with you and connect with your clients. Finally, to the families who participated in the interviews: Thank you for the chance to enter your lives and share your stories.

## ABSTRACT

This qualitative study examined the lived experiences of twelve parents who have a child or children diagnosed with deafness, and the meaning these parents have made of their experiences. The researcher conducted individual, semi-structured interviews and analyzed the data in accordance with the practices of phenomenological research. Thirty-seven themes were identified in the interview data, which were discussed in terms of their implications for efficacious clinical services to this population, as well as for the field of counselor education.

## TABLE OF CONTENTS

DEDICATION .....	iii
ACKNOWLEDGEMENTS.....	iv
ABSTRACT .....	v
LIST OF TABLES .....	vii
CHAPTER 1: INTRODUCTION.....	1
CHAPTER 2: REVIEW OF LITERATURE.....	15
CHAPTER 3: METHODS.....	41
CHAPTER 4: RESULTS.....	57
CHAPTER 5: DISCUSSION.....	121
REFERENCES .....	142
APPENDIX A – DEMOGRAPHIC INFORMATION FORM.....	148
APPENDIX B – INVITATION LETTER .....	149
APPENDIX C – PRE-INTERVIEW SCRIPT.....	151
APPENDIX D – INTERVIEW QUESTIONS .....	152

## LIST OF TABLES

Table 4.1 - Parents' Lived Experiences (Cognitive) .....	117
Table 4.2 - Parents' Lived Experiences (Behavioral) .....	118
Table 4.3 - Parents' Lived Experiences (Affective) .....	119
Table 4.4 - Parents' Meaning Making .....	120



# CHAPTER 1

## INTRODUCTION

The purpose of this study is to gain a deeper understanding of the lived experiences and meaning making of parents who have a child or children diagnosed with deafness.

Deafness affects individuals in the way they acquire language and communicate (Leybaert & D'Hondt, 2003). Additionally, deafness may affect an individual's cognitive and social development (Decker, Vallotton, & Johnson, 2012). Parents of children diagnosed with deafness may experience a sense of grief, loss, and anger as they learn of their child's diagnosis, begin the process of making decisions related to their child's ongoing treatment and therapy, and begin the coping process (Bingham, Correa, & Huber, 2012; Jackson, Traub, & Turnbull, 2008; Luterman, 2004). Counseling services may assist parents as they move through this process of decision making and adjusting to and coping with their child's deafness (Luterman, 2004; Patrick-Ott & Ladd, 2010).

### **Impact of Deafness**

There exists no evidence that children who are diagnosed with deafness do not seem to differ neurologically from their peers who are able to hear. They do differ in that the way they acquire language tends to be primarily visual as opposed to auditory (Leybaert & D'Hondt, 2003). They also may differ in the amount and quality of linguistic exposure. A study by Yoshinaga-Itano, Sedey, Coulter and Mehl (1998) demonstrated that children diagnosed with significant hearing loss before six months old developed better linguistically than peers diagnosed later than six months. Children

diagnosed with deafness whose parents communicate with them orally, or who attempt to communicate using sign language without basic proficiency, may not have access to the linguistic stimulation required for ongoing development (Leybaert & D'Hondt, 2003). The lack of linguistic stimulation can cause language-related neurological development to stop or become retarded (Leybaert & D'Hondt, 2003).

A study conducted by Moeller (2000) found that early linguistic interventions begun during the first eleven months of life for children diagnosed with deafness led to positive linguistic outcomes. These children tested within an average range compared to their hearing peers related to vocabulary and verbal reasoning. These average scores stand in contrast to the scores of children diagnosed with deafness who began linguistic interventions later than twenty-four months old, and who scored significantly lower in these areas than their hearing peers. The study also found that family involvement in linguistic interventions for children diagnosed with deafness had a positive effect on outcomes, and that highly involved families might have contributed to later-identified children scoring closer to their early-identified peers (Moeller, 2000).

The acquisition of language and the ability to communicate effectively with others is a critical component of cognitive and social development (Decker, Vallotton, & Johnson, 2012). The parents of children diagnosed with deafness must often make decisions regarding communication early in their child's life in order to allow development to occur appropriately. These choices are often made difficult by the ways in which deafness is viewed, and the influence of these models of understanding deafness on parental decision-making. The model often presented by physicians and the medical community is the medical model of deafness, which focuses on the pathological absence

of hearing and views deafness as disability (Senghas & Monaghan, 2002). This model stands in contrast to the sociocultural model of deafness, which views deafness in terms of being a minority linguistic community that has its own language and culture (Senghas & Monaghan, 2002).

### **Parental Experiences, Responses, and Coping**

Parents who have a child recently diagnosed with deafness, or any other significant disability, go through a process of grieving the loss of the child they expected to have. Professionals writing about the grief associated with having a child with disabilities have compared it to grief due to the loss of a family member (Luterman, 2004). In contrast to grief associated with the loss of a family member, however, the grief experienced by families who have a child with a disability is different in that it is ongoing. Additionally, it may serve to isolate parents from friends and other family members who are unable to understand the parents' thoughts and feelings due to a lack of experience with disability (Luterman, 2004). Mothers also report experiencing intense emotions such as shock and anger following diagnosis, while fathers report a focus on "fixing the problem" more so than on grief and strong emotional responses (Jackson et al., 2008).

In addition to experiencing grief and other strong emotional responses, parents of a child recently diagnosed with a disability must often manage unexpected barriers and requirements, decisions (related to communication, assistive devices, services for the child and the family, and education), and a new language related to the disability (Bingham, Correa, & Huber, 2012; Jackson et al., 2008). Families of a child diagnosed with deafness report a post-diagnosis focus on assisting their child with maximizing his

or her potential, a desire to develop a plan of action, and a decision-making process involving trial and error due to information that is often biased or difficult to find (Jackson et al., 2008).

These situations, decisions, and experiences are stressors that parents must eventually cope with as they engage in adjusting to having a child with a disability. Coping has been defined as thoughts and behaviors utilized to effectively manage the demands of stressful situations (Folkman & Moskowitz, 2004). Strategies used in coping may be palliative and “include denying, questioning, or wishful thinking” or problem solving and include “searching for information, seeking social support, reframing, and seeking spiritual support” (Bingham et al., 2012, p. 379). These strategies are not necessarily discrete, and may be used in conjunction at various times to meet the coping needs of parents (Bingham et al., 2012).

### **Counseling**

Counseling may be an important component of the process of parental coping related to a child’s disability. Counseling strategies to assist parents with coping related to their child’s disability may include such interventions as addressing parents’ anger and unaddressed fears, exploring the connection of parental guilt with over-protection or over-dedication, and building parental confidence to reduce denial (Luterman, 2004). Counselors may also encourage parents to participate with other parents in group therapy, use psychoeducational materials to become better educated about their child’s abilities and disabilities, and consider in-depth counseling as needed as the child grows to adulthood (Patrick-Ott & Ladd, 2010). These strategies address parents’ emotional

responses to their child's disability, needs to connect with others in a similar situation, and needs related to better understanding the implications of the child's disability.

### **Statement of the Problem**

#### **Background of the Problem**

Parents of children diagnosed with deafness face many decisions after their child's deafness has been diagnosed. Decisions may involve the child's and the family's mode of communication, assistive devices, needed services for the child and the family, and decisions related to education. Families with a child diagnosed with deafness may experience the deafness' impact in terms of the ways in which the family interacts, the family's resources, and the supports needed by the family (Jackson et al., 2008). During this time, parents may experience a variety of emotions, including shock, anger, fear, inadequacy, uncertainty, and a sense of being overwhelmed by new information and necessary decisions (Bosteels, Van Hove, & Vandenbroeck, 2012; Jackson et al., 2008).

During the course of the literature review for this study, the researcher found several qualitative studies exploring the experiences of parents of children diagnosed with deafness. These studies were conducted in Belgium (Bosteels et al., 2012), a state in the western United States (Luckner & Velaski, 2004), and a variety of locations in the United States (Northeast, Northwest, Midwest, and Southwest) (Jackson et al., 2008). The study by Bosteels et al. (2012) focused on the *early experiences* and meaning making of parents who have a child diagnosed with deafness. Luckner and Velaski (2004) focused their study on the identification of factors that support healthy family functioning. The focus of Jackson's et al. (2008) study was the perceptions and experiences of parents after the early identification of their child's deafness.

This study is similar to the study of Bosteels et al. (2012) in that it focuses on parental experiences and meaning making, although it is geographically different, being located in the United States. This study differs from the other two studies in that its focus is broader than Luckner and Velaski (2004), and that it focuses on meaning making unlike the study by Jackson, et al. (2008). This study seeks to increase the knowledge base related to parents who have a child diagnosed with deafness by researching the lived experiences of these parents in a state located in the southeastern United States.

Increasing the knowledge base related to parents who have a child diagnosed with deafness may assist counselors when working with this population. This study may add depth to the profession's awareness and understanding of these parents' strengths and needs related to coping and coping skill development. Additionally, greater knowledge of this population may allow counselors to develop and provide strategies and services that are specific to them and more appropriately address their experiences, strengths, and needs.

### **Problem Statement**

At present, more information is needed regarding the lived experiences of parents who have a child or children diagnosed with deafness. These lived experiences might include the impact of the child's deafness on family functioning, successes and challenges experienced by the family/child, and the family's interaction with service providers.

Greater knowledge about these parents' experiences may be of benefit to counselors and other professionals serving families with a child diagnosed with deafness. Additionally, this research may benefit families who are seeking out information about the experiences of other families who are facing a similar situation. Due to the study's focus on the lived

experiences and meaning making of parents who have a child diagnosed with deafness, all participants will be members of this population, and will be recruited from Beginnings SC, a nonprofit in South Carolina that works to address the communication and other needs of parents who have a child diagnosed with deafness.

## **Research Questions and Nature of the Study**

### **Research Questions**

- 1) What are the lived experiences of parents who have a child diagnosed with deafness?
- 2) What meaning do these parents make of their experiences?

### **Nature of the Study**

This research study will use phenomenological research methods to address the problem and attempt to respond to the research questions. In order to document the parents' lived experiences, the researcher will conduct an interview with each participant parent. These interviews will be individual and semi-structured, and focus on the parents' lived experiences related to having a child diagnosed with deafness, as well as the meaning that the parents make of these experiences. Interviewing each participant individually will allow the research to focus on each participant and his or her individual lived experiences and meaning making. Semi-structured interviews will allow the researcher to ask the participants specific questions, but will also allow flexibility to explore details and information shared by the participants with more depth. Further discussion of the research questions and nature of the study continues in chapter 3.

### **Purpose of the Study**

The purpose of the study is to document the lived experiences of parents who have a child diagnosed with deafness. This research will be done in order to gain insight into the experiences of these parents and the meaning they make of their experiences. Documentation efforts will focus on experiences that the parents believe are typical, experiences the parents believe are important or particularly meaningful, as well as the meaning these parents make of their experiences. The anticipated product of this study is a greater understanding of the lived experiences of the parents of children diagnosed with deafness and the meaning the parents make of these experiences. It is also anticipated that a greater understanding of these parents' experiences and the meaning making will lead to recommendations for counselors who serve this population.

### **Theoretical Framework**

This study is qualitative in nature and uses phenomenology as its theoretical framework. Phenomenology "focuses on the experiences of participants and the meaning they make of that experience" (Seidman, 2013, p. 16). This approach to research was introduced initially by Husserl and developed further by Heidegger and Gadamer (Jones, 2001; Koch, 1999; Pringle, Hendry, & McLafferty, 2011). Using this framework, researchers interview participants and ask them to share their experiences and reflect on the meaning they have given to their experiences. The goal of the phenomenological approach is to gain as much of an understanding as is possible of the participants' subjective view of their experiences (Seidman, 2013). In order to gain this understanding, the researcher must also learn of the context within which the participants' lived experience occurs.



In using a phenomenological approach to interviewing, interviews are recorded and transcribed to create a written text document. This is done so that the participants' words, which are the embodiment of their thoughts, are portrayed reliably and accurately. In addition, this document allows the researcher to demonstrate his or her accountability to the interview data (Seidman, 2013). Participants will be given the opportunity to review the transcription of their interview for accuracy and clarification, the goals of which are to increase the researcher's accountability and likelihood that the transcriptions capture the participants' lived experiences and meaning making. Once the interview data has been transcribed, it is analyzed and coded, a process involving "reading and rereading data, thoughtful reflection, and integrating responses into higher levels of synthesis" (Perry, 2013, p. 272). The coding process takes the data and organizes it into categories based on relevant and emergent concepts (Perry, 2013). Organizing the data allows the researcher to identify the commonalities and differences of the participants' lived experiences and meaning making. As with the interview transcripts, participants will have the opportunity to review the results of the analysis and coding.

### **Terms and Definitions**

The participant parents interviewed for this study have a child diagnosed with deafness. For the purposes of this study, "parent" will be defined based on the definition of "family" as used by A. Turnbull and H. Turnbull (2001): "two or more people who regard themselves as a family and who perform some of the functions that families typically perform. These people may or may not be related by blood or marriage and may or may not usually live together" (p. 12). In this study, parents are defined as individuals who self-identify as parents and who perform some of the functions that

parents typically perform. They may or may not be biologically related to the child diagnosed with hearing loss and may or may not usually live together. "Deafness" in this study will be defined as "a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification," which is the definition set forth by the Individuals with Disabilities Education Act (2004).

### **Assumptions, Limitations, Scope, and Delimitations**

The assumptions of this study are related to several areas. The first of these is the assumption that parents of children recently diagnosed with deafness have related lived experiences, and that these parents have made meaning of the lived experiences. The second is that parents will give honest and thorough responses to interview questions, and that interviews and observations will illuminate the parents' lived experiences and the meaning they make of these experiences. In addition to these, there is an assumption that the interview process will allow parents to illustrate accurately their lived experiences and the meaning they have made of these experiences. Encouraging the participants to review the interview transcripts and analysis results may provide support for the accuracy of these assumptions.

The use of a qualitative research design limits the study in several ways. First, the in-depth nature of the interviews and observations, which are a part of qualitative inquiry, limit the number of interviewees that can be reasonably accommodated in the study. This, and the qualitative data consisting of the interviewees' responses to interview questions, may create difficulties related to applying the study's results to a larger population. An additional limitation may be demographic similarity among the participants as well as an inequality in the numbers of mothers and fathers who

participate in the study. In addition, qualitative research focuses on the individual's experiences and his or her understanding of these experiences, which is inherently subjective, as well as the researcher's interpretation of this subjective understanding of experiences.

The scope of this study is limited by a number of factors, the first of which is its focus on the specific problem of the lived experiences of parents who have a child diagnosed with deafness and the meaning they make of these experiences. The identified problem narrows the focus of the study to a specific population (parents), situation (diagnosis of child's deafness), and area of interest (lived experiences and meaning). This highly specific focus may limit the opportunity to explore the influence of other factors on the parents' lived experiences, such as the impact of socioeconomic status, the lived experiences of other family members, and religious beliefs and faith.

The scope of this study is also limited due to the small number of participant parents, the geographic area in which they live, and their involvement with a new and relatively small non-profit organization in South Carolina that addresses communication and other needs of parents who have a child diagnosed with deafness. Qualitative research designs tend to restrict the number of participants in an effort to explore fully the experiences of the participants through in-depth interviews and participants' thick, descriptive responses to interview questions (Glesne, 2011; Patton, 2002). The depth of information obtained by limiting the number of participant parents may contribute to the richness and depth of the data collected. Participant parents in this study live in South Carolina; therefore, the study may not be applicable to families who live in other geographic regions. The limited scope may affect the applicability of this research to a

wide variety of other parents and situations, due to its specificity. The sacrifice of the broad applicability of this study may allow for a much more detailed understanding of the participants' lived experiences and meaning making.

### **Significance of the Study**

#### **Knowledge Generation**

There appears to be a limited amount of research in the professional literature related to this topic. Much of the research related to this topic has occurred in countries other than the United States and in other regions of the United States. This study seeks to contribute to the research and professional knowledge bases by exploring and documenting the lived experiences of parents who have a child diagnosed with deafness and the meaning made of these experiences by the parents.

#### **Professional Application**

This study seeks a deeper understanding of the lived experiences of parents who have a child diagnosed with deafness, as well as the meaning made of these experiences by the parents. Due to the nature of qualitative inquiry, clinicians may not be able to generalize the results of this study to a larger population of parents who have a child diagnosed with deafness. However, a greater understanding of this topic contributes to the ongoing professional dialog regarding best practices when working with individuals and families from a variety of backgrounds and populations. This study's contribution to the ongoing professional dialog may offer insights to clinicians working with this population. A better understanding of participants' lived experiences and meaning making may allow counselors to better address the strengths and needs of this population through counseling, psychoeducation, and case management efforts. This study may also

encourage further research in this area, particularly by encouraging researchers who seek to capture data that might be generalized to a larger population.

### **Social Change**

Children who are born deaf or who lose their hearing prelingually have a limited window of time in which to begin the process of language acquisition necessary for linguistic skill development similar to their hearing peers (Yoshinaga-Itano et al., 1998). Therefore, the parents of these children must make a number of decisions related to language and language acquisition quickly, and often these decisions must be made during a time typified by mixed emotions, grieving, and stress. Due to the number of struggles often experienced by parents during this time, language acquisition may not begin or may not optimally occur during this window of opportunity. By contributing to the professional knowledge and ongoing dialog surrounding best practices when serving this population, this study seeks to accomplish several tasks. These tasks include improving the counseling offered to the parents of a child diagnosed with deafness, better assisting these parents while raising their child, and allowing the children of these parents to develop similarly to their hearing peers and to become healthy, productive members of society.

### **Summary**

The lived experiences of parents who have a child diagnosed with deafness, the meaning they make of their experiences and the actions taken by these parents as their children grow and develop may have a significant impact on the future successes and difficulties experienced by the children. The purpose of this study is to gain insight into the lived experiences of these parents, and the meaning they make of their experiences.

A deeper understanding of this topic has potential implications for a number of significant areas: counseling best practices when working with this population, counselor training programs and education, and professional understanding of the lived experiences of this population. Even more important than these, there are implications for the parents of children diagnosed with deafness, whose decisions may be either of benefit or of detriment to their children. The exploration of this topic will continue in the following chapters to include a discussion of the relevant professional literature, the study's design and methodology, the results, and finally, the discussion of the results, conclusions, and suggestions for further research.

## CHAPTER 2

### REVIEW OF LITERATURE

The review of the professional literature addresses the following points, which were briefly addressed in Chapter 1: the impact of deafness, parental experiences, responses and coping, and counseling related to parental coping. The review of the literature will also address in detail the methods and methodologies utilized by this study. The review is organized first around the themes initially addressed in the Introduction section of Chapter 1, and then around the theoretical framework and methodologies utilized by this study. The literature included in this review was acquired by searches conducted during February 2013, March 2013, April 2014, and July 2014 utilizing EBSCO (Academic Search Complete) and Google Scholar. Terms used in searching these databases included family, parent, parental coping, experiences, lived experiences, deaf, deaf child, deafness, disability, counseling, language, American Sign Language, phenomenology, phenomenological, and qualitative research.

#### **Impact of Deafness**

Past studies related to language development in hearing children have indicated a relationship between left-hemisphere language specialization and linguistic skill development. While there is no evidence that deaf children generally differ neurologically compared to hearing children, deaf children's neurological structures related to language development do not receive stimuli in the same way (Leybaert & D'Hondt, 2003). These authors hypothesized that if deaf children do not have

appropriate linguistic stimuli during an early critical developmental period, they are at risk for distorted or missing left-hemisphere development. The results of their study indicated that deaf children who receive intensive education during this critical development window using cued speech or sign language “display more evidence of left-hemisphere specialization for the processing of their native language” than children who miss exposure during this period, (Leybaert & D’Hondt, 2003, p. S34). Results of their study also indicated that a lack of linguistic stimulus during the critical developmental window creates a risk of missing or distorted left-hemisphere linguistic specialization. Lack of linguistic specialization may lead to difficulties with effective communication, which is a requirement for healthy development, including cognitive and social development (Decker, Vallotton, & Johnson, 2012).

Deaf and hearing children differ in that the primary source of linguistic stimulus for deaf children is visual. They also differ in that hearing children tend to receive ongoing linguistic stimulus from birth, while deaf children often spend the first few years of life in linguistically deprived environments, unless visual communication is used (Leybaert & D’Hondt, 2003). The use of hearing aids to strengthen a deaf child’s residual hearing early in life is often not sufficient to allow for auditory linguistic stimulus, and parents who are unable to communicate fluently in sign language may not be able to provide sufficient visual linguistic stimulus. A lack of early linguistic stimulus may lead to missing or distorted linguistic specialization, due to a lack of development or slow development of the necessary neurological structures (Leybaert & D’Hondt, 2003).

A study conducted by Moeller (2000) sought to explore the relationship between the age of deaf and hard-of-hearing children enrolled in early intervention services and



linguistic development outcomes for these children at five years of age. A lack of early linguistic development may create disadvantages and difficulties related to “academics, social-emotional development, and self-esteem” (Moeller, 2000, p. 8). The author hypothesized that age of enrollment is related to language development, with children enrolled in early intervention services at the youngest ages scoring similarly to hearing peers. More specifically, the study’s findings indicated that children enrolled in early intervention services prior to eleven months of age had stronger linguistic skills at five years of age than later enrolled children. These children’s scores related to vocabulary and verbal reasoning skills were average compared to hearing peers. “In contrast, average vocabulary scores for later enrolled children (eg, >24 months old) were 1.0 to 1.5 SD below their hearing peers” (Moeller, 2000, p. 6).

In addition to the importance of age of enrollment in services, Moeller’s (2000) results indicated that family involvement was related to variance in linguistic scores. In response to questions related to the ability of later-identified children to “catch up” with earlier identified peers, the study’s results suggested that families with a high degree of involvement may “buffer the effects of late enrollment to some degree” (Moeller, 2000, p. 6). The results of this study suggested that children who are enrolled early in intervention services perform at a higher level than later enrolled children, regardless of familial involvement. Higher outcomes might be best attained when family involvement is high and the child is enrolled earlier in intervention services, thus allowing for family support as they become involved in the child’s development.

In a paper discussing a South African early intervention project, Storbeck and Calvert-Evers (2008) further supported the need for early detection, diagnosis, and

intervention related to hearing loss. The authors suggested that successful interventions after diagnosis require such elements as “a team of healthcare professionals, primary health care services, hospitals, and early interventionists” in addition to the involvement of the child’s family (Storbeck & Calvert-Evers, 2008, p. 319). They also suggested caution when working with families who may be unable or unwilling to take the lead in managing their child’s care due to such issues as single parenthood, low socioeconomic status, and limited education. Families with such issues may have difficulty expressing needs to the intervention team, or they may not receive complete information from team members who assume that more costly interventions may not be an option for the family. To better address issues such as these, they suggested an increase in parental education programs to better equip families to manage their child’s care (Storbeck & Calvert-Evers, 2008).

Yoshinaga-Itano et al. (1998) investigated the linguistic skills of children identified with hearing loss before and after six months of age. The results of the study indicated that the earlier identified children had greater receptive and expressive linguistic skills than those children identified later. The difference in linguistic performance was almost a full standard deviation higher for the earlier identified children compared to later identified children. This outcome was found regardless of such variables as “age, gender, socioeconomic status, ethnicity, cognitive status, degree of hearing loss, mode of communication, and presence/absence of other disabilities” (Yoshinaga-Itano, et al., 1998, p. 1169). The authors indicated that the first year of life, and particularly the first six months, is a critical window of opportunity for early identification and intervention related to hearing loss. Results indicated that children

whose hearing loss is addressed during this critical window have average linguistic scores later in childhood.

### **Parental Experiences, Responses and Coping**

The parents of a child diagnosed with deafness often experience a number of decisions and challenges related to the child's deafness. These decisions and challenges often include communication/language, assistive devices, appropriate education and service providers, finances, helping others understand deafness, and friendships for the child who is deaf (Jackson et al., 2008; Luckner & Velaski, 2004). Deafness also has a cultural component, so families may also have to assist their child with the impact of both Deaf and Hearing cultures and cultural identities (Bat-Chava, 2000; Jackson & Turnbull, 2004). As families make these choices, they are often subject to an overwhelming amount of information, technical knowledge, and intervention strategies, particularly if the parents had no prior knowledge of deafness (DesGeorges, 2003; Bosteels et al., 2012).

### **Parental Experiences**

Families who have a child diagnosed with deafness begin to acquire a great deal of information from a number of sources after their child's diagnosis. These sources may include other families who have a child diagnosed with deafness, members of the Deaf and Hearing communities, medical specialists, and education specialists (DesGeorges, 2003). While these sources of information may assist the family in developing a viable support system, they may also create a sense of uncertainty and stress for parents when the information is controversial or when the sources of information have opposing viewpoints, such as the use of spoken language versus sign language (DesGeorges, 2003;

Jackson & Turnbull, 2004). Luckner and Velaski (2004) reported that parents found assistance from educational professionals in the areas of "emotional support, the ongoing provision of information about resources for learning sign, additional speech therapy, cochlear implants, financial assistance, and suggestions about issues such as communication, behavior, speech, and the use of amplification" (p. 330). In this same study, parents indicated they were hindered by medical professionals' lack of knowledge and biases related to mode of communication (Luckner & Velaski, 2004). Jackson et al. (2008) found that families' negative experiences with support services included "lack of information, inadequate social supports, having to advocate for options and services, limited access to services, and limited access to funding" (p.91).

Post-diagnosis, parents often express concern related to their child's future speech and linguistic development and education, which are difficult for audiologists to answer definitively based on infant hearing tests (Kurtzer-White & Luterman, 2003). At this point and soon after, parents must make a variety of decisions related to early interventions, assistive technology, and communication. Parents must often make these decisions without the benefit of a definitive diagnosis. The decision making process may also be made more difficult due to the variety of contradictory opinions and biases, as well as confusing information related to hearing loss, language, and learning (Kurtzer-White & Luterman, 2003, Feher-Prout, 1996).

Parents may also struggle with misperceptions of technology that may assist individuals with hearing impairment, such as cochlear implants. The media and other professionals may lead parents to believe that cochlear implants are "a key for success in the 'hearing world'" (Kurtzer-White & Luterman, 2003, p. 235). Parents who accept

these claims as truth may experience an end to their grief, as they believe that the cochlear implant will “cure” their child’s deafness, only to experience disappointment and reinstated grief when the cochlear implant does not provide a cure. Some parents may continue to search for the cure that will make their child “normal,” and in doing so, “not learn to accept their child as he or she is, both the child and the parent can never integrate the deafness in their lives in a way that allows them to get beyond it” (Kurtzer-White & Luterman, 2003, p. 235).

Freeman, Dieterich, and Rak (2002) studied the efforts of urban parents to assist in their deaf or hard-of-hearing child’s linguistic development. Emergent themes in the study included “parents struggles to (a) get a diagnosis, (b) resolve their grief, (c) develop mutually accessible language with their child, and (d) deal with systemic barriers and the urban environment” (Freeman et al., 2002, p. 39). Mothers involved in the study indicated an awareness of something being wrong long before diagnosis, which lead to feelings of not being listened to by medical staff and other professionals. These difficulties, in turn, lead to families having an inherent distrust of other professionals. In addition to these issues, parents also indicated barriers to their child’s linguistic development, including “inexperienced, semiskilled clinicians and high rates of clinician turnover; the inclusion of other ‘non-categorical’ students in educational settings with their children; difficulties with aspects of program delivery such as scheduling, amount, range, location, and transportation; and family dysfunction” (Freeman et al., 2002, p. 40).

### **Parental Emotional Responses**

According to Kurtzer-White and Luterman (2003), Luterman (2004), and Patrick-Ott and Ladd (2010), parents of children with hearing loss may experience non-finite

grief and loss over the child's lifespan. This type of grief is different from the type of grief experienced with the death of a loved one, which tends to be limited in terms of time, and episodic. Additionally, the sort of grief experienced by parents who have a child with a disability tends to be ongoing and unaccompanied by activities to assist with closure, such as a funeral service/burial when an individual dies. The chronic type of grief experienced in relation to a child's disability may be experienced throughout the child's lifespan, due to an ongoing difference between the parents' hoped-for child and the reality of their child's disability. Parental grief may intensify during trigger events, such as birthdays and developmental milestones. Also during this time, however, parents may address their grief by proactively searching for "information, techniques, and services to bring to light the small, seemingly insignificant changes for their child and the life of the disability" in an effort to "[become] at ease with being imperfect and [allow] their child to be imperfect as well" (Patrick-Ott & Ladd, 2010, p. 84).

When parents first learn of their child's diagnosis, they often experience shock, an inability to concentrate, and emotional numbness (Kurtzer-White & Luterman (2003). Parents may also experience anxiety, sadness, and fear, as well as a defiant belief in the lack of permanence of the diagnosis. Parents may exhibit this defiance by searching for a way to fix the problem. Information offered to parents that supports a hopeful outlook may be accepted while less hopeful information may be rejected. As parents come to greater acceptance of the reality of the diagnosis, they may experience emotional responses, such as anger and despair related to hopelessness.

Parents who have recently become aware of their child's diagnosis of hearing loss may also experience feelings of anger and guilt. Parental anger may be related to feelings

of inadequacy, loss of control, and the loss of their hoped-for child (Kurtzer-White & Luterman (2003). Parents may also feel anger directed toward individuals working with their child due to feelings of powerlessness on the parents' part. Maternal guilt may be related to feelings of having caused the hearing loss, while paternal guilt may be related to feelings of not being able to protect the family. According to Kurtzer-White and Luterman (2003), parents may attempt to cope with these feelings of guilt and powerlessness by avoiding the acceptance of responsibility for making decisions regarding their child's ongoing care and treatment.

Bristor (1984) proposed that Schneider's wholistic model for grief could be applied to parents of a child born with a disability. The initial stage of this model is "initial awareness," in which families may experience shock at the diagnosis, guilt, and panic, which then may negatively affect physical wellbeing. The second stage of this model is "strategies to overcome loss." In this stage, the ambiguity of the ongoing impact of the child's disability may drive the family to utilize coping methods "which vacillate with feelings of holding onto the image of the perfect child and normal family routine to letting go of that image in dealing with the inevitable changes that must ensue" (Bristor, 1984, p. 27). In the third stage, "awareness of loss," the family often attempts to explore and understand the implications of the disability, which may lead to exhaustion, self-neglect, loneliness, resentment, and cynicism. "Completions," the fourth stage, "has three separate functions and/or benefits: healing, acceptance of loss, and resolution" (Bristor, 1984, p. 28). The final two stages include "resolution and reformulations" and "transcending loss." In these final stages, parents may experience a greater sense of power, freedom from intense, ongoing grief, and renewed life-balance.

## **Parental Coping**

The experiences described above, as well as other experiences and emotional responses of parents who have a child diagnosed with deafness, are experiences with which these parents must cope in some fashion. Folkman and Moskowitz (2004) described coping as “a complex, multidimensional process that is sensitive both to the environment, and its demands and resources, and to personality dispositions that influence the appraisal of stress and resources for coping” that is “strongly associated with the regulation of emotion, especially distress, throughout the stress process” (p. 747). They also described coping as a process in which individuals may use a variety of tactics to regulate emotion. These tactics may be associated with a wide variety of outcomes relative to coping based on the type of tactic, the individual’s personality, and the characteristics of the stressor. Stressors related to a child’s disability diagnosis may be characterized by such elements as “the time lapse between suspicion and diagnosis, the uncertainty of the diagnosis, [and] the difficulty in predicting outcomes” (Bingham, Correa, & Huber, 2012, p. 381). The authors indicated that coping tactics are skills that can be taught (Folkman & Moskowitz, 2004).

In addition to the above descriptions of coping, it has also been defined by Feher-Prout (1996) as:

an ongoing process that consists of a series of appraisals and responses to the stressful event. There are three types of appraisal: (1) primary, in which the person evaluates the significance of the event for his or her well-being, (2) secondary, in which the person evaluates the event with respect to available



options and resources, and (3) reappraisal, which occurs as new information (from within and without) is received and processed (p. 156).

This author went on to indicate that coping consists of multiple processes, such as taking or not taking action, searching for information and thought related processes. These processes are all related to emotional management and individual adjustments to the environment. Parents must utilize coping resources in order to address grief, understand the implications of deafness, and make decisions related to their child's future treatment and education (Feher-Prout, 1996).

A study by Bingham et al. (2012) sought greater understanding of the coping tactics utilized by mothers initially coping with their child's disability diagnosis. The results of the study indicated that mothers used palliative and problem-solving tactics. Palliative tactics included such things as "denying, questioning, and wishful thinking," and offered a reduction in stress temporarily, although they may not have been effective for ongoing stressors (Bingham et al., 2012, p. 379). Problem solving tactics involved activities such as "seeking professional support, searching for information, seeking social support, reframing, and seeking spiritual support" (Bingham et al., 2012, p. 381). The authors indicated that, regardless of coping tactics used, all of the mothers who participated in the study were persistent and deliberate in their actions to manage their child's disability and cope with the diagnosis.

For parents of children recently diagnosed with hearing loss, coping may involve managing feelings of inadequacy and being overwhelmed by the prospect of managing their child's hearing loss (Kurtzer-White & Luterman, 2003). Feelings of inadequacy and a lack of self-efficacy may decrease the ability of these parents to address their child's

needs appropriately. When a child is born deaf or hard-of-hearing, families may learn of the diagnosis during a time characterized by vulnerability due to such stressors as maternal recovery from delivery, familial identity and role shifts in relation to the new child, and emotional resources being spent connecting with the new child. Families may also experience stressors related to a lack of frame of reference if they have little or no experience with deafness and hearing loss. Additionally, parents may have to address lost dreams and assumptions, such as their and their child's future relationship and ability to communicate.

### **Parental Behavioral Responses**

Snell and Rosen (1997) attempted to understand how parents who have a child with a disability master the job of parenting. Participants involved in this study discussed traumas they have experienced since becoming parents of a child with a disability. Trauma and the experience of tragedy have the potential to bring out hidden strengths that individuals were unaware of, or they may uncover past traumas and difficulties that negatively impact mental health and coping (Taylor, 1982). The most significant of these traumas included the initial process of understanding the implications of their child's disability and the ongoing reminders that their child is "different" in some way. The study also highlighted four parental coping methods used to manage these and other traumas, including "family congruence, cognitive coping, defining boundaries, and external system management styles" (Snell & Rosen, 1997, p. 431).

Families were better able to manage traumas by being congruent, which refers to the family's ability to discuss and come to agreement regarding such issues as interventions for the family member with the disability and familial self-concept. Parents

also used a variety of cognitive coping strategies, such as “attributing cause and meaning to the disability, assigning a special purpose to the child, construing benefits, making favorable comparisons, redefining events, normalizing, and seeing themselves as in control” (Snell & Rosen, 1997, pp. 432-433). Families defined boundaries often by deciding who was “in” and who was “out” based on individuals’ reactions to the child and the disability. Finally, families were found to effectively cope by effectively managing the systems outside of the family that were involved in their child’s care, treatment, or education. Parents in the study were found to manage their interactions with these systems in a manner that ranged from being highly controlling to following professionals’ advice and treatment plans without question. The most effective parents may have worked to build balanced partnerships that “allowed them to make final decisions, yet gave them frequent access to the expertise of the professional” (Snell & Rosen, 1997, p. 436).

Snell and Rosen (1997) also found that parents who were successful in mastering the task of raising their child diagnosed with a disability had experienced at least one “worldview shift.” These shifts involved some change in the parents’ perception of themselves in relation to others. Examples of these provided by the study’s authors included such shifts as “a redefinition of ‘motherhood’ or ‘family,’” letting go of “the ‘American dream’ that hard work and ‘clean living’ would prevent bad things from happening,” and finding “new ways of relating to authority figures such as physicians, parents or in-laws” (Snell & Rosen, 1997, p. 437). Parents reported that some of these shifts in worldview were difficult or painful and involved relinquishing lifelong, deeply held beliefs.

## **Societal Views of Disability**

Woolfson's (2004) study focused on psychosocial aspects of disability and the impact of cognitive appraisal on familial coping with disability and addressing child behavioral issues. According to the author of this study, parental beliefs about disability may be influenced by societal beliefs about disability, which may, in turn, affect the parents' ability to effectively discipline their child. The first societal view addressed in this study was the perspective that disability is a medical problem. This societal view assumes that disability is "the key feature in understanding the needs of the disabled child and then defining the child as a person" (Woolfson, 2004, p. 5). Families accepting this societal belief may view all of their child's behaviors as a result of the disability, and therefore choose to not discipline their child appropriately. Parents may also assume that their child's behavioral issues can only be effectively addressed by a professional, and therefore not intervene themselves to address behavior. It is possible, however, that parents who accept this societal view may be effective parents by having high expectations for their child and taking an active part in their child's development and only using professionals as necessary.

The second societal view of disability that may affect parental coping and discipline was the perspective that disability is a tragedy (Woolfson, 2004). Parents who accept this belief may feel as though they inherently owe their child due to the child being born with, or acquiring, a disability. Parents may not be able to discipline their child effectively due to feelings of pity, which lead to parents not wanting to upset their child by providing discipline and addressing behavioral issues. Parents who accept this belief may not be able to address their child's behavioral issues effectively. However,

parents who choose to take a positive view of their child, and “view their role as helping the child to become a worthwhile member of the community and expect him or her to learn appropriate social rules of behavior for this” may be better able to address their child's behavior (Woolfson, 2004, p. 9).

The final societal view of disability in Woolfson’s (2004) study that may affect parental coping and the ability to effectively discipline was the perspective that people who have disabilities are dependent and need protection from demands for independence. Families who accept this belief and are not effective develop “a culture of overprotection and dependency in which the disabled child grows to view him- or herself as passive and dependent, and may be less likely to persevere with tasks or develop good problem-solving skills” (Woolfson, 2004, p. 10). Parents who accept this belief but are more effective are aware of their child’s potential limitations, but encourage their child’s independence and sense of self-worth.

### **Counseling**

Ziolko (1991) suggested the application of a counseling model used by Gilliland, James, and Bowman for working with families who have a child diagnosed with a disability. The first stage in this counseling model requires the therapist to work toward building trust and rapport with the family. During this time, the counselor should attend to the grief process and related needs of the family, and reinforce appropriate behaviors and skill development related to caring for the child. Once trust and rapport have been established, the counselor should encourage family members to explore and verbalize their reactions and feelings, to assess familial strengths and needs, and to assist the family with connecting to local resources during the second stage.

During the third, fourth, and fifth stages, the family should work to identify appropriate means to address the child's and the family's needs, and commit to a plan to address the various needs. The counselor's role at this time is to assist by "helping the client to decide which alternatives are appropriate and by teaching, modeling, or mentoring when needed" (Ziolko, 1991, p. 33). During the sixth and final stage, the counselor and family evaluate client efficacy and goals, and revisit prior stages as needed. In addition to engaging the family in family counseling, the counselor may also refer the family to a group in which the family can receive support from and offer support to families with similar experiences.

### **Tasks of the Counselor**

Wilgosh and Scorgie (2006) also recommended that professionals assist parents and families during the process of constructing new images of their child and family, making meaning of having a child with a disability, and by engendering feelings of confidence related to decision making and effectively meeting the child's needs. Professionals may be able to assist parents in the process of creating new and hopeful images of their child "by celebrating and focusing on the child's strengths while remediating areas of need and providing the parent with information about disability that is realistic, yet expectant" (Wilgosh & Scorgie, 2006, p. 217). Finally, professionals may best serve parents by remaining aware that adjustment is not necessarily a linear process, and that parents might benefit from revisiting certain aspects of image making, meaning making, and decision making as the family and the child continue to develop.

Opirhory and Peters (1982) indicated that a trusting relationship must exist between the parents of a child recently diagnosed with a disability and the counselor

before effective counseling can begin. The process of building trust may be made more difficult by the emotional impact of the diagnosis on the parents. In order to facilitate the building of trust, the counselor should reassure parents as well as encourage them to begin discussing their reactions to the diagnosis. Additionally, the counselor should show the family unconditional valuing and acceptance, as well as exhibit genuine interest in and concern for the family. As trust begins to develop, the counselor should attend to parental grief and also offer positive reinforcement as the family begins adjusting to having a child with a disability.

Opirhory and Peters (1982) also recommended that counselors act as case managers as the family begins the process of seeking out early interventions and other care for their child. The counselor should make appropriate referrals to community resources, share information related to available therapeutic and educational interventions, both for the present and in the future, and assist parents with locating these resources. Counselors should also make parents aware of any special care that their child might need and provide education related to developmental signs and normal developmental variations. As parents continue to adjust to their child's disability, counselors should continue to validate parental feelings, such as anxiety, and provide ongoing reinforcement and information.

Prescott and Hulnick (1979) recommended that counselors address parental statements "that reflect unusual and extreme points of view considering the issue of personal responsibility" (p. 264). Parents may often feel victimized by their child's disability or blame themselves for the disability. Both of these positions are limiting in that they focus on blaming others or assigning unjustifiable blame to themselves. The

counselor may effectively address these extreme points of view by discussing the notion that parents are not responsible for their child's disability, but they are responsible for what they think and feel about their child and his or her diagnosis, as well as how they manage their child's ongoing care and treatment. By accepting personal responsibility for their thoughts, feelings, and actions, parents should become empowered to take a more active role in their child's care and treatment.

Prescott and Hulnick (1979) also discussed the difficulties of parents who feel as though reality is not fair and should be more in line with what they want. Counselors who must address these parental beliefs may effectively do so by working with parents to help them realize "that, try as we might, we simply may not have the power to alter reality," and that the best solution may be to "accept reality and learn to come to terms with it" (Prescott & Hulnick, 1979, p. 265). Parents are encouraged by the counselor to accept reality as it is, their own feelings, their child, and their child's disability.

Harnett and Tierney (2009) discussed the importance of positive communication with parents and families regarding their child diagnosed with a disability. These authors suggested best practices, such as referring to the child by his or her name instead of by his or her diagnosis and not sharing possible future outcomes that are disproportionately or unnecessarily negative. They also suggested indicating the availability of stable and ongoing support. Positive messages from professionals are encouraged because they:

can help to ensure that parental expectations are as positive as possible in order to influence the developmental opportunities afforded to the child. Low expectations modeled by authoritative sources at times when parents are likely to



be particularly vulnerable can have a detrimental impact on the outlook of parents (Harnett & Tierney, 2009, p. 263).

The authors stressed the importance of these realistic, yet positive, messages due to their potential impact on self-fulfilling future outcomes. Parent support groups and the availability of literature and other educational initiatives may further strengthen these messages. For parents of children diagnosed as deaf or hard-of-hearing, these educational initiatives should include information such as communication needs and modes of communication (Eleweke & Rodda, 2000).

### **Parental Experiences and Counseling Interventions**

Parents who have a child with a disability and are in the midst of the grief process may experience a variety of emotional responses. Anger is one of these possible emotional responses to having a child with a disability, and may occur when parental expectations of having a “normal” child are not met (Luterman, 2004). Parents may also experience anger related to a perceived loss of control, or to fears related to their ability to cope successfully with their child’s deafness or concern that the child may have other, unknown disabilities. Luterman (2004) suggested that anger is not necessarily a negative emotion, and may provide the parents with energy if appropriately addressed. Additionally, counselors may assist parents by confronting feelings of anger in order to reach unexpressed parental fears.

Parents of a child with a disability may also experience feelings of guilt upon learning of their child’s diagnosis. Maternal guilt is often related to concerns about what caused the disability, while paternal guilt often connects to feelings of failure as the family’s protector (Luterman, 2004). Parental guilt may lead to overprotective families,

or families that focus exclusively on the child who has the disability and neglect the family as a whole. Families who are overprotective of their child may create a “fearful child who has limited capacity to cope with the world on his or her own” (Luterman, 2004, p. 218). Families who focus on their child at the expense of the family as a whole may encounter issues with siblings or marital problems because of the neglect. Counseling efforts related to guilt may involve exploration of the origins of the guilt as well as addressing the guilt-related behaviors.

Parents may also experience a great deal of stress related to managing the process of addressing their child’s needs and anxiety related to feeling unable to successfully address their child’s needs (Luterman, 2004). Parents may often feel as though they do not have the knowledge or skills to appropriately manage their child’s physical, psychological, and educational needs (Reio, Jr. & Fornes, 2011). Overwhelming stress and anxiety may lead to parents using denial as a coping strategy to function. Counselors may effectively address parental stress and anxiety, and the accompanying denial by providing case management and coordination services, and by working with parents to enhance feelings of competency and confidence. Counselors who directly confront denial may create “the passive aggressive parent” who “does not follow through with the prescribed therapy” (Luterman, 2004, p. 219). Counselors may more effectively address stress, anxiety, and denial by actively listening, trusting the parents to find their own solutions that are best for their family, and by providing emotional support.

Reio, Jr. and Fornes (2011) discussed interventions that may be appropriate when working with parents of a child who has disabilities. One of the recommended interventions was educating the parents regarding effective parenting skills and aspects of

their child's disability in addition to providing support and encouragement. Facilitating parental empowerment focusing on skills, knowledge, involvement, and efficacy is also recommended. This parental empowerment "includes a willingness to learn new parenting skills and become active in the child's treatment program, community resources, and political system" so that parents can "acquire competencies to solve problems, meet their child's needs, and attain family goals" (Reio, Jr. & Fornes, 2011, p. 57). The authors also suggested that counselors view parents as the experts on their child, and give them the responsibility for deciding how to manage family tasks and daily routines.

Ziolko (1991) discussed the processes that parents who have a child with a disability go through after learning of their child's diagnosis, which include processes of adjustment and adaptation, as well as a process of grieving. Parents who experience difficulties with these processes may physically or emotionally withdraw from their child. Hopefully, as time passes, parents will be successful in their adaptation and managing their grief, so that they can take an active part in their child's care, work for normalcy in the family's routine, and treat their child as normally as possible, given the realistic limitations of the child's disability.

Wilgosh and Scorgie (2006) discussed a parental transformation process model that describes ways in which parents transform during their adaptation to having a child with a disability. This model suggests that professionals have their own beliefs and opinions related to disability, as well as preferred ways in providing services and interventions. These beliefs, opinions, and preferences held by professionals may influence parental reactions to the disability diagnosis. The authors recommended that

professionals become increasingly aware of the messages they send parents during interactions in order to strive for messages that are hopeful and affirming. Professionals should also be aware of the numerous societal, cultural, familial, and personal variables that might influence parental reactions and beliefs regarding disability so that these might be addressed appropriately following diagnosis.

### **Theoretical Framework**

Phenomenology as a qualitative research method involves the search for a deeper understanding of particular everyday experiences and the meaning of those experiences (van Manen, 1990). Phenomenological research is done in what Husserl (1970) described as the lifeworld. According to Husserl, the lifeworld includes the individual's consciousness of the world, the individual's objects or experiences, and the individual's context (Bevan, 2014; Husserl, 1970). Further, phenomenological research focuses on the natural attitude of the individual within the lifeworld, an attitude separate from reflection or theorizing (Bevan, 2014; van Manen, 1990). This natural attitude, separate from reflection or application of theory, which involves the immediate consciousness of experiences, is lived experience at its most basic form (Dilthey, 1985; van Manen, 1990). Individuals may only reflect on their lived experiences once the experience itself has passed. Therefore, phenomenological reflection that focuses on the meaning of lived experience is recollective reflection (van Manen, 1990).

The goal of phenomenological research is not the creation of theory to better explain or control the world; rather, the goal is to gain insight into our human experiences and come into greater contact with the world (van Manen, 1990). Phenomenological researchers are less concerned with facts of a particular experience than they are with a

deeper understanding of the "nature or essence" of the experience (van Manen, 1990, p. 10). Phenomenology may be described as postmodern, in that it acknowledges the complexity of human experience, the intersubjectivity of the human world, and the inherent meaning in human experience (Bevan, 2014; Mason, 2002). Phenomenology's point is to understand a particular aspect of experience with the context of human experience: "particular to the universal, part to whole, episode to totality" (van Manen, 1990, p. 36).

According to Seidman (2013), phenomenological research consists of four essential themes. The first of these themes is that human experience is temporary and transitory. Future experiences always become present experiences and then fade into past experiences. Therefore, researchers must ask participants to "reconstruct and reflect on" past experiences in an effort to try to grasp the essence of the past experiences (Seidman, 2013, p. 16). This does not mean the experiences occur only in the distant past and are not related to the individual's current life situations. Whether lived experiences occur in the distant past or more recently, they are experiences the individual may reconstruct and reflect upon. The second theme is the participants' subjective understanding. Phenomenological researchers must choose questions in an attempt to understand the participants' experiences from their subjective viewpoint. The third theme is that lived experience is the foundation on which the phenomenon of study is constructed. The words we choose to use as researchers influence the responses of our participants and the ways in which they reconstruct their experience. Finally, the fourth theme is phenomenology's focus on meaning and context. Phenomenological researchers attempt

to understand the context in which participants' experiences occur and encourage participants to reflect on the meaning and context of their experiences.

In order to collect data, phenomenological researchers conduct interviews with participants. These interviews tend to use open-ended questions with the goal of exploring participants' reconstructed lived experiences (Seidman, 2013). According to van Manen (1990), the two purposes of the phenomenological interview are that:

(1) it may be used as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of the human phenomenon, and (2) the interview may be used as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of an experience (p. 66).

When conducting research from a phenomenological perspective, the researcher acknowledges his or her role as the instrument, and while he or she encourages the participant to reconstruct lived experiences and reflect on the meaning, he or she also recognizes that the participant's meaning making is influenced by the interaction (Seidman, 2013). In order to minimize the researcher's influence on the participant's meaning-making and on subsequent analysis, the researcher engages in "bracketing," which is the abstention from utilizing what is previously known about the phenomenon of study (Bevan, 2014; Husserl, 1970).

### **Summary**

Although the professional literature includes several studies whose focus is the experiences of parents who have a child diagnosed with deafness, there are only a limited number of studies, and no studies were found that were located in the southeastern United

States. This study seeks to contribute to the body of professional knowledge by attempting to document the experiences of parents who have a child diagnosed with deafness and who reside in this geographic region. In this chapter, the researcher has addressed the following topics identified in the professional literature: impact of deafness; parental experiences, tasks, and coping; counseling; and theoretical framework.

This study is qualitative in nature and uses phenomenology as its theoretical framework. This framework is used because it allows the researcher to document the lived experiences of parents who have a child diagnosed with deafness, and to explore the meaning of these experiences with the parents. Analysis of the lived experiences of the participants will be done in an effort to explore the meanings the parents attach to their experiences.

The purpose of this study is to gain greater understanding of the lived experiences of parents who have a child diagnosed with deafness, and the meaning they make of these experiences. The literature has demonstrated that a critical window exists for children who are born deaf in which communication and other deafness-related issues should be addressed in order to achieve the most promising outcomes. Greater understanding of these parents' lived experiences and meaning making may allow for a deeper knowledge of how the parents in this study addressed these and other issues, as well as the parents' own understanding of this critical window and their role in their child's treatment. Parents' lived experiences and the meaning they make of these experiences may be highly related to their child's future successes and difficulties. This study is valid in part due to the potential implications for professional practice, for the professional knowledge base,

and for programs training future counselors. Even greater than these are the implications for children diagnosed with deafness and their parents and families.

The exploration of this topic will continue in the following chapters to include an explanation of the study's design and methodology, the results of the research, and finally, a discussion of the results, conclusions, and suggestions for further research



## CHAPTER 3

### METHODS

This study seeks to contribute to the body of professional knowledge related to the lived experiences of parents who have a child diagnosed with deafness and the meaning made by these parents of their experiences. Although it may be possible to measure certain aspects of the parents' lived experiences using instruments and rating scales, this sort of inquiry could only provide the researcher with high level, aggregate data regarding parental likes/dislikes or approval/disapproval of certain aspects of their experiences.

While this data could be useful for some studies, the purpose of this study is to understand the nuances of the parents' lived experiences and the meaning they make of their experiences. As such, this study collects data related to the problem that is in the parents' own words and describes their lived experiences in as much detail as they are able to provide. This depth of understanding is not easily accessed through quantitative inquiry.

Qualitative research designs fit well with the problem this study addresses and with the data this study proposes to collect and analyze. According to Glesne (2011), researchers using qualitative designs see their role as being “that of accessing others’ interpretations of some social phenomenon and of interpreting, themselves, other’s actions and intentions” with the goal of “understanding human ideas, actions, and interactions in specific contexts or in terms of the wider culture” (p. 8). The purposes of this type of research are to gain understanding and provide interpretation, as opposed to

more quantitative designs, which seek to provide causal explanations that may be generalized to a population and used for prediction (Glesne, 2011). This research study does not seek to provide causal explanations or generalities, but to gain a deeper understanding of the participants' lived experiences and meaning making, and thereby increase the professional knowledge base related to this particular population.

### **Design**

This study used phenomenological research as its qualitative paradigm. Phenomenological research was an appropriate design that fit well with the focus of this study, which was to gain a deeper understanding of the lived experiences of parents who have a child diagnosed with deafness and the meaning these parents make of their experiences. The focus of this paradigm is on not only understanding human experiences, but also moving beyond the facts of experiences to look at the commonalities of experiences (Jones, 2001; Pringle et al., 2011). In phenomenological research, the researcher interviews participants regarding their lived experiences and the meaning they have made of their experiences as related to a particular phenomena of interest. Therefore, qualitative inquiry and phenomenological design were an appropriate fit for this research study.

Among the various other qualitative research paradigms, phenomenological research seems to be the most appropriate choice. Case study focuses more on the issue or problem than on the individual being interviewed regarding the issue (Creswell, Hanson, Plano Clark, & Morales, 2007). Grounded theory research focuses on processes and collects data related to the processes in order to create a theory using the collected data. Narrative research collects the participants' stories over time, organizes the stories,

and analyzes them in order to discover meanings, commonalities, and patterns within the stories themselves. Participatory Action Research is a form of qualitative inquiry that overtly seeks societal change as an outcome of the research (Creswell et al., 2007). Although the number of qualitative research designs far exceeds the appropriateness of addressing each one in turn as part of this study, the paradigms discussed above lend support for the researcher's choice of phenomenological research as the chosen paradigm. The above paradigms do not focus on the collection of data specifically related to individuals' lived experiences and meaning making, as well as the commonalities of those experiences, which is the focus of this study.

### **Role of the Researcher**

For the purposes of this research study, the researcher acted as interviewer, transcriber, and primary coder. After the researcher established contact with the potential participants and they agreed to be part of the study, the researcher scheduled an individual interview with each participant parent. The researcher visited participants in their homes, or other mutually agreed upon locations, in order to conduct the interviews. During the initial contact and the interview process, the researcher worked to build rapport and trust with the participants. The researcher did not take the role of a disinterested observer, but attempted to engage the participants and share with them regarding experiences related to the research and working together as appropriate. Engaging and sharing with participants may have encouraged rapport and trust building, which may have lead to participants sharing a greater quantity and quality of information than they might otherwise have been comfortable sharing.

Once the interviews were completed, the researcher transcribed the interviews and shared the transcriptions with the participants in order to confirm accuracy and resolve any outstanding issues. Participants had an opportunity at this time to clarify any statements made during the interviews, to affirm or disaffirm their belief that the transcriptions were accurate, and to share any additional thoughts or concerns related to the interviews and interview questions. No data was added or withdrawn by the participants. After the researcher and the participants agreed on the accuracy and completeness of the interview transcriptions, the researcher began the process of analyzing the transcripts by hand in order to identify relevant themes and common patterns from each individual interview and across interviews. The researcher enlisted two additional individuals to assist with the analysis and to triangulate the data and increase confidence in the conclusions. Once the analysis was completed, the researcher contacted participants by email to share the results of the study and confirm the relevance and applicability of the findings.

### **Researcher as Instrument**

#### **Training and Background**

I hold a Bachelor's degree in Psychology and a Master's degree in Rehabilitation Counseling from a public university in the Southeastern United States. Additionally, I worked as a counselor for the South Carolina Department of Mental Health - Deaf Services from 2008 until 2012. At the time this study was conducted, I have been working on a doctorate of Counselor Education and Supervision since 2011.

### **Assumptions Related to the Research Questions**

Based on my prior knowledge of this population and the information found during the literature review, I made assumptions related to the lived experiences of parents who have a child diagnosed with deafness. The following are several of these assumptions:

- Parents may have encountered difficulties receiving an accurate diagnosis of their child's deafness.
- Parents may have had a number of difficult experiences related to their interactions with medical professionals, mental health professionals, and educational professionals.
- Parents may have experienced a grief and loss process related to their child's diagnosis.
- Parents may have difficulties communicating with their child.

Additionally, the following are several of my assumptions related to the meaning these parents have made of their experiences:

- Parents' understanding of their parental role and their sense of self-efficacy may be affected by their lived experiences.
- Parents' view of their child may be affected by interactions with others, including professionals, family members, and friends.
- Parents who are able to communicate with their child effectively may experience meaning making differently than parents who are less effective with communication.

During the interview process, I attempted to remain aware of these and other assumptions I made regarding these parents' experiences and meaning making, and attempted to

bracket these assumptions so that they did not negatively affect my rapport with interviewees and the data collection process.

### **Interview Questions**

The researcher developed the following interview questions using a method of phenomenological research that focuses on four separate cognitive processes that are central to consciousness and experience and are engaged in by all individuals, assuming no cognitive disability (Lonergan, 2003; Perry, 2013). These processes are experiencing, understanding, judging, and deciding, and they all occur within a particular context and situation. The following interview questions were developed using prompts based on Perry's (2013) Transcendental Method for Research with Human Subjects. The questions are related to the interviewees' cognitive processes and to their developmental context.

The researcher developed the initial set of questions in order to guide the study participants "into a self-reflective mode of inquiry," to access their cognitive operations in the aforementioned areas, and to explore their lived experiences within a situational context and the meaning they have made of their experiences (Perry, 2013, p. 266).

Based on this phenomenological research method, the questions were aligned as follows:

- Question 1: Experiencing: Can you tell me about the time when you became aware of your child's deafness?
- Question 2: Understanding: Can you tell me about any significant questions or concerns you have had since your child's diagnosis and how you have sought out answers to the questions/concerns?
- Question 3: Judging: Can you tell me about any conclusions you have reached about being the parent of a child diagnosed with deafness?

- Question 4: Deciding: Can you tell me about any decisions you have made since becoming the parent of a child diagnosed with deafness that stand out to you or seem important?
- Question 5: Developmental Context of the Study Participant: How has this experience influenced your development as a parent?

The researcher conducted two pilot interviews (pilot interviews included one father and one mother). The purpose of these interviews was to verify the connection between the interview questions and the research questions. Additionally, pilot participants were given the opportunity to provide feedback relative to the interview questions. No changes were made to the interview questions after the pilot interviews. The pilot interviews were included in the data conducted during the study, and the data was analyzed as a complete data set.

### **Context, Procedures, and Methods**

This research study focused exclusively on parents who have a child diagnosed with deafness. The participants for this study were recruited from the client base at Beginnings SC, which is a non-profit organization in South Carolina that addresses communication and other needs of parents who have a child diagnosed with deafness. This organization does not provide early intervention services per se. It provides counseling as an initial step to connecting parents with resources to address the family and child's deafness-related needs. This counseling focuses specifically on the grief and loss process and psychoeducation related to better understanding deafness. The researcher accessed these parents through the staff at Beginnings SC, who informed their clients of the possibility of participating in this research study, and ascertained the

clients' interest and their willingness to participate. Contact information for the clients who agreed to be contacted was sent to the researcher, who then made contact by phone or email with the potential participants, responded to any initial questions, and scheduled interview appointments.

During the initial planning stages for this research study, the researcher considered a number of available referral sources in South Carolina. The researcher conducted a Google search using the following keywords: resources, deaf, individuals, families, and South Carolina. This search identified the following potential referral sources: South Carolina School for the Deaf and Blind, South Carolina School for the Deaf and Blind - Career and Technology Education/Postsecondary Programs, South Carolina Department of Education - Office of Exceptional Children, South Carolina Vocational Rehabilitation Department - Deaf and Hard of Hearing Services, South Carolina Department of Mental Health - Deaf Services, South Carolina Association for the Deaf, and Beginnings SC.

All potential referral sources other than Beginnings SC were eliminated due to their mission or focus. The two resources connected with the South Carolina School for the Deaf and Blind and the South Carolina Department of Education were eliminated due to their focus on the education of children. The South Carolina Vocational Rehabilitation Department was eliminated due to its focus on employment and vocational needs. The South Carolina Department of Mental Health was eliminated due to its focus on the treatment of mental illness. The South Carolina Association for the Deaf was eliminated due to its focus on advocacy for all Deaf individuals in the state. Beginnings SC, with its stated mission of "empowering parents of children who are deaf or hard of hearing



through education and support," is the resource most likely to connect the researcher with the parents who are the focus of this study.

During the initial contact with the participant parents and during the interviews, the researcher attempted to establish rapport and a working relationship with the participants. In order to establish rapport and a working relationship, the researcher shared with participants his personal history as it pertained to the current research, and described his reasons for interest in the topic. The researcher attempted to answer all participant questions related to the researcher and the research study in a way that was clear and open. Additionally, the researcher described how this research could be of benefit to future families who have a child diagnosed with deafness and the counselors and other helping professionals who work with them.

### **Ethical Protection of Participants**

Participants received a document regarding involvement in the research study, and the researcher reviewed this document with participants to ensure understanding. The document addressed topics including any reasonably expected risks, potential benefits of the study, a description of how confidentiality will be maintained, and a statement clarifying the voluntary nature of the research that explains the right of the participant to discontinue participation in the research study without any negative impact. As part of the documentation, information was provided detailing the researcher's role in relation to the participants and the researcher's and research supervisor's contact information. The document was written in clear, easily understood, and concrete language.

The interviews were recorded using an HD video camera and a digital voice recorder for redundancy. In order to maintain confidentiality, participants were not videoed directly in such a manner that they could be visually identified. Prior to beginning the recordings, the researcher requested participant consent to be recorded and addressed any participant concerns regarding confidentiality. In addition, participants were given the option of using a pseudonym during the recorded interview, however, no participants desired the use of a pseudonym. All identifying participant information was redacted in written documentation. Removing identifying information protected participants and their families from being identified by readers of the study. Participants may have felt a greater degree of comfort sharing their lived experiences and meaning making with the knowledge that they were protected from identification through their anonymity.

In addition to the use of these procedures to protect participants, the researcher engaged in ongoing evaluation of all practices during the research study to ensure that the research was ethical, safe, and was in the best interests of the participants. The researcher did not identify ethical or safety related needs, and did not adjust practices in an effort to maintain ethics and safety.

### **Selection of Participants**

Participants in the study were selected from among the families who were clients of Beginnings SC at the time of the study. As such, the participants resided in South Carolina and had a child diagnosed with deafness at the time of the study. The staff at Beginnings SC provided client families with information about the study. For the purposes of this study, participants were individual parents as defined by the definition

set forth in Chapter 1. Any parents who agreed to be contacted by the researcher and to participate in the interview were eligible to participate.

Participants for this research study were limited to twelve individual parents. These parents represented six heterosexual couples from intact families. The researcher interviewed six male parents and six female parents individually for this study, in order to have each group represented equally in the findings. The limitation on the number of participants was due to the planned depth of inquiry. The focus of the research study was the lived experiences of parents who have a child diagnosed with deafness and the meaning the parents have made of their experiences. An interview with each individual parent elicited their stories related to these topics in an effort to understand the parents' experiences and the meaning made of their experiences in great depth. The researcher anticipated collecting lengthy and involved stories during each of the interviews, which became the data used to identify phenomenological themes. This data focused on the lived experiences of each individual parent separately.

The researcher chose the number of interviewees based on the desire to reach saturation of the data collected. Data saturation is a concept that describes the point at which a researcher has collected all relevant data specific to a particular topic and is finding only redundant data as he or she continues that data collection process (Glaser & Strauss, 1967; Guest, Bunce, & Johnson, 2006). According to Glesne (2011), it is difficult for researchers to know when the point of data saturation has been reached. Additionally, researchers may incorrectly assume saturation has been reached due to unfavorable conditions, such as a pool of participants that is not large enough to represent a true breadth of available data related to the topic. A review of the literature reflects this

difficulty, with limited information being found to support a specific number of interviewees that can be assumed to lead to data saturation. In conducting this study, the researcher found that saturation was reached by interviewing twelve participants. However, it is possible that saturation was reached with twelve interviews due to the homogeneity of the sample. Further studies that have greater diversity in the sample of participant parents may require a greater number of interviewees in order to reach saturation.

An article written by Guest, Bunce, and Johnson (2006) sought to address this lack of information by doing a post hoc analysis of their data collection and analysis processes during a qualitative study in which they interviewed sixty female sex workers in West Africa. After examining their procedures, the researchers determined that "data saturation had for the most part occurred by the time [they] had analyzed twelve interviews," and that after this number, "new themes emerged infrequently and progressively" (Guest et al., 2006, p. 75). These researchers also found that the definitions they used in coding stabilized at twelve interviews. Reaching saturation and code definition stability at twelve interviews was attributed to the similarity of questions asked of all interviewees, the content of the study being a topic that was familiar to all participants, and the homogeneity of the participant sample (Guest et al., 2006). In discussing the results of their analysis, the researchers also indicate that for research involving "high level, overarching themes...a sample of six interviews may have been sufficient to enable development of meaningful themes and useful interpretations" (Guest et al., 2006, p. 78).

## **Data Collection and Analysis**

Data collected included demographic information for each participant and all recorded participant responses to the interview questions. The researcher collected demographic information from each participant prior to the beginning of each interview. Demographic data the researcher collected was based on demographic data collected in prior studies by Bingham et al. (2012), Bosteels et al. (2012), Jackson et al. (2008), Luckner and Velaski (2004), and Snell and Rosen (1997). The collected demographic data included the following: Mother/Father; Parent Age; Educational Level; Employment; Ethnicity; Children in Family; Family Income; Type of Family: Two Parents, Single Mother, Single Father; Location in South Carolina; Community Type: Urban, Suburban, Rural; Community Size: Small, Medium, Large; Number in Family who are Deaf; Child's Age; Child's Age at Diagnosis; Child's Sex; Hearing Loss of Child: Moderate, Severe, Profound; Communication Method; and Sensory Device.

The interview questions were directly related to the research questions outlined in Chapter 1. Responses to these questions were collected during the interview with each individual parent. The researcher recorded the interviews using an HD video camera and a backup digital audio recorder, and then the researcher transcribed the interviews. After all interviews were completed, the interviews were transcribed. The transcription included all spoken dialog and notated nonverbals such as pauses, laughter, and added emphasis. This was done in order to capture all relevant data that may be used in the process of analysis and interpretation. Participants had the opportunity to review their interview transcripts for accuracy and clarification.

After the researcher transcribed the interviews, the researcher and two assistants analyzed the interviews by hand to identify relevant themes and common patterns. The analysis process utilized in this research study was based on that proposed by Smith, Flowers, and Larkin (2009), and is as follows:

- Read transcript through several times, making notes and comments.
- Identify and label emerging themes and meanings with the text.
- Relate back and link themes to quotes in text, using a cyclical process.
- Look for potential links between themes that may lead to master/super-ordinate themes.
- Repeat the process with subsequent transcripts.
- Connect/cluster the themes from the texts into super-ordinate themes, with related subthemes.
- Examine texts more closely for greater depth of meaning and interpretation.
- Produce a summary table of themes for the group, and a detailed, interpretive, reflexive written account. (Pringle et al., 2011, p. 15)

Prior to beginning the analysis process, the researcher and the two assistants met to discuss the analysis process and address questions or concerns. At this meeting, the researcher provided the coding assistants with hard and soft copies of the interview transcripts. After completing the analysis process, the researcher and the assistants met to review the line-by-line analysis of the transcripts. The researcher and the coding assistants discussed each emergent theme and meaning in the transcripts, as well as the process of coding itself. As part of the analysis process, identified themes were noted for

each case and across cases. Discrepancies in the identified emergent themes and meaning were resolved through researcher and assistant discourse and agreement on all of the identified themes and meaning. After this meeting, the researcher finalized the themes and interpretation and presented them to the coding assistants for review and feedback. After the assistants had an opportunity to provide feedback, the researcher sent the themes to participants via email. Participants were encouraged to provide feedback related to the identified themes and interpretation. Participant feedback, both positive and negative, will be recorded and noted in the results of the study.

### **Summary**

The purpose of this study is to gain greater understanding of the lived experiences of parents who have a child diagnosed with deafness, and the meaning these parents make of their experiences. The researcher has identified phenomenological research as the type of qualitative inquiry that is most appropriate for addressing this topic. During the course of the research, the researcher's role will shift between that of interviewer, transcriber, and primary coder. The researcher has chosen parents who have a child diagnosed with deafness as the population for this study.

Participants will receive informed consent documentation that they will review with the researcher before beginning the interview process. The researcher will maintain and protect participants' confidentiality by not filming them directly, and by using pseudonyms. For the purposes of this study, the researcher will conduct one individual interview with each participant parent. Once the interviews are complete, analysis of the data will commence with results being reported at the completion of the analysis.

Chapters 4 and 5 will contain details regarding the collection and analysis of the data, as well as what meaning may be derived from the collected data.



## CHAPTER 4

### RESULTS

The purpose of this research study was to document the lived experiences of parents who have a child or children diagnosed with deafness. This research was done to gain insight into the experiences of these parents and the meaning they make of their experiences.

The following research questions were the foundation upon which this study was built:

- 3) What are the lived experiences of parents who have a child diagnosed with deafness?
- 4) What meaning do these parents make of their experiences?

During interviews, the researcher asked participants to share their lived experiences related to being the parent of a child or children diagnosed with deafness, and to share the meaning they made of their experiences. Interview questions focused on the time when parents learned of their child's deafness, questions the parents had and how they sought answers to their questions, conclusions the parents made related to being the parent of a child diagnosed with deafness, decisions parents made that seem significant, and how the parents believed the experience shaped them as a parent. The findings detailed in this chapter are based on the analysis of the transcribed interviews.

This chapter begins by describing the process of data generation, data gathering, and data recording, as well as the systems used for tracking data and emerging understandings. Findings of the research study are then reported, as well as discrepant

cases and non-confirming data. The chapter ends with support for the evidence of quality.

## **Process**

### **Data Generation**

The researcher prepared an invitation letter explaining the research process, the goals of the research, and the participants' rights, and forwarded the invitation letter to Beginnings SC. The staff at Beginnings SC emailed the letters to nine of their client families who have a child or children diagnosed with deafness. Six of the nine families responded to the email invitation, and the researcher scheduled interviews with the six families.

The data generated by this research study and reported in this chapter is based on participant responses to the interview questions outlined in Chapter 3. For this research study, the researcher conducted twelve individual interviews with twelve participants who each self-identified as a parent of a child or children diagnosed with deafness. These participants represent six married, male/female couples. The participants all resided in South Carolina at the times of the interviews. All participants indicated that they lived in a suburban community, with ten participants indicating their community was of a medium size and two participants indicating their community was of a small size. All participants identified ethnically as being White or Caucasian.

Of the twelve participants, six participants identified as fathers and six participants identified as mothers. All participants identified as being part of two parent families. The participants ranged in age from thirty-two years old to fifty-five years old. In terms of educational level, two participants completed high school, one participant

completed some college, one participant earned an associate's degree, three participants earned bachelor's degrees, and five participants earned a master's degree. Three participants identified as "stay at home wives/mothers" or "housewives," one participant identified as "retired," and eight participants identified as working "full time" or by their chosen profession or the name of the company/business for which they worked. In terms of family income, one participant did not report family income; two participants reported family income of \$25,000 - \$35,000; four participants reported family income of \$65,000 - \$75,000; and five participants reported income of greater than \$75,000.

Eight of the twelve participants (four couples) reported having two children in their family; four participants (two couples) reported having three children. Ten of the participants indicated they have one child in their family diagnosed with deafness, while two participants (one couple) indicated they have two children diagnosed with deafness. Children diagnosed with deafness in these families ranged in age from three years old to fourteen years old. Six participants reported having a male child diagnosed with deafness, four participants reported having a female child diagnosed with deafness, and two participants reported having a male and a female child diagnosed with deafness. Participants reported their child's age of diagnosis ranging from at birth to three years old, with all children reported as having severe to profound hearing loss. All participants reported the use of spoken language with their children for communication, with four participants indicating their children used some sign language in addition to spoken language. While it was not true of all clients at Beginnings SC, all participants in this study reported their children used cochlear implants as a sensory device.

## **Data Gathering**

During the course of each interview, the researcher asked the participant parents to respond to the questions outlined in Chapter 3. In their responses to the questions, the participants shared their lived experiences related to being the parent of a child diagnosed with deafness and their meaning making related to their experiences. The participants' narratives all contributed to the themes identified in this research study. Not all participants described or discussed each identified theme. Primary themes were discussed by at least three participant parents.

## **Data Recording**

The researcher recorded participant interviews using a digital audio recorder device as the primary recording device and a high definition video recorder as a backup device in the event of primary device failure. The researcher did not directly film participants during the interviews in order to protect confidentiality. The researcher used the interview recordings from the digital audio recorder as the primary data source for the purposes of interview transcription and analysis.

## **Systems for Tracking Data**

Upon completion of the interviews, the researcher transcribed the interviews using Dragon Naturally Speaking Premium version 11 voice to text software and Microsoft Word 2007. The researcher used a "stop/start" method of transcription in which he played a brief portion of interview dialog, paused the recording, and then spoke the interview dialog into a microphone connected to a computer running Dragon Naturally Speaking and Microsoft Word. After completion of the interview transcription using this method, the researcher would then replay the interview while reading the

transcription in order to verify accuracy. The researcher made corrections to the transcriptions during the review and verification process.

Upon completion of the transcription, the researcher and two coding assistants conducted a line-by-line analysis of the twelve interviews using the methods described in Chapter 3. The coding assistants were both doctoral student peers of the researcher in the Counselor Education and Supervision program at the University of South Carolina. Although both coding assistants identified themselves as counselors, neither identified as a Rehabilitation Counselor. Additionally, neither assistant indicated familiarity with the focus of the research study, nor with the previous literature. During the coding meetings, the coding assistants presented their analysis and codes prior to the researcher, in an effort to minimize potential bias and threats to objectivity. The researcher kept notes regarding themes and meanings on hard copies of the interview transcripts. Themes and meanings identified by the researcher and the coding assistants were similar. During the processing of the coding, there was consensus among the researcher and the coding assistants related to the identified themes and meanings.

Upon completion of the coding process, the researcher created tables using Microsoft Word to organize the themes and meanings and their supporting quotes. The researcher organized the collected data by categorizing the data as fathers' experiences and meaning or mothers' experiences and meaning. Experiences were further categorized as cognitive, behavioral, or affective experiences.

### **Findings**

The researcher and the coding assistants identified thirty five themes during the process of coding and analyzing the interviews. Twenty eight themes were in the

category of experiential. Nine themes were in the category of meaning. The following sections take a closer look at these categories. The researcher organized the experiential themes using the categories "Experienced by Both Fathers and Mothers," "Experienced by Mothers," and "Experienced by Fathers." The experiential themes are further organized into the pre-selected categories "Cognitive," "Behavioral," and "Affective." The researcher chose these categories based on Van Manen's (1990) statement that phenomenology's "aim is to construct an animating, evocative description (text) of human actions, behaviors, intentions, and experiences," (p. 19) and on Byrne's (2001) assertion that phenomenological interviews explore "thoughts, feelings, concerns, and worries" (p. 831). The themes related to meaning are organized using the categories "Meaning Making of Both Fathers and Mothers," "Mothers' Meaning Making," and "Fathers' Meaning Making." For the purpose of reporting the findings, parents with corresponding numbers represent one couple. For example, Father #1 and Mother #1 are the parents in one family.

The following twenty-eight themes are related to the lived experiences of parents of a child or children diagnosed with deafness. Both mothers and fathers discussed the initial eighteen themes, and quotes from both mothers and fathers are included in support of these themes. A summary of the findings related to lived experiences are presented in Tables 4.1, 4.2, and 4.3 at the end of Chapter 4.

### **Lived Experiences of Both Mothers and Fathers**

#### **Cognitive**

**Awareness of deafness at birth.** Both participant mothers and fathers discussed having an awareness of the potential for deafness at or near the time of their child's birth.

The parents described this awareness being due to their child failing one or more newborn hearing screens.

Father #3 described the experience in this manner:

It was probably a couple of days after my son was born. They did the newborn hearing screening and he failed it, I believe four times.

Father #6 commented:

Our son, our second child overall, and the first child that was diagnosed with deafness, deafness entered into the equation with him, I believe, the day after his birth when the newborn hearing screening, he failed that screening.

Mother #2 described not receiving an official diagnosis until several weeks after her child's birth, yet being aware of an issue with her child's hearing prior to the diagnosis.

We were, she failed her newborn hearing screening which was a red flag and then we began to watch her, after that we had her screened again. She did a screen at six weeks at a local audiology office and failed that screen. Then we went down to MUSC and they did an ABR and she was diagnosed with severe to profound hearing loss at that point and that was at seven weeks old. So, the official diagnosis was seven weeks old but we were aware something was not right as a newborn.

Mother #6 described her son failing the newborn hearing screen several times.

So, that newborn hearing screening, he failed it. Okay. Come back. I think they did that a couple of times before we left the hospital. And they told us to come back in two weeks. He failed it again.

**Clinical process.** Participant fathers and mothers discussed their experiences with the clinical process used to diagnose their child's deafness. Parents described this process as beginning when their child failed the initial screening and continuing after discharge from the hospital.

Father #1 shared the following account of the clinical process:

In South Carolina, many of our hospitals do an at birth screening, and so the day after he was born I took him down to the room where the technician - I believe her name was Jennifer, if memory holds - put some electrodes on him, on his head, and little tiny earplugs, and then ran some diagnostic tests, and said that he didn't respond.

So we came back a couple of weeks later and he did not respond again, uh, to the screening, and so then we went to, uh, we were referred to an audiologist who ran a, uh, a little bit more in-depth testing on, uh, and she determined at that point he had a moderate hearing loss.

Father #6 described the clinical process as one that required several tests over the course of more than a month in order to diagnose his child's deafness.

When the second newborn hearing screening, I believe a week later approximately, he failed that one as well. Definitely became much more of a greater possibility in our minds. So we scheduled testing with an



audiologist at that point. I believe there may have been one more newborn hearing screening, but that initiated a series, over the coming month and a half to two months, of doing several tests, all of them building the case for deafness and confirming that this is a lack of ability to hear in this child.

Mother #2 shared that in her family's experience, the clinical process took several weeks based on the scheduling of a follow up appointment.

Yeah the newborn screening, you know, obviously, newborn, we are still in the hospital so, and then when we were discharged they had set up the appointment for her. They set it as a six-week follow-up at a local audiology office and so we just that appointment and went at that point when she was six weeks, so when she failed that screening they suggested diagnostic tests.

Mother #6, who has two children diagnosed with deafness, shared about the clinical process being more expedient when her second child was born.

With our second child, she failed her newborn hearing screening in the hospital and the screener, you know, said, "we'll do this again tomorrow." And really didn't know that we had a deaf child already. So I do think that they came back in and maybe screened her again and she failed it. But at that point we were, I think I e-mailed [audiologist], and said she, "failed her screening." She called me and said "when can you come" and we took her at about two weeks, we took her to Charleston. And they did, I guess it was an ABR, and I'm terrible with all of the names of the tests and everything that we did, but within just a few minutes she knew that it was

profound and we went ahead and had the genetic testing done at that point while we were there, and things moved a lot faster with our daughter because we knew what to do.

**Implantation and communication decisions and questions.** Participant parents discussed the decisions they made related to implantation and communication as well as the questions they had regarding the implantation process and communication options. This decision was described by Father #4 as "the biggest decision we had to make."

Father #2 described the concerns that drove the family's decision to implant their child.

I think the big one is choosing to have her implanted with the cochlear implant. She was in a very gray area even with her right ear, the severe to profound. She wasn't really getting much access with a hearing aid in that ear so we just felt that was, that the cochlear implant was going to give her the best access to succeed. It was just going to make things easier for her in life. And so I know that's, to me that's the biggest decision.

As Father #6 and his family considered implantation and communication options, he reported questions related to the impact of his child's deafness on future relationships.

We knew, and will be able to, and were willing to do whatever it takes to communicate, to learn to communicate with our child, but will our families, our extended families, have the same kind of relationship that they have, will they have the same kind of relationships with our deaf child that they have with our hearing child?

Mother #3 discussed questions and concerns she had related to the opinions and beliefs of the Deaf Community regarding cochlear implantation.

Yeah, I guess the two biggest were the decision whether or not to implant. Well, you know, when you did it, obviously, and I'm sure you know, some very different opinions about cochlear implants. That was something I'd read about, the deaf community in general, especially. Some of the more outspoken ones, who very much hold dear their community and their language. You know, were we doing the right thing for him? Were we taking away something from him, the culture that he would have been a part of. But really, the culture-- I don't know any deaf people. We're not really in a deaf community, and I don't know anybody that signs. I don't know how to sign. I do feel like we would have hindered him by not getting the implants. So, that was probably one of the biggest decisions.

Mother #6 briefly shared regarding the significance of the decision to implant.

Definitely getting cochlear implants was a huge decision that gave them an opportunity to hear. That's been the biggest impact I think, for them, that we could do.

**Decision making process.** Participant mothers and fathers shared about their experiences related to the decision making process and the factors that influenced their decisions.

Father #1 shared the following statement regarding his decision making process:

I had just been doing some research on the Internet and the like about, uh, the deaf community and their, and many of, many with their rejection of

the cochlear implant as a cultural, end of a culture, uh, and I was a little concerned about that, but decided, we decided to take him with the audio – verbal approach to give him, uh, more of a chance at a mainstream life.

Father #4 shared the following when discussing the factors that influenced and informed his decision-making:

Just more or less the research that I read about cochlear implants.

Listening to the professionals tell me about it, and everything.

Mother #1 shared her experiences with the professionals who were a part of her family's decision-making process.

Well, fortunate for us, the folks that, our son wore hearing aides to begin with, and the audiologist that fitted him was closely tied into MUSC and the cochlear implant candidacy process. And she was very up front with us when she said "I can't help your son anymore. I think he is a candidate for a cochlear implant." I think if we were perhaps with someone else that just wanted to sell us another hearing aid, you know, instead of focusing on our son we'd be in a different boat.

Mother #5 spoke about information she found in her personal search for information and the impact of the information on her decision-making.

I did do a lot internet research, a lot of it. I called. I would go on the internet, there's not, at that point again, fourteen years ago, it's not quite the same that you can get now, so I would find out the various agencies and I would call, and they would send me information. Like I remember the, remember about, probably still have the information somewhere but

one, it was definitely a deaf culture advocacy kind of agency, and they sent me information, that packet. And in it I read a story about a child who was deaf, and the isolation that he felt. And the isolation was because his parents, although they learned some sign language and they chose that for him as his primary means of communication, the mother was the only one that really excelled in the sign language. Then the child surpassed her, eventually. At family functions he was often left out unless the parent was able to sit and interpret for him. It was really a sad story and I'm glad that they included it in their information. I think their purpose was more to say, "It's your responsibility for everybody in your family to learn this mode of communication." But we're asking everyone in our family to learn American sign language for our child. And the likelihood of that happening was very low. We had everyone in our family saying, "Hey, we will do whatever you need us to do." But at the same time, reality is, people have lives. And we were in the midst of a crisis and of course they're going to do everything they need to do. But are they going to practice sign language everyday in their own homes, because you need to in order to do it? Well, for us we would have only been speaking with him and it would have been a long journey. When we realized that wasn't our only option, we decided to do something else.

**Education/school/school system.** Participant parents reported both affirming and disaffirming experiences related to their child's education and the school system.

Father #4 made the following statements related to his child's education:

The biggest concern I have is her education and the ability to obtain an education. Yes sir, the educational system lacks a lot in teaching a deaf child.

This father also indicated that he believes the educational system is lacking in the following areas related to his child:

Knowledge on how to reach and to make a deaf child understand. The techniques to teach them.

Conversely, Father #2 reported experiences with the educational system providing needed resources.

Once, we've gotten to the point now where she is three and now are kind of involved in the school district stuff. They get involved and offer their services. Now we've stepped back a little bit from, well I don't want to say stepped back, but now she is involved with school, like our speech was at home twice a week where this therapist came to the house and now that the school district is involved her speech is done at her preschool.

Basically it's almost three times a week. From that aspect we're not involved as much because her speech is there versus being here at the house but when you do the speech therapy here at the house and we were still taking her to MUSC twice a month you're doing a lot.

Mother #4's statements regarding her child's education also focused on the difficult experiences her family and child have had finding appropriate educational resources.

I would think finding someone who can help her, because she's not really getting it at school. It's just hard to try and find something, someone to help do this. To help her out. It's still ongoing research because we are fighting right now with the school. I think that she needs an interpreter but the schools thinks that she don't. That's kind of a hard place because she still doesn't understand what's going on in school. If her hearing aid and cochlear go out then there's nobody there to teach or for her to watch to see what's going on because nobody knows it. She's left sitting there not knowing anything.

In contrast, Mother #6 shared about the variety of education related options she and her family have identified for their child.

Yeah, and just, there's just so many options out there [laughter] that to think when he was a baby, when our son was a baby, to think what I thought his life was going to look like, it hasn't, none of that has been a way we've needed to go. I think we've been able to just do what we would do for, just as we've done for our child who has normal hearing. We don't feel like we have to make special decisions just for him, although that was a question I had early on.

**Big questions.** Participant parents shared about the "big" questions they had about their children that focused on long-term wellbeing and overall success in life.

Father #6 shared the following "big" questions he had about his children.

Really, we wondered, will our kids, just from a point of ignorance, we wondered will our kids be normal? Questions about current time but also

future times. Will they be able to find someone to marry? Will they be able to find employment?

Father #2 discussed his and his family's initial concerns for their child, and the questions related to those concerns.

So, to come from where we were at the beginning, nonstop worry. Here I was at the time I was working at an amusement park and all I would do is just walk around and look at kids and see them laugh and run around. Is my daughter ever going to be like this?

Mother #1 also discussed this early fear and questions about the future.

Gosh. Tons. I guess initially, you know, we were just being frightened, not knowing how he is going to get along in the world.

Mother #3 shared about her "big" questions related to the success of their choice to implant her child.

The biggest concerns are concerns that a parent would have for their kids: Is he going to be different? Is he going to be able to talk? Is he going to be able to talk the way that his therapist and audiologist tell me that he's going to talk? Is it going to work? So we were hoping his, that they just worked and that he would actually end up talking.

**Resilience.** Participant parents shared about their and their family experiencing resilience as they have moved past their child's initial diagnosis and the early fears and questions.

Father #1 discussed his perspective on his and his family's experience of his child's deafness.



It is what it is. It's just life. We all have things that we've got to deal with. If it's whatever, you know we all have issues that we've got to deal with, and this is just another issue. Just another thing. That's what, that's life.

Father #2 shared about his family's decision to have other children in light of the knowledge they could have another child diagnosed with deafness.

So, obviously, I told you we have a little boy that's about to turn two. Knowing what we were going through at the time it still didn't slow us down from wanting to have another child and we were willing to take that chance that if he, if our other child was born with hearing loss we now know that it can be okay. We can give him access to sound or whatever it may be. It'll be okay. There are things out there, like I said if we had to go through the whole thing again we were definitely willing to do it.

Mother #1 (who also has a daughter with a visual disability) shared about her experience of her children's resilience as they grow and develop.

Today, I find I make it more of a deal than they do. I worry when, if my son is going to go somewhere, go to Carowinds, whether he's going to secure his processor properly when he gets on the roller coaster [laughter]. Or I worry about my daughter going to the mall and not being able to see everything. But they're like "mom, we are okay. Push us out of the nest."

Mother #3 shared about valuing resilience and encouraging it in her child.

I want to make a point with him to encourage him to do anything he wants to do, even if I feel like it's not like the safest, or his head might get hit,

but to encourage him in whatever he does. Because he can succeed regardless. So that's probably the biggest one that I've decided.

**Impact of technology.** Participant parents shared about an awareness of the impact of technological advancements on their children and the opportunities provided by these advancements.

Father #5 compared what might have been his experiences had he been born with deafness compared to his child's experiences today.

Especially in today versus you know if I had been born deaf in 1966, I would've gone to deaf schools and signed and would not have speech now, whereas my son has difficulties hearing in certain situations but he's able to assimilate and it, deafness, doesn't exclude him from anything I don't think. It's amazing. I remember [Dr. B.] was the surgeon who did my son's implants and he kind of offhandedly said, because we were talking about how, I think this may have been after he was implanted or before, I'm not sure. But anyway he said, I thought it was interesting, him being a professional, that he said, "yeah, it's practically magic." I thought as far as my mind goes it is magic. He's deaf but he hears pretty well.

Father #6 discussed the impact of cochlear implant technology on children's ability to access the world around them effectively.

I can't imagine a child with the possibility of having a cochlear implant having the same kind of ease of existing in a hearing world, not that there's not other outlets for someone who doesn't have that ability to hear through cochlear implant, but it's just that, that device does open up the hearing

world to them in a way that I don't know of any other intervention that can do that.

Mother #1 succinctly described cochlear implant technology as being "a true miracle in our house."

Mother #2 described cochlear implant technology as a tool to enhance children's lives, similar to other assistive devices.

Why would we not offer this, why would you not give your child glasses, why would you not give them a prosthetic leg? People live their life without those things but it's so much easier with it. That was sort of our philosophy; if we've got the access to it then we're going to get it.

**No personal experience with hearing loss.** Participant parents shared regarding their limited or nonexistent personal experience with hearing loss or deafness.

Father #2 shared about his lack of experience in the following statement:

At the time, I was never aware of hearing loss. Nobody in my family had it. It's just not something I had been around like that.

Father #3 shared similar sentiments in his statement regarding his lack of experience with hearing loss.

He was our first deaf child so we didn't know anything. We never looked into having a deaf child. We never thought that we would have a deaf child.

Mother #4 shared the following regarding her shock upon learning of her child's deafness:

It was shocking to find out that she was deaf. I went to school with a girl that was deaf when I was in high school, but other than that I didn't know anybody.

Mother #2 shared her surprise when she learned of her child's diagnosis of deafness. She indicated that deafness was not one of the potential issues she considered or was concerned with when she was pregnant, due to her lack of prior experience.

Yeah, we definitely did. We wanted to get some answers because deafness was not something that we were familiar with. It wasn't something that ran in my family. Not something that we had encountered in our social groups. So it was very new to us. It was very unexpected. Not something that we thought about at all during our pregnancy. You know you want to make sure your baby has a heart that works and its organs are there and it's got all its parts as far as we can see and tell throughout the pregnancy it did. So it took us very much by surprise.

## **Behavioral**

**Professional resources.** Participant parents shared about their experiences with professional resources and the significance these resources had for their children and their families.

Father #1 shared about his family's experiences with their school district, and the early education program they offered.

The school district here, has a program where they take kids who have speech and hearing issues and bring them into the learning environment early, uh, so that by the time that they start off in school, in kindergarten,

they are already acclimated to the classroom and have had, uh, several, uh, several, uh, or a long time within that environment, uh. That teaching is often times not directly hearing related, but doing other things, developing fine motor skills and the like, uh, so that the kid, the child, doesn't have to learn how to hear and cut with scissors at the same time.

Father #2 shared about the experiences he and his family had with their audiologist at the Medical University of South Carolina.

Thankfully, the audiologist at MUSC, she has a handle on all the great resources and she was there to be able to put us in contact with other parents. Like I said before, pretty much the majority of our answers, the majority of our questions were answered at MUSC. They have an amazing audiologist there, [M. Smith]. She was able to provide us with any answers we had or she was able to put us in contact with any people that we, that may help us.

Mother #1 shared about her family's lack of personal information related to their child's deafness and their need to trust the professionals.

We did what the professionals told us to do. I guess parents have intuition that they have to listen to, but we knew from the very beginning we had no expertise in this area at all. We just had to trust the people that were put in our path.

In contrast to the other parents interviewed for this study, Mother #4 stated the following about her family's experiences with accessing professional resources:

It is hard trying to find stuff to help her. It's not something that's really put out there. You've got to search for it. No. You've got to hunt for it.

**Commitment to treatment.** Cochlear implantation is a step in a lengthy treatment process that also includes an ongoing program involving appointments with a variety of doctors and therapists. Participant parents discussed the commitment to treatment that was required to ensure the greatest likelihood of their child's success.

Father #1 discussed his family's commitment to ensuring that his child attended all of his appointments and that the family did what they were required to do.

We did, and at the height of my son's therapy after being implanted he had as many as eight hearing sessions a week and my wife mostly carted him all over town. Just drove him from one place to another to another and we just fully committed to whatever the professionals told us we needed to do, we did. That was because we fully committed to giving our son the best possible chance that he had. That was one big decision, or one big commitment.

Father #2 shared about his family's daily work to engage their child in therapeutic activities.

Even in the evenings you're doing speech therapy stuff and everything, we call it the learn to listen. We're doing things. It's just a daily thing. We find ourselves sometimes when we're out at a restaurant or wherever just making it, you know, making things an activity for her to try and learn. I don't know. We have fun with it, and it's good.

Mother #2 shared about her family choosing to make lengthy trips in order to see the audiologist they believed was most qualified to treat their daughter.

That just wasn't a decision, however, we were put in contact with a local speech therapist who was great, but we also made a decision/sometimes sacrifice to continue having our daughter seen at MUSC with the speech therapist there, because she was certified in the type of therapy that we were made to understand/aware of through our research and through the contact with that therapist was the best thing for her. Our local speech therapist was not certified. It's the same style that she does, she just doesn't have the certification yet and we wanted also sort of that second opinion so we made those appointments as much as possible which was about a two-hour drive from our home and we were doing that anywhere from two to four times a month depending on what we could make and we were going twice a month. So that was, I suppose, a decision that we actually had to make to continue those trips to Charleston two hours away for her to get that additional therapy that she might not have gotten here.

Mother #5 discussed her family's decision to move to an area that would be the best fit for their child and his ongoing support and treatment.

So that's been a big thing and then when we moved here, we had an opportunity to move anywhere in the southeast, my husband's job as an Account Executive he was covering the southeast for his company and I remember we talked about it and we went to all these cool places, just sort of talked about where we want to live and we both came to the decision

that we really needed to live somewhere where there was a decent school system, not just for regular education but for special education, that we needed to live somewhere nearby an implant center and somewhere where we could feel the support of people who were similar to us in terms of having a child who was deaf.

**Advocacy/commitment to advocacy.** Participant parents discussed their experiences with advocacy. Some parents demonstrated advocacy by their willingness to share information and resources with other parents of children diagnosed with deafness, while other parents' advocacy efforts focused on self-advocacy for their child.

Father #3 discussed his family's efforts to meet with other parents and share their knowledge.

I think the most important thing that we have done is to talk to other parents with a deaf child. I know our audiologist and therapist, they recommended people. See, we came into this blind. So we had no idea and we've learned a lot and we're just kind of passing on our knowledge to other parents, more so my wife because she's a stay-at-home mom and I normally work during the days or sometimes nights. So she's more apt to talk to people but we have made a lot of friends that we continue to talk with and invite to parties and cookouts. We just had a couple of parents over a few weeks ago with their child that had an implant and we are just happy to pass on our knowledge that we've learned in all of our trials and tribulations that we've had to go through and to pass them on to another



parent or set of parents that have no idea what they're doing. I think we just, I think it's great that we're doing that.

Father #5 discussed his wife's efforts to advocate for their child with the school system.

Don't get me wrong, we've had, I think we've been very fortunate with the school district and they have been most accommodating, but not always as quickly and as appropriately as we would like and probably would not have been, period, if we were, my wife especially, were not so up-to-date and knowledgeable about what his needs were. She has kind of been driving that ship the whole way and I think the school district has learned quite a bit from the success that we've had through trial and error.

Mother #2 shared about her experiences with her child motivating her to become an advocate for parents who had less access to resources and support.

I think that's part of what made that process even, made me want to fight harder, because there's people who, I mean that is it. They don't have family. They don't have money. We could have scrounged the money somehow. We could have. It was our kid. We would have gotten the money. There's people who that's just not an option. And to think that they are going to get blown off because somebody hasn't signed a piece of paper and faxed it just infuriated me. I said it's not going to happen. So I became, I think somebody said one time, a bulldog [laughter]. I just became a more aggressive person. I chose the battles and I fight them hard.

Mother #3 shared briefly about learning to be an advocate for her child in the educational system.

I've kind of learned to be an advocate or a little, I'm not overly outspoken, but I learned that I have to kind of stick up for my kid a little more. Be more of an advocate, be assertive. It's important when you're the parent of a child who has IEPs, and I've learned that.

**Giving back.** Participants discussed "giving back" to the community of parents of children diagnosed with deafness by developing relationships with other parents and families, and by offering support and sharing information.

Father #2 shared about his family seeking out information and sharing the information with other families.

There's a celebration, a cochlear implant celebration they do in Orlando every couple of years. Anything like that we try to go to and get as much information as we can. Not only for ourselves, but we want to, like I told you before, we want to have all this information to pass on to other parents and to be there for somebody if they don't necessarily have the answers they can get the answers from somewhere or maybe they don't feel as comfortable. I don't know why I'm just saying this but maybe they don't feel as comfortable with the doctors and so they want to talk to a parent. They want to talk to somebody who's actually been involved. So we try to have those answers, to get all the information so we have those answers or we tell them, hey, if we don't have it we'll find a way to get you the information.

Father #4 discussed his work to gather information and make it accessible for other parents and families, due to his own difficulties finding information and resources.

I am currently compiling a big plethora of information because there's not, I mean, if you search on the Internet there's not just one kind of, I'd say one stop, of course I'm not going to try and make a one-stop, but just a place that's got ideas and places to go to look for answers about this, because we searched and searched for years to learn about sign language and it was not until I contacted the English department at Clemson University until I found out about their sign language program.

Mother #1 mentioned her family connecting face-to-face with other parents who have a child diagnosed with deafness.

We try really hard to reach out to folks. Not too many months ago we went out to supper with the family with a little baby that was getting implanted.

Mother #6 shared about her desire for other families to have the same access to resources that her family had.

You can only get that feel if you have experienced it, but just the desire for families to have access to what we had access to. For it to be that easy. To know who to call, and who to talk to, and the boxes to check so that you can get where you want to be.

**Proactive response.** Participant parents discussed proactively responding to their child's diagnosis by seeking out information and following up with involved professionals.

Father #2 shared his family's decision to follow up regarding his child's failed hearing screen, despite reassurances from professionals.

When our daughter was born we were told in the hospital that she failed her newborn screening test, but we were told right away by multiple people, "don't worry about it, you know, this happens all the time with kids, and for multiple reasons. It's no big deal. We'll get you something set up later." It was kind of like it was just, you know, put on the back burner. No big deal. Well, so we didn't think much of it, you know, necessarily. She was, you know you clap and do little things and you would see her move, like she's fine. There's no way that she can't hear. But we still followed up right away with our things. The first place we went to was a place up in Myrtle Beach and we did the testing there and she failed the screening there. And they also were saying, "well, we're having issues with our equipment and we're just not sure." It was just kind of a headache, you know. We weren't getting like definite answers. We decided right away somebody had referred us, somebody had told us about the clinic at MUSC. So we went ahead and scheduled an appointment right away and went down.

Father #6 shared about his family's awareness that they needed to educate themselves about their child's deafness prior to a confirming diagnosis.

Our son was the first child in any of our family to ever have a lack of hearing. We were very virgin to the idea of deafness, seeing it mainly just on TV and hearing about it on radio or things of that nature. It really was

an awakening to us, something that we immediately, even before it was confirmed, knew that we needed to educate ourselves on for the possibility that it was going to play out the way that it actually did play out.

Mother #2 described her proactive information seeking related to her child's diagnosis as a method of coping and managing the grieving process.

So by aggressively seeking information I think that was sort of our solace that kept us busy, help us move through that grieving process because we felt like we were doing something. So that constant seeking of information and knowledge, and we still do that now, we still, we go to any kind of function that we're able to get to.

Mother #3 also shared similar sentiments about her successful coping being tied to her decision to engage in proactive activity.

And it kind of came back to if there's something wrong-- I don't know if you're a parent, but you would do anything for a child, so if there was something going on I wanted to know about it, I wanted to know what we needed to do, and I'm better when I'm acting, like when I'm doing something about it, I wasn't going to sit back. So as soon as we could get appointments with the screening, and everything else, we were doing it.

**Community connections/engagement and support.** Participants discussed the value of connecting with a community of other parents and families who have a child or children diagnosed with deafness, who uses cochlear implants to assist with hearing. Parents related the value of this community in terms of emotional/social support and providing/sharing information.

Father #2 discussed the opportunity his family had to meet another family whose child had a cochlear implant before their own child was implanted.

Before our daughter was even implanted we were able to go and meet with the family that actually lived at the time maybe five miles from us. Their son was born with a profound hearing loss in both ears and he has bilateral implants. They invited us to their house and answered any questions we had. I don't want this to sound any certain way, but they let us see their child and the implants. They showed us his equipment and let us watch him and see how he does with his, he was able to communicate and talk.

Father #5 briefly described the value of a parent support group his wife established in terms of acquiring information.

So that was definitely for me the way that I got answers to our questions was through that.

Mother #2 discussed her family's willingness to share their experiences with other parents. She also shared about the value of sharing these "real life" experiences and the difference between these experiences and advice of professionals.

Yeah, we help, we talk about our experiences to folks just like our friends talked to us and people on the Internet talked to us about the things that the professionals can't tell you. They can give you the equipment. They can give you the documentation, but until you try and arrive home from the hospital with a kid with hearing aids in her ears and to get constant feedback from the car seat and the climbing out and all of those things they know about and they try to give you advice, but until you actually

have a kid doing it and I can call that person and say, hey, what did you do with little Johnny, because my angel will not keep her hearing aids in, or whatever it is. We actually had a very different experience than most people I think. Our baby was really good about [laughter] keeping her hearing devices on, but we tried all kinds of things and we're able to share that with people that the hearing professionals might not be able to or might not be as in tune to. I think they know all the things that we know probably, it just sometimes feels better coming from a person who's actually doing it.

Mother #5 shared about her experiences with the parent support group she created and the sense of support and community the group offered.

And it was very successful and still lives on to this day there are chapters all over North Carolina and the upstate of South Carolina and that was probably the best thing we ever did. It changed our lives because we had that community support. We were the first of our kind, we had people come in and speak from all over the place and they did it for free because they cared and they were willing to let us know, what was going on. It was kind of awesome because we all just felt that sort of courage that comes into a community, people that are experiencing similar things.

**Adaptive parenting.** Participants discussed an ongoing process of adapting to the strengths and needs of their children.

Father #1 described his need to be aware of his son's energy level and ability to work, and adapt his expectations based on those parameters.

And we've learned since then that we kind of need to back off a little bit when he says he's tired, he's very tired from having to work, and depending upon the environment that he's in, sometimes he has to work even harder. So we have to keep that aware.

Father #5 shared his awareness of the importance of considering his son's specific, individual needs.

Definitely, you know we have to consider what our son's needs will be, I guess, at every developmental step along the way, versus what another hearing child would encounter.

Mother #3 described a process of adaptation that begins with grief related to the initial diagnosis and then improved coping as the family adapts.

Well, it always gets better than the initial diagnosis, like it's devastating, and you grieve and you cry and you, all that, but really, once you get the hang of things, it always seems to get better.

Mother #5 shared that she is more honest with her child than she might have been were he not diagnosed with deafness.

I might not have treated them as honestly when they came to me with questions, but I felt like, I feel like because they both have issues that they need to know that they can come to their parent and have honest discussions about anything.

**Internet/social media as a resource.** Participants discussed the internet and social media being a source of information and support.



Father #2 shared his family's use of email and Facebook as social resources.

Most of them we do try to at least communicate through e-mail or there's groups on Facebook that we utilize that are really good too.

Father #6 discussed using the internet as an information resource prior to his child's implantation.

The Internet definitely was the number one source to just see what others have done, what their experiences were, where FDA approval was at the time for how early can implantation happen.

Mother #2 shared about her family's use of Facebook as both a source of information and support.

We are members of a group. I don't know who found it. I think we just sort of came upon it. I'm a member of the Facebook group, parents of children with cochlear implants, and it is awesome. Everybody is very respectful of one another and it's very rare that a harsh or insensitive word is spoken. I think sometimes we all want to be a bulldog for kids and defend our positions. Maybe twice I've ever seen that and then people say oh I'm so sorry I got caught up in the moment. We want the best for our kids. It's always, you can put a question out there or what did you do when so-and-so happened and the flood of responses is unbelievable.

Mother #6 described her family's use of the internet to search for success stories related to children who have cochlear implants.

We used the Internet a good bit looking for positive stories of children who had gotten cochlear implants and who had been successful with them who had learned to talk and hear and all that.

### **Affective**

**False hope.** Participants discussed experiencing a sense of false hope related to reassurances from providers after their child failed the newborn hearing screen. Parents reported professionals telling them not to worry about the failed screen or giving them alternate reasons for a failed screen other than deafness.

Father #5 shared about his family's not having a sense of concern due to reassurances from professionals.

He did have a screen, I remember, in the hospital at that time which he did not pass. We were told sort of not to be too concerned with not passing it at that point.

Even after the initial screening, from my point of view, we were told not to be too concerned so we were hoping that it wouldn't be the case.

Father #6 described his family's experience of false hope that his child's failure of the hearing screen could be related to fluid in his child's ears.

He failed that screening, and the technician told us, "it's probably a false positive, it could be a false positive, we're going to schedule you to do a secondary test to get validation from a repeat test or to show hearing."

I think the next week or so, and they also gave us a little bit of hope too that it was a false positive by telling us that it was probably fluid in the

ears that just needs to dissipate over time, fluid that could've entered in from the birthing process, that it's not unheard of.

Mother #1 also shared her family's similar experience when they were told the hearing screen failure could have been due to fluid in her child's ears.

The technician was very sweet. She's like "it's probably fluid. Come back in two weeks and we'll retest." It turned out not to be, and then we were referred to Midlands audiology.

Mother #6 discussed her appreciation for a professional providing her with a realistic understanding of the possibilities related to her child's deafness.

Yeah, and it's not going to be any easier or harder to hear, I think, just hearing, "there's something you can do and here's what you need to do," rather than, "it's okay."

But yeah, it was really helpful to just have somebody to say, "this maybe isn't what you want to hear, but this is what you're dealing with, and this is what, we know people who've been through this before and there's a way, there's a journey, it's just a different journey."

### **Lived Experiences of Mothers**

The researcher identified six themes among mothers. Five themes were cognitive and included **social impact of deafness with cochlear implant; parents of hearing children do not share same meaning; normal/small questions; prior knowledge of deafness; and cause of deafness**. One of the themes was behavioral (**personal/financial sacrifice**). There were no affective themes identified by mothers only.

#### **Cognitive**

**Social impact of deafness with cochlear implant.** Participant mothers discussed the social implications of the cochlear implant on their children's development.

Mother #5 shared about her child's conflict and struggle with being different from his peer group.

Kind of what I see with my son right now is he is a little conflicted because he's been raised as a hearing child with a cochlear implant. He still is hard of hearing with the cochlear implant. He still doesn't hear everything but he hears very well. But still, he's different from his peer group and I think that's a struggle for him.

Mother #6 discussed her fears and concerns about the social aspects of her children having cochlear implants.

I think sometimes the social aspect of it, and wondering how they will deal with other people asking questions and so far that's something that I've worried about. We want them to know other kids with cochlears and we've met some other kids and that's always really neat, but they haven't, over time, we've just learned how to, our friends know, and our friends that don't know ask, and they just explain it to them and talk to them about it and that's all been okay, but I would say that's one thing that I've, that I did worry about.

**Parents of hearing children do not share same meaning.** Participant mothers discussed their experiences and the meaning of those experiences differing in some ways from the experiences and meaning-making of friends/family members who have hearing children.

Mother #2 shared about her perception of the differences in her reactions to her child's successes versus the reactions of her friends with hearing children.

My friends without deaf children they are just like, oh yea, you rhymed.

It's just different. It's just a little bit different when my child hears [2 words that rhyme] versus little Johnny up the street [laughter].

Mother #5 explained not wanting other parents to feel sorry for her and this being the impetus for her to seek out other parents of children diagnosed with deafness.

But when you have a child with an issue, you can't go to a play group.

First of all they don't want to hear about it, and the second thing is they are so glad they are not you, they just, you are creating a big pity party and you don't want that. Because that was the other thing, I was like, "Don't feel sorry for me. Don't do that." Because I could sit down and feel sorry for myself and I don't need any encouragement and I'm not going there. [laughter] So that is not happening. But that was also part of the impetus to reach out and find other parents that were going through what we were going through.

**Normal/small questions.** Participant mothers discussed the "normal" or "everyday" questions they have about their children.

Mother #1 described the types of questions and concerns she currently has about her child.

We've had some questions, small things about his, can he wear polyester or can he sit in a plastic chair at school. Those questions to me are not significant. Today, those are the kinds of questions we have: battery life.

Mother #6 shared about her questions related to the assistive devices her children may need in the future.

Now I do have concerns like, "well, when he's on his own or when he goes to college, our two children with hearing loss share a room now, and so we don't have any modifications for a fire alarm detector, alarm clocks, things like that. How will they be completely independent? We are trying to teach them that, but there will be things that they'll have to figure out how to do, like how to wake up in the morning. And I know there are options out there for vibrating alarm clocks and lights for fire alarms.

**Prior knowledge of deafness.** Participant mothers discussed the impact of their having prior knowledge of deafness on their decisions related to their children.

Mother #5 shared about her prior experience working with the Deaf community and the influence of her experiences on her beliefs about deafness.

One of the problems that I had was, I had been a social worker. I had worked with clients who were deaf, and none of them were successful. They had all attended a school for the deaf. They had a very limited education. Their ability to find work was very limited. There was a lot of substance abuse, and I didn't want that for my child.

Mother #6 discussed the influence of her experiences with her first child diagnosed with deafness, and the influence of those experiences on her decisions regarding her second child who was born deaf.

I don't feel like I've said much about my daughter, but just having that second child with hearing loss and how, and this all kind of ties into being

connected to other families and just knowing what to do, it made it so easy, it made it seem like not a big deal.

The same mother also made the following comment:

Because it was just so different. It was so different with her. We weren't so fearful and we weren't, I wasn't hesitant. My husband will tell you what he thinks, but I just wasn't hesitant at all because we knew it was a good thing and we wanted the same thing for her.

**Cause of deafness.** Participant mothers discussed the cause of their child's deafness, which included illness as well as genetic factors.

Mother #5 shared about the virus that the doctors identified as the cause of her child's deafness.

Well, officially he was born early, and so he was in the NICU for quite a while after he was born, and he was sick, and he has CMV which is, I don't know if you're familiar with that, it's a common cold virus but it's Cytomegalovirus. There's generally, it's not something that affects any adult that's healthy in any way, shape or form other than maybe have like just the sniffles, and apparently I'd caught that which is very detrimental to the fetus. One of the most common issues that results of that is deafness.

Mother #3 described her experience of learning of the genetic mutation that is the cause of her child's deafness.

But the blood test for the genetic mutations came back, I am the carrier of a recessive genetic mutation. My husband is a carrier of the same mutation, and our son got both of our bad copies, it's called Connection

26. It's one of the most common causes of hearing loss, from my understanding, among Caucasians. So we finally had an answer for that, you know, just bad luck. So we have, me and my husband together have, when we make children, have a one in four chance of having a deaf kid. So our son was that 25%, which was good news for us because that does not come with any other developmental issues.

## **Behavioral**

**Personal/financial sacrifice.** Participant mothers discussed the personal or financial sacrifices they and their families made related to their child's treatment and the value of those sacrifices.

Mother #3 described the financial sacrifice she and her family have made, the implications of that sacrifice, and the value of that sacrifice.

And then our family's biggest decision was that I chose to quit my job. Like I said, my husband and I were both police officers. I was taking a lot of time off of work to get him where he needed to go. We knew after he was implanted it would be even more work. The work starts when you get implanted, really, and I felt like he was not going to get what he needed with me working full time. I also felt like I wasn't going to be able to do my job to the best of my ability by taking off, a day off a week. That probably wasn't going to work, so we had to sit down with a pen and piece of paper and calculator, and figure out if we could pull it off, and we couldn't pull it off with the numbers, it didn't add up. And we just kind of took a leap of faith and my husband got a second job, and I went on a



leave of absence from work, and when my leave of absence was up they said, it was like six months, and they said, "Hey, are you going to come back?" And I said no, I wasn't, and then, but it worked out. So, that was really, for my family was the biggest decision we had to make was going from two full-time incomes and no kids to two full-time incomes to one kid and then one income, and by the time we made that decision we had a second one on the way. And now we have a third, and we're still really off of one income. So, that was the hardest thing for our family was to decide to do that in the best interest of our kid. Looking back, I felt we did the right thing. We did what we could do. We did the right thing, we don't go out to eat, we don't shop, we don't drive new cars, but it was totally worth it.

Mother #5 shared about her decision to leave her job and focus on caring for her child.

Well, I left my job. That was a pretty big deal, because that was not something I ever intended to do. My intention had been to take off about a year or two, and then go back to work. So that's definitely a big one. And sometimes I've regretted it.

### **Lived Experiences of Fathers**

The researcher identified four themes among fathers. One theme was cognitive (**importance of early intervention**), one theme was behavioral (**anticipate needs/provide additional supports**), and two themes were affective (**coping** and **success bolsters satisfaction with choices/leads to greater self efficacy**).

#### **Cognitive**

**Importance of early intervention.** Participant fathers discussed the importance of early intervention as related to their child's treatment and overall level of success.

Father #1 shared his gratitude for early intervention programs and their impact on the timeliness of diagnosis.

We've been a great proponent ever since of the early intervention programs, and the checks at birth. One of the things that South Carolina does well is that program, and we're very grateful for that. Otherwise, we would not have known for several months.

Father #2 discussed his wife's efforts to encourage increased early awareness of deafness to address children's early access to sound.

That's something that she's been trying to work with I think with the girls from Beginnings, to do something about that. As far as, you do need to worry about it because these kids, you know, the earlier you can get them in there and give them access to sound, the better they'll be.

## **Behavioral**

**Anticipate needs/provide additional supports.** Participant fathers described a process of trying to anticipate their child's needs and providing additional supports as necessary to encourage their child's success.

Father #1 discussed his desire to provide supports in anticipation of his child's needs.

That's the big thing, to anticipate where he might have problems and try to put something in place beforehand to reduce that delay or that stress that's on him.

Father #2 described the steps he and his family have taken to address his child's needs and increase the likelihood of her success.

I think we've gone a couple steps farther as far as making sure our child has everything she needs to succeed no matter what it is. We've always been in the process too, well I shouldn't say always, we didn't at first, but we've been in the process of learning some sign language just to have that as well. I guess you could say for like a backup if something ever happens and she doesn't have her implant or her hearing aid, she's not going to be able to hear one thing a person is saying, so eventually we would like for her to be able to communicate that way too if she needed to. We just tried to do everything we can for her, and like I said I know a lot of parents say that but we just want to give her all the resources that we can and just make things as easy for her as we can.

### **Affective**

**Coping.** Participant fathers discussed an early concern being how they might cope with their child's deafness.

Father #2 shared his early experiences of his child's diagnosis giving rise to questions about coping.

At the time she was not even two months old [laughs]. You have so many emotions when you have a newborn, and then all of a sudden this is just kind of put on top of you. Where do you go from here?

Father #1 mentioned that one of his family's earliest questions was related to coping.

I guess the biggest question was at first how were we going to kind of cope, uh, with everything.

**Success bolsters satisfaction with choices/leads to greater self-efficacy.**

Participant fathers discussed the influence of their child's success on their satisfaction with treatment and communication choices, and on their sense of self-efficacy.

Father #1 discussed his belief that his family made the right decisions concerning cochlear implantation based on his child's later successes.

Of course, for us it turned out to be the right approach, I mean for us it was the right decision. My son, he's, he's just a mainstreamed guy, smart as a whip, now he's twelve, you know, so he's, like a friend said, he's starting to grow out his rooster feathers a little bit [laughter] but he's just, he just works, both kids, my daughter too, you know, it was the right decision.

Father #5 shared similar sentiments regarding his child's accomplishments and successes.

I would say so, and from my point of view, just watching my son accomplish things that we were initially either told or concerned that he would not be able to do, you know, his determination and ingenuity, I guess, in overcoming those kind of things just sort of reinforced what we thought and hoped.

**Meaning Making**

The following nine themes are related to the meaning the participant parents have made of their lived experiences of being the parents of a child or children diagnosed with

deafness. Both mothers and fathers discussed the initial three themes, and quotes from both mothers and fathers are included in support of these themes. A summary of the findings related to meaning making are presented in Table 4.4 at the end of Chapter 4.

### **Meaning Making of Both Mothers and Fathers**

**Increased awareness, understanding, patience, and empathy.** Participant parents discussed having increased awareness, understanding, patience, and empathy. Parents attributed this development at least in part to their experiences as a parent of a child diagnosed with deafness.

Father #1 shared about the influence of his experiences as the parent of a child diagnosed with deafness on his patience, empathy, and ability to anticipate his child's needs.

To hear some of the struggles that some of the parents go through, man, it just breaks your heart. It has certainly tenderized me as well, so patience, empathy, and anticipation, those are the three big areas in which I've been... Because everybody, look at the Shriners, commercials on TV for St. Jude's Hospital or Make-A-Wish, or any of these other organizations that are just great organizations, and everybody tugs on their heart a little bit, but there's some distance there. I was just reading this morning an author that I read a lot of, he was talking about this particular, the distance that we feel from these situations. That's why we're not, yes we're sympathetic, but we're not necessarily empathetic. Being the parent of a disabled child has greatly increased, no it made me empathetic. It didn't increase it, it made me empathetic because there would've been very, there

is some sympathy, but there would've been no empathy. Now, I can't not be around kids and parents, especially dads.

So it's made me empathetic. It's made me more patient. It's made me anticipate, be more of an anticipator, and try to fix those problems that I can fix, or smooth the path anyway if I can. It's helped me. It's helped me as a father. It's helped me as a parent. It's helped me as a human. It really has.

Father #3 mentioned the impact of his experiences on his awareness.

I think it's greatly increased my awareness.

The same father also discussed his child's lack of patience influencing his own patience.

I really like, he's taught me a lot of things. To be patient, I'm not such a patient person. Sometimes he's not patient, so we kind of have to learn to be patient together.

Mother #2 described the development of her greater awareness of the present moment and of the "little things" due to her experiences.

I think being in tune to the small things would be the most significant, and it's definitely affected me in all aspects of life, not just in parenting. Even when I'm not in the midst of parenting I'm still, it's my job, in the community, in social groups, when I allow myself to be in the moment I can pick up on things that I might not have if I was just there and not really absorbing the moment. One thing with being pregnant, was just like, okay, people just get pregnant and have babies and they come out and

they're great and fabulous and you get home and feed them. Well, that's not the case. So I'm definitely more in tune to things like that when someone has a baby or it's a miracle to make sure that they're eating right and hearing and talking. I certainly cheer on those children more than I might have before. Oh great, they said a word but now it's, oh wow, do you know how much it took to, for them to say the word mama.

Mother #6 shared about the influence of her experiences on her empathy toward other parents and families.

Right, and families who aren't necessarily going through hearing loss, but maybe just have a child who's got behavior issues, anything. We've got a niece who has got some Aspergers, autism, something, and it's just made us understand, not what they're going through, but just that we've all got this journey and we're trying to figure out how to do the best thing for our kids. It does make us want to be sympathetic and understand people and give them grace that they're doing the best they can.

**No "breaks" for disability.** Participant parents described not allowing their children to have unnecessary "breaks" related to their deafness. The "breaks" these parents did not allow were related to expectations for learning how to communicate, behavior, and academic performance.

Father #1 shared his expectations for his son and his ability to communicate using the audio/visual approach.

We do know that he uses, he's very visual, we do know that, I guess we have to play on that but not diminish his hearing at all. He still has to learn how to listen. Still has to learn how to hear.

Father #2 discussed his early concerns regarding behavioral expectations and discipline, and his current decision regarding discipline.

At first I was, I was concerned about discipline with her because it's very hard to do, difficult to do when you have a child that is basically born deaf. You still have this feeling that you, oh my gosh I'm yelling at my child. You kind of feel bad like well maybe she doesn't quite get it or whatever. All of these things go through your head, but that's totally not the case. I feel like I discipline her just like I do my son and there's no bad feelings.

Mother #5 shared her family's stance that her son is not allowed to use his deafness as an excuse for poor performance.

There's no excuse just because you can't hear, you can always ask for clarification and I do feel for him, I do, because it is a struggle for him but only he can choose to overcome it.

Mother #6 discussed her decision to not feel sorry for her children and not to make unnecessary accommodations for them.

I think one conclusion is not to feel sorry for my kids, which I kind of experienced that early on with my son. Was feeling like someone felt sorry for us, whether she did or not, she didn't say that, but that's just, and maybe because I felt sorry for us, and felt sorry for him. I spent a lot of



time his first year, just feeling sorry for him. He couldn't hear his mom. He couldn't hear me tell him that I loved him. Although he was an incredibly happy baby, and didn't seem to be bothered by the fact that he couldn't hear. But I just think that that's the worst thing that I could do to them. To continue feeling that way for them, and making accommodations for them, because they're deaf, when they can figure it out on their own, and this is the path that God has for them. I want them to just embrace it, and go with it, and use it for the good, and not ever think, "because of this, I can't do this or I can't be this." I don't want them to feel like that, and I don't, so I don't want to feel like that for them either.

**Gratitude.** Participant parents described themselves and their families having a sense of thankfulness or gratitude for their experiences, their children, and their child's and family's successes.

Father #3 briefly shared his sense of thankfulness for his experiences.

I'm thankful that I can be here and go through it. I wouldn't change it for the world.

Father #6 discussed his belief that his children are a blessing and have inherent value and an ability to do or bring about good things.

As someone who believes that I am blessed with children that have a different way of doing life, or different way of hearing life, I see good things that have come from it, and I expect my kids to be impacted from their deafness in a way that will enable them to be used by God to do

different things. I have to believe that this will be turned into a tool and a good thing.

Mother #3 described her child as a gift and explained her sense of gratitude for her child's strengths, abilities, and overall health other than his deafness.

So that was, that's been the difference in my thinking. That no matter when you have a child, whether they are healthy or not, you're going to love them, and you may even love them a little more because there is something different about them or wrong with them. Whatever people want to call it. So that was probably my biggest growth. I think I grew as a person. And really appreciating the little things, one, that I was given the gift of children, just period. A lot of people don't even have that happen to them. That I was only given a child with hearing loss, because you go to a hospital, children's hospital, and there's so many other kids with so many other things wrong with them. And I sit there with my deaf child and go, "Oh, my gosh, that parent is having to deal with that, and all I have is a deaf kid." Like, give me a deaf kid any day. It puts things in perspective. So I've gained a lot of perspective as a parent just realizing that things could have been a lot worse, and just being grateful for what my child does have. And then appreciating the little things, like his first words were so much more important to me than probably a child without hearing loss. So the things that that kid can hear, it's amazing. I can whisper to him, and he'll come whisper in my ear. And every time I whisper to him, and he hears, I'm in awe. So, almost daily something happens, he hears or

says, I'm flabbergasted that he can understand or says that, or, "Wait, I didn't teach him that word, where did he learn that word from?" Long words, or he says a sentence that has ten syllables and I'm like one, two, three, four, five, six, seven, eight, nine, ten. Holy smokes, kid, that was awesome.

Mother #6 shared her sense of thankfulness that her family has two children who are connected by their shared diagnosed of deafness.

So even though we were a little disappointed when we found out that she was deaf, and we had that moment of, "we don't want to call anybody yet, we want to sort of just take this in, take a deep breath, because we know what's ahead," there was a big part of us that was just thankful for him to get to be her cheerleader, to get to teach her how to do things, and then down the road when they're teenagers some of those questions I have now about how they'll experience life, they'll have each other to talk to and to get into trouble with or whatever they do. I was really thankful.

### **Mothers' Meaning Making**

The researcher identified three themes among mothers. The identified themes were **hope for the future; not focusing on deafness/disability; and just a normal kid.**

**Hope for the future.** Participant mothers described having a sense of hope related to their child and their child's future functioning and success.

Mother #3 shared her sense of excitement related to her child's future academic and vocational pursuits.

So, I think it'll be fun in fifteen, twenty years when he's decided what he wants to do for a living and he's in school that we get to see what these kids can do. And not just him, but there're lots of other kids that we know.

Mother #5 discussed her belief that her child has unlimited future potential and described her pride in her child's accomplishments thus far.

Well, now, I mean I'm really proud of my children and I think that they, that's the only thing I would say as I really am proud of them. I think that despite the things that they have had to go through and particularly my son diagnosed with deafness, he's a pretty amazing kid. He is just a can-do kid and I have great respect for that, and I really am interested to see what kind of man he will become, so that's all. I just don't think, I really do believe that he has unlimited potential and so does his brother. It's just a matter of helping them to see that, that they really can do. And that's all.

**Not focusing on deafness/disability.** Participant mothers described their practice of acknowledging their child's disability without allowing the disability to become either the focus of their interactions with, or the expectations they held for their child.

Mother #1 shared about her family's approach to her child's deafness.

We just never sat around and cried about where we were. We always got up and did what we had to do, and tried not to make a big deal out of my son's or my daughter's disability.

Mother #5 shared about her child's success with tasks and activities that professionals told the family her child would never do well, as well as her belief that her child is successful in part because she and her husband have not set artificial limitations for their child.

My son is in seventh grade. He is in the academically gifted program full time. In all classes, he's an A, B, student. He could probably be straight A if he'd give it a shot, but he doesn't work that hard at it, which is funny because he's in that gifted program, and it is a lot of work. But he reads, he has the highest reading level that his academically gifted teacher in ELA has ever seen in her entire career. He reads at 1653, that was at the beginning of the year. And it tops out, the reading levels top out at 1700, then they don't test you anymore after that, I guess. He is on the Quest Team, which is an academic competition. He wrestled this year. He's done so many things that the neurologist said he'd never do, because we'd just never tell him that the neurologist said, "You're probably never going to do this." He is amazing, but you know, its not because he does not work hard, it's because he may never work hard academically because he just has kind of weird photographic memory but he has always been a fighter.

**Just a normal kid.** Participant mothers shared their belief that their child is like other children, despite their child's deafness. Statements from participant mothers focused on others' awareness of their child's deafness and the difference between deafness-related misbehavior and typical child misbehavior.

Mother #3 shared her belief that her child is like other children.

I think it's nice for people to come up to me and say, "You know, I would have never guessed he was deaf. He seems just like every other kid." I'm like, "That's great, because he is just like every other kid."

Mother #5 shared her awareness of her child's misbehavior being unrelated to his deafness.

Actually when I saw Josh Swiller [international deafness/disability advocate], the last time we spent some time talking about misbehavior and that kind of thing, I laughed and said, "95% of the time if I get a call from the school about misbehavior," which is rare nowadays, but it was like, "it didn't have anything with them being deaf, it had everything to do with them being just a boy." [laughter]

### **Fathers' Meaning Making**

The researcher identified three themes among mothers. The identified themes were **deeper/more intentional relationship; sometimes we forget; and deafness does not limit potential.**

**Deeper/more intentional relationship.** Participant fathers discussed having a relationship with their child that may be deeper or more intentional than it would be in different circumstances.

Father #1 described the possibility of his relationship with his child having greater depth due to his need to better understand the source of his child's issues.

The doctors have been able to fix his hearing but they keep telling me that they can't put a switch on that helps his listening [laughter], and

sometimes I don't know the difference, whether it's a hearing issue or a listening issue. That only comes from having a deeply personal relationship, that is maybe on a different level than maybe dads with normal kids have. Maybe there's just another level in there somewhere.

Father #3 described his experience of being the parent of a child diagnosed with deafness has encouraged his intentionality related to being attentive and present with his children.

I think it's greatly increased my awareness and need to be a better father. To pay attention more to him as well as my other two kids. You need to be there. He has shown me that work is not important. There's being home with the family. He's growing up so fast and he's learning new things all the time.

**Sometimes we forget.** Participant fathers discussed the effectiveness of the cochlear implants, and how at times, this efficacy leads them to "forget" their child's deafness.

Father #2 discussed the challenges his family have had working with their child to achieve success with the cochlear implant. He also shared how that success has lead to his child functioning similarly to a hearing child.

It is tough in the beginning. I never would've thought that I am, and my wife can speak for it too, the way we are now about it. Even in these couple of years sometimes, yes we know we have a deaf daughter, but with her cochlear implants and her implant and her hearing aid and all the speech therapy she's had and you know, we have, we work all the time,

daily, nonstop with her, and I think sometimes we kind of forget it.

Because she does so well that we just sometimes, she's got her, you can see her equipment on her head, but you wouldn't know she's a deaf child.

Father #5 made a brief statement similarly describing his family's forgetfulness regarding his child's deafness, due to his child's success.

Sometimes we forget about the deafness because that's handled most of the time.

**Deafness does not limit potential.** Participant fathers shared their belief that their child's deafness does not limit their potential.

Father #5 succinctly made the following statement regarding his belief about his child's potential.

I think that I've concluded that deafness is not, does not limit, deafness alone does not limit a person's potential.

Father #6 shared his beliefs about his child's potential and the lack of impact deafness has on her potential or her future opportunities.

So when our daughter came along, she didn't have the ability to hear, but we knew what to do. We knew the answers to those questions. Yeah, she's going to have a beautiful personality. She's as worthy as anybody, and she is going to have any opportunity that she wants to. Her potential is not limited by her inability to hear with what God has given her because there's, she's got potential to develop, with technology that God has allowed others to give to her. That's our perspective, that her potential is unlimited.



### **Discrepant Data and Non-Confirming Cases**

Father # 4 and Mother #4 represent one of the two parent families. They differ from the other parents in several of the demographic categories. Their ages (45 and 44 years of age) are close to the average age of the participant parents (42.4 years of age). In terms of educational level, the mother completed high school and father completed some college, which is a lower level of education than the majority of the participant parents. Neither parent worked outside of the home, with the father reporting being retired and the mother reporting being a stay at home mother/wife. These parents reported their income range as being \$25,000 - \$35,000, which was less than the other participant parents' reported income ranges by at least \$30,000 per year. These parents also reported living in a small community, while the other participant parents reported that they lived in communities of medium size.

While the majority of the parent experiences related to the availability and appropriateness of resources and educational opportunities for their children were positive, this family shared about their experiences that tended to be described as difficult and frustrating. The mother shared the following comments regarding the availability of resources:

It is hard trying to find stuff to help her. It's not something that's really put out there. You've got to search for it.

The father briefly described his family's lengthy search for resources:

We searched and searched for years to learn about sign language and it was not until I contacted the English department at Clemson University until I found out about their sign language program.

This mother also discussed the difficulties she has communicating with her child:

Hard to teach her. I want to teach her what's right, but I can't because I can't really communicate with her. I can communicate some with her in sign, but otherwise it's just hard. When I talked to her, she'll ask me, "what?" She'll stick her hand up to my mouth so that she can understand what I'm saying. It's just difficult to do.

In a possible summation of his experiences as the parent of a child diagnosed with deafness, the father made the following statement:

It's been an uphill battle all the way.

### **Evidence of Quality**

To ensure the quality of this research study and the accuracy of the data, the researcher used the following methods: trustworthiness, member checking, and the use of coding assistants for triangulation.

#### **Trustworthiness**

The researcher recorded each interview using a digital recording device and an HD video camera. The researcher listened to each interview several times during the process of transcription. The researcher then listened to each interview an additional time while following along with the typed transcription in order to determine the transcription's accuracy. The researcher made any required edits to the transcription during this review process.

#### **Member Checking**

After the transcription process was completed, the researcher sent copies of the transcripts to the participant parents for their review and commentary. Each participant

parent was emailed a copy of his or her interview transcription with a request to review the transcript and respond with either approval or edits within seven days. Of the twelve participant parents, one participant mother responded to the email. She made edits related to minor grammatical issues, but did not make edits related to the content or meaning of the interview.

Upon completion of the coding and analysis process, the researcher created a master list of themes that included a brief description of each identified theme. The researcher emailed this master list to the participant parents with an invitation for the parents to provide any feedback regarding the identified themes, as well as an offer for the researcher to provide participants with further details regarding any of the identified themes. The email included a request that participants respond to the email within seven days. None of the participants responded to the email.

### **Coding Assistants**

The researcher recruited two coding assistants to ensure the accuracy of the coding and data analysis. Both coding assistants were doctoral candidates in the Counselor Education and Supervision program at the University of South Carolina.

Upon completion of the transcription process, the researcher provided copies of the interview transcriptions to the coding assistants. After the researcher and the coding assistants each individually coded the transcripts, the researcher and the assistants met to go through each transcription line by line and processed the identified themes. During this processing, the researcher and the coding assistants came to consensus regarding the identified themes and the descriptive codes used to group the themes and meanings. The

researcher and the coding assistants discussed and agreed upon any differences in the descriptive codes and the identified themes and meanings.

### **Summary**

The researcher began this research study seeking to document the lived experiences and meaning making of parents who have a child or children diagnosed with deafness. Specifically, the researcher sought to answer the following research questions:

- 1) What are the lived experiences of parents who have a child diagnosed with deafness?
- 2) What meaning do these parents make of their experiences?

The results of this research study are comprised of the participant parent's recollections of their experiences and the meaning they have made of their experiences. Thirty-seven themes were identified during the course of this study. Twenty-eight of the themes were related to parents' lived experiences. Nine of the themes were related to meaning the parents made of their lived experiences. These results and their implications will be discussed further in Chapter 5

Table 4.1 - Parents' Lived Experiences (Cognitive)

Lived Experiences	Mothers and Fathers	Mothers	Fathers
<b>Cognitive</b>	<ul style="list-style-type: none"> <li>• Awareness of Deafness at Birth</li> <li>• Clinical Process</li> <li>• Implantation and Communication Decisions and Questions</li> <li>• Decision Making/Process</li> <li>• Education/School/School System</li> <li>• Big Questions</li> <li>• Resilience</li> <li>• Impact of Technology</li> <li>• No Personal Experience with Hearing Loss</li> </ul>	<ul style="list-style-type: none"> <li>• Social Impact of Deafness with CI</li> <li>• Parents of Hearing Kids Do Not Share Same Meaning</li> <li>• Normal/Small Questions</li> <li>• Prior Knowledge of Deafness</li> <li>• Cause of Deafness</li> </ul>	<ul style="list-style-type: none"> <li>• Importance of Early Intervention</li> </ul>

Table 4.2 - Parents' Lived Experiences (Behavioral)

<b>Lived Experiences</b>	<b>Mothers and Fathers</b>	<b>Mothers</b>	<b>Fathers</b>
<b>Behavioral</b>	<ul style="list-style-type: none"> <li>• Professional Resources</li> <li>• Commitment to Treatment</li> <li>• Advocacy/Commitment to Advocacy</li> <li>• Giving Back</li> <li>• Proactive Response</li> <li>• Community Connections/Engagement and Support</li> <li>• Adaptive Parenting</li> <li>• Internet/Social Media as a Resource</li> </ul>	<ul style="list-style-type: none"> <li>• Personal/Financial Sacrifice</li> </ul>	<ul style="list-style-type: none"> <li>• Anticipate Needs/Provide Additional Supports</li> </ul>

Table 4.3 - Parents' Lived Experiences (Affective)

Lived Experiences	Mothers and Fathers	Mothers	Fathers
Affective	<ul style="list-style-type: none"><li>False Hope</li></ul>		<ul style="list-style-type: none"><li>Coping</li><li>Success Bolsters Satisfaction with Choices/Leads to Greater Self Efficacy</li></ul>

Table 4.4 - Parents' Meaning Making

<b>Meaning Making</b>	<b>Mothers and Fathers</b>	<b>Mothers</b>	<b>Fathers</b>
<b>Themes</b>	<ul style="list-style-type: none"> <li>• Increased Awareness, Understanding, Patience, and Empathy</li> <li>• No "breaks" for disability</li> <li>• Gratitude</li> </ul>	<ul style="list-style-type: none"> <li>• Hope for the Future</li> <li>• Not Focusing on Deafness/Disability</li> <li>• Just a Normal Kid</li> </ul>	<ul style="list-style-type: none"> <li>• Deeper/More Intentional Relationship</li> <li>• Sometimes We Forget</li> <li>• Deafness Does Not Limit Potential</li> </ul>



## CHAPTER 5

### DISCUSSION

The purpose of this research study was to document the lived experiences of parents of a child or children diagnosed with deafness, and to document the meaning these parents have made related to their experiences. Moeller's (2000) research suggests that family involvement and enrollment in early intervention services are key components for linguistic skill development. Yoshinaga-Itano et al. (1998) demonstrated through the results of their research that children whose hearing loss is identified earlier have greater linguistic skills than do their later identified peers. Thus, parents' knowledge of their child's deafness, and their ability to quickly and efficiently make decisions regarding their child's communication and linguistic development may be a critical resource in their child's future success.

The two research questions for which the researcher sought answers are:

- 1) What are the lived experiences of parents who have a child diagnosed with deafness?
- 2) What meaning do these parents make of their experiences?

Counselors and other helping professionals working with parents from this population may benefit from a greater depth of understanding related to the experiences and meaning making of these parents. A deeper understanding of the experiences and meaning making of parents from this population may assist counselors in optimizing interventions to assist these parents and their children.

The researcher utilized phenomenological inquiry as a methodological base and conducted in depth interviews with twelve participants who were identified as the parent of a child or children diagnosed with deafness in order to seek answers to these questions. The researcher conducted individual, semi-structured interviews with each parent. Interview data included approximately six and a half hours of recorded interviews and one hundred eleven pages of interview transcription. The findings of this research study include parents' experiences related to cognitive (*awareness of deafness at birth; clinical process; implantation and communication decisions and questions; decision making/process; education/school/school system; big questions; resilience; impact of technology; and no personal experience with hearing loss*), behavioral (*professional resources; commitment to treatment; advocacy/commitment to advocacy; giving back; proactive response; community connections/engagement and support; adaptive parenting; and internet/social media as a resource*), and affective (*false hope; coping; and success bolsters satisfaction with choices/leads to greater self-efficacy*) themes. Additionally, findings include various meanings the parents have made related to their experiences (*increased awareness, understanding, patience, and empathy; no "breaks" for disability; gratitude; hope for the future; not focusing on deafness/disability; just a normal kid; deeper/more intentional relationship; sometimes we forget; and deafness does not limit potential*). The purpose of this chapter is to report the interpretation of the findings, including implications for social change and implications for counselor educators and counselors. This chapter also includes recommendations for further study and the researcher's reflections upon completion of the study.

## Interpretation of Findings

### Parents' Lived Experiences

The first research question sought to document the lived experiences of parents who have a child or children diagnosed with deafness. Based on the participant parents' responses to the interview questions, this group of parents shared a number of similar lived experiences. The researcher categorized the participant parents' responses related to their lived experiences as cognitive, behavioral, and affective. These responses comprise a portion of the results of this study, and are presented in the following sections as they relate to the larger body of literature on this topic.

**Cognitive.** Participant parents shared information related to cognitive aspects of their experiences. These cognitive aspects focused on the parents' awareness of certain details or components of their child's deafness and the related treatments or other concomitant concerns, or the parents' questions and decisions related to aspects of their child's deafness and treatment. Ten of the cognitive aspects of the parents' experiences were congruent with or supported by articles found during the literature review.

Participant parents shared details related to having an **awareness of deafness at birth**, as well as their experience with the **clinical process**. Bristor (1984), Freeman et al. (2002), and Kurtzer-White and Luterman (2003) wrote about early parental experiences related to diagnosis and awareness of their child's deafness at or near the time of their child's birth. Additionally, Freeman et al. (2002) wrote about urban parents' experiences with the clinical process of diagnosing and addressing their child's deafness, while Bosteels et al. (2012) wrote about the clinical process in Belgium.

Participant parents shared information regarding their **implantation and communication decisions and questions**, particularly as they related to their decision to implant their child. Jackson and Turnbull (2004), Luckner and Velaski (2004), and Jackson et al., (2008) wrote about parents' experiences including decisions related to communication. Decker, et al. (2012) wrote about the importance of these decisions due to the critical nature of communication skill and language development as related to cognitive and social development.

Participant parents discussed the **decision making process** they engaged in related to their child's communication. Parents in this study spoke of doing their own research, speaking with a number of individuals, receiving some conflicting information at times, and being aware of the variety of clinical and sociocultural viewpoints and biases regarding deafness. These themes, particularly conflicting information and the variety of viewpoints regarding deafness are similar to those previously reported by Kurtzer-White and Luterman (2003), Feher-Prout (1996), and Senghas and Monaghan (2002).

Kurtzer-White and Luterman (2003) identified education as one of the concerns that parents of a child or children diagnosed with deafness often have concerning their children. One of the cognitive themes identified by the participant parents in this study involved dealings with the **education/school/school system**, which was congruent with previous studies. The parents shared their experiences related to their successes and difficulties regarding interactions with the school system and the school system's ability to meet their child's needs with varying levels of success.

Taylor (1982), Bristor (1984), and Snell and Rosen (1997) wrote about **resilience** as related to the experiences of parents who have a child with a disability. This resilience relates to overcoming loss and discovering strengths and abilities. Parents in this study demonstrated resilience through acceptance of their situation, belief in their family's and child's ability to be successful, and encouraging their child to strive for success. One parent also mentioned her experience and awareness of her children's resilience.

The majority of parents interviewed for this research study indicated they had **no personal experience with hearing loss**. DesGeorges (2003) and Bosteels et al. (2012) noted this theme related to the lack of personal knowledge/experience for parents who have a child diagnosed with deafness, particularly in regards to the amount of new information they encounter as they begin the process of addressing their child's deafness. Kurtzer-White and Luterman (2003) noted the difficulties some parents may experience when receiving their child's diagnosis of deafness due to a lack of experience or frame of reference.

Participant fathers discussed the **importance of early intervention** as a cognitive aspect of their experiences. This finding is congruent with several of the studies found during the literature review. Early linguistic interventions were found by Moeller (2000) to have a positive influence on linguistic outcomes. Additionally, the results of a study by Yoshinaga-Itano et al. (1998) indicated that early identification of hearing loss lead to children developing greater receptive and expressive linguistic skills than their later identified peers do.

Participant mothers shared their experiences related to an awareness of a belief that **parents of hearing children do not share the same meaning**. This dissimilarity of

experiences, and feelings of isolation and invalidation were discussed by Luterman (2004). Additionally, Luterman recommended that parents who have a child diagnosed with deafness meet with parents who have had similar experiences as a source of support and validation.

Participant mothers shared their desire to know the cause of their child's deafness and their discovery of the **cause of deafness** of their child. While none of the participant mothers expressed feelings of guilt related to their child's deafness, prior research links guilt with a maternal desire to know the cause of deafness. Kurtzer-White and Luterman (2003) and Luterman (2004) wrote about parental guilt and mothers' expression of this guilt through concerns related to the cause of their child's deafness.

In addition to the preceding themes shared by parents that were supported by or congruent with the literature, participant parents reported cognitive aspects of their experiences during the interviews related to **big questions** and **impact of technology** that were not found during the literature review. Participant mothers also discussed the following themes related to their cognitive experiences, which were not found during the literature review: **social impact of deafness with cochlear implant, normal/small questions**, and **prior knowledge of deafness**.

**Behavioral.** Participant parents shared information related to the behavioral aspects of their experiences. These behavioral aspects involved the participant parents' recollections of taking some action related to their child's deafness or in the interest of their family related to their child's deafness. Articles found during the literature review were congruent with five of the behavioral aspects of the parents' experiences.

Participant parents shared information related to their connections with **professional resources**, such as audiologists, speech therapists, and educators. Parents also shared details about the influence these resources had on their understanding of their child's deafness and their decision making process. The significance of this relationship with professionals is congruent with the findings and suggestions of Storbeck and Calvert-Evers (2008), who indicated the importance of the child and family utilizing a team of helping professionals from a variety of disciplines. The benefit derived from connections with professional resources is also supported by Luckner and Velaski (2004), who reported that educational professionals may be able to assist parents with meeting a variety of their child's needs.

Participant parents discussed their **commitment to treatment** and **proactive response** to their child's diagnosis of deafness. These themes are congruent with information reported by Jackson et al. (2008). These researchers reported that in spite of biased and hard to find information, families of a child diagnosed with deafness desired to maximize their child's potential and develop a plan of action for addressing their child's deafness.

Participant parents shared their experiences related to the theme **community connections/engagement and support** by sharing details of connecting with other parents and families to offer support and encouragement, and to share information. This theme is consistent with DesGeorges (2003), who reported that parents who have a child diagnosed with deafness often acquire a great deal of information, one of the sources of which is other families who have a child diagnosed with deafness.

In addition to sharing details about difficulties they and their children have experienced, participant parents discussed the theme **adaptive parenting** and shared how they were able to adapt to their child's deafness and the requirements of treatment. Snell and Rosen (1997) and Taylor (1982) discussed similar themes. Parents who have a child diagnosed with deafness may find through their experiences that they have strengths and resources of which they were unaware. Additionally, parents have the ability to develop skills in order to manage responses to their experiences related to their child's diagnosis.

The following behavioral aspects of experience were discussed by participant parents, but were not found during the literature review: **internet/social media as a resource**, **advocacy/commitment to advocacy**, and **giving back**. Additionally, participant mothers shared information about their **personal/financial sacrifice** and participant fathers shared about their desire to **anticipate needs/provide additional supports**, both of which were not found during the literature review.

**Affective.** Participant parents shared information related to the affective aspects of their experiences. Affective aspects of parents' experiences involved their emotional responses or reactions to their child's diagnosis, treatment, and successes.

Participant fathers shared information about **coping** with their child's deafness. Coping is a topic that a number of researchers have explored, and the details that fathers shared related to their coping are congruent with the findings of previous research, including Folkman and Moskowitz (2004), Bingham, Correa, & Huber (2012), Feher-Prout (1996), and Kurtzer-White & Luterman (2003).

Participant parents shared details about their initial experiences related to the diagnosis of their child's deafness and the **false hope** that was engendered by



professionals who tended to downplay the possibility of the child's deafness by giving alternate reasons that might be indicative of a false positive newborn hearing screen result. This false hope encouraged parents to take the possible diagnosis of deafness less seriously, and therefore decrease the likelihood of timely follow up. This theme was not found during the literature review. In addition to this affective aspect of the parents' experiences, participant fathers reported a theme related to **success bolsters satisfaction with choices/leads to greater self-efficacy** which was also not found in the literature review.

### **Parents' Meaning Making**

The second research question sought to document the meaning the participant parents have made of their lived experiences as the parent of a child or children diagnosed with deafness. The parents' responses related to meaning making are presented in the following section.

**Meaning.** Participant parents discussed a number of themes related to the meaning they have made of their experiences related to being the parent of a child or children diagnosed with deafness. The theme **increased awareness, understanding, patience, and empathy** is similar to themes related to "transformation" found in a study by Wilgosh and Scorgie (2006). These researchers also found that parents of children with disabilities tended to construct new images of their children that focused on positives. This theme is similar to the following themes found in this study: **not focusing on deafness/disability and just a normal kid.**

While not specifically related to meaning making, Woolfson (2004) wrote about parents of children with disabilities developing affirmative beliefs related to their child's

disability, and the potential for this affirmation to have a positive influence on the child's behavior. These affirmative beliefs are similar to the following themes found in this study: **no "breaks" for disability, hope for the future, sometimes we forget, and deafness does not limit potential.**

Meaning related themes found in this study not supported by or congruent with the professional literature found during the literature review are **gratitude** and **deeper/more intentional relationship.**

### **Implications**

#### **Social Change**

Children who are born deaf or who lose their hearing prelingually have a limited window of time in which to begin the process of language acquisition. Therefore, the parents of these children must make a number of decisions related to language and language acquisition quickly, and often parents must make these decisions during a time typified by mixed emotions, grieving, and stress. This research study sought to improve the counseling offered to the parents of a child or children diagnosed with deafness. Improved counseling services may better assist these parents not only during the initial process of decision making, but continuing throughout their child's childhood and adolescence, thus allowing these children the opportunity to develop similarly to their hearing peers and to become healthy, productive members of society.

The results of this study lead to implications for counselor educators, practicing counselors, and for further research. The researcher will discuss these implications in the following sections. However, these implications are driven by broader implications for social change.

There was little discussion by participant parents related to seeking out or utilizing counseling services, beyond those offered by Beginnings SC, as part of their decision making process or the process of adjusting to their child's deafness. This absence of discussion does not mean that parents did not seek out or participate in counseling services. However, it is noteworthy that parents did share details related to interactions with a number of other helping professionals such as doctors, technicians, and audiologists. If it is the case that parents are not being made aware of, nor are they connecting with, counselors trained in working with individuals with disabilities and their families, this is an area that the counseling profession should address in order to ensure these parents and families are not losing access to potentially beneficial counseling services. Further research is needed to determine if other helping professionals are making parents aware of counseling services and encouraging parents to connect with these services.

### **Knowledge Generation**

This study sought to generate knowledge based on the documentation of lived experiences and meaning making of the parents of a child or children diagnosed with deafness. Based on the literature review, there appeared to be a limited amount of research related to the topic, with much of the research that did exist occurring in countries other than the United States and in other regions of the United States. An unexpected characteristic of this study's sample was that all of the participant parents had chosen cochlear implantation and an audio-verbal approach for their child's language and language development. This study contributes to the research and professional knowledge bases through the documentation of the lived experiences of parents who have

a child diagnosed with deafness and who chose cochlear implants to assist their child with hearing and the meaning made of these experiences by the parents.

### **Professional Application**

The goal of this study was to achieve a deeper understanding of the lived experiences of parents who have a child diagnosed with deafness, as well as the meaning made of these experiences by the parents. While the results of this study do not include participant parents sharing experiences related to receipt of counseling services, they do offer insight into the experiences parents have had related to their child's diagnosis, treatment, and education. A greater understanding of these experiences contributes to the ongoing professional dialog, and may provide insight to counselors when working with individuals and families from this population. This study may also encourage further research in this area, which the researcher will also address in this chapter.

### **Recommendations for Action**

#### **Counselor Educators**

Participant parents discussed their awareness of the beliefs and opinions of some members of the Deaf Community, who have a strong opposition to cochlear implantation. The parents who were aware of these beliefs indicated that their decision making process was impacted by concerns for their children's future contact and interactions with the Deaf Community. In order to prepare counselors to work with this population, counselor education programs may consider intentional inclusion in their educational programming related to multicultural awareness of the Deaf Community and Deaf Culture as a linguistic minority cultural group.

## **Counselors-In-Training**

Based on the findings of this study, counselors seeking to work with this population, or any population of parents who have a child diagnosed with a disability, should seek out coursework that addresses the following topics: multicultural counseling; psychosocial aspects of disability; medical aspects of disability; case management; and assistive technology. CORE accredited rehabilitation counseling programs should address these topics in detail. Courses that address these topics should give counselors greater insight into the family's adjustment to their child's disability, the specifics of the child's diagnosis, the influence of cultural factors, the availability and benefits of assistive technology, and the process of connecting with needed resources. While a single program may not offer all of these as standalone courses, these topics should be addressed during the educational process. Counselors with an educational background including these topics should be better equipped to understand and work with parents from these populations.

Counselors-in-training who are seeking out clinical sites for practicum and internship experiences may explore the possibility of working with agencies and community programs that work with parents and families who have a child diagnosed with a disability. Examples of such programs include BabyNet, ProParents, Department of Disabilities and Special Needs, Beginnings SC, the Department of Mental Health, and area hospitals. Experiences at such programs and agencies would allow practicum and internship students the opportunity to work directly with these populations and to receive clinical site supervision from supervisors who are experienced in this area. Additionally, practicum and internship students may wish to seek out a clinical supervisor who has a

Certified Rehabilitation Counselor (CRC) certification in addition to other certifications and licenses. The certification denotes a counselor who has training specifically focused on working with individuals who have disabilities and their families.

### **Counselors**

Participant parents did not share information about seeking counseling services as part of their process of coping with their child's deafness and adjusting to their child's disability. Counselors should engage in advocacy efforts for this population by reaching out to hospitals, audiologists, and agencies/resources to support parents from this population and discuss ways in which counselors might benefit this population, pre- and post-diagnosis. Counselors seeking to work with this population could offer individual, family, and group counseling services. The overarching goal of these services would be assisting parents and families with developing a repertoire of coping and stress management skills, with addressing parental grief and loss, and with adjusting to their child's deafness.

In addition to raising the awareness of hospitals and audiologists of the availability of counseling services, counselors should make these service providers aware of the role they can play in providing case management services to this population. Case management services might include connections with area service providers, other helping professionals, and informal resources within the community. Counselors working with this population should keep a database of these providers and resources. Additionally, this database should include contact information for other parents who are part of the informal community who share information and offer each other social and emotional support.

Counselors engaging in advocacy and case management efforts with this population should also teach and encourage the use of advocacy and case management skills, so that parents might begin to self-advocate for their children and better navigate the system of agencies and resources on their own. Parents who are empowered to seek out services themselves and self-advocate for their children may be better able to link their children with needed services and follow through on the linkages during the course of childhood and adolescence. These empowered parents may also be better able to teach these skills to their children as they grow to adulthood, in the hopes that they encourage in their children a sense of efficacy and empowerment.

Participant parents shared details of the cognitive, behavioral, and affective aspects of their experiences, as well as the meaning they made of their experiences. Counselors working with this population should consider each of these aspects of experience, as well as meaning making when working with parents from this population. Counselors working from a holistic perspective with parents from this population may be less likely to overlook or avoid addressing significant aspects of these parents' experiences and their meaning making.

Participant fathers and mothers shared details of their experiences related to having a sense of false hope due, at least in part, to the responses of the specialists who made them aware of their child's failure to pass the newborn hearing screen. Counselors who work with this population might consider advocating for parents who have a child who fails a newborn hearing screen by offering training to medical professionals involved in the presentation of the results of the newborn hearing screen, so they might present the failed screen in a sensitive, yet realistic manner.

To provide case management and advocacy services effectively, counselors working with this population, or parents of any child diagnosed with a disability, should have a working knowledge of the disability. This knowledge should include the diagnostic process, prognosis, typical milestones and needs, and effective treatments/therapies/assistive technology. While counselors should not use this knowledge to make diagnoses or clinical recommendations outside of their area of knowledge, training, and licensure or certification, this knowledge may allow the counselor to have a deeper, more holistic understanding of their clients and their clients' experiences.

### **Recommendations for Further Study**

#### **Parents Who are Deaf**

All of the parents who participated in this study are Hearing. The researcher did not have the opportunity to collect interview data from parents who are Deaf, and/or identify as part of the Deaf Community. Therefore, this researcher recommends further study to explore and document the lived experiences and meaning making of parents who are Deaf and/or identify as part of the Deaf Community. Further study in this area may assist helping professionals develop a deeper understanding of parents who are Deaf, and/or whose experiences may be influenced by connections with the Deaf Community.

#### **Parents of Varying Socioeconomic Status**

Ten of the twelve parents (five couples) interviewed for this study reported household incomes of at least \$65,000 per year. Two of the parents interviewed in this study reported income of not greater than \$35,000 per year. The responses of these two parents seemed to indicate greater difficulties connecting with community resources,



educational resources, and information. These parents' responses also seemed to indicate that their child has communication and educational struggles related to this lack of resources and information. The researcher recommends further study focusing on the experiences of parents from this population who are of lower socioeconomic status. This further study might prove beneficial in order to have greater understanding of the influence of greater financial and social capital on these parents and their children.

### **Parents Who Choose to Not Implant**

All of the parents who participated in this study made the decision to implant their children. Although the cochlear implant is an assistive device that does not "cure" deafness per se, these parents report their children function similarly to hearing children. Most of the parents indicate their children do not have contact with the Deaf Community and do not know or communicate using American Sign Language. The researcher did not have the opportunity to collect any interview data from parents who chose to not implant their child or children. Therefore, this researcher recommends further study to explore and document the lived experiences and meaning making of parents who have decided to not implant their children. Further study in this area may assist helping professionals develop a deeper understanding of parents who come to different conclusions regarding communication choices and education, and the influence of those conclusions on these parents and their children.

### **Single or Divorced Parents**

All of the parents who participated in this study were part of two-parent, married families. The researcher did not have the opportunity to collect any interview data from single parents, parents who are unmarried partners, or divorced parents. Therefore, this

researcher recommends further study to explore and document the lived experiences and meaning making of parents who are single, are divorced and share custody of their child or children, or who are the unmarried partners. Further study in this area may assist helping professionals to develop a deeper understanding of parents who are not part of two-parent, married families, and the potential influence of these relational and environmental circumstances on these parents and their children.

### **Parents from the LGBTQI Community**

All of the parents who participated in this study were members of heterosexual married couples. The researcher did not have the opportunity to collect any interview data from parents who are members of the LGBTQI Community. Therefore, this researcher recommends further study to explore and document the lived experiences and meaning making of parents who identify as members of the LGBTQI Community. Further study in this area may assist helping professionals to develop a deeper understanding of parents who are part of the LGBTQI Community and are single, part of two-parent, married families, unmarried partners, or divorced parents, and the potential influence of these relational and environmental circumstances on these parents and their children.

### **Themes not Found in the Professional Literature**

Participants shared information and details related to the following experience related themes not found during the literature review for this research study: **big questions, impact of technology, social impact of deafness with cochlear implant, normal/small questions, prior knowledge of deafness, internet/social media as a resource, advocacy/commitment to advocacy, giving back, personal/financial**

**sacrifice, anticipate needs/provide additional supports, false hope, and success bolsters satisfaction with choices/leads to greater self-efficacy.** Additionally, participant parents shared the meaning related themes **gratitude** and **deeper/more intentional relationship**, but these themes were not found during the literature review. It is suggested that further research be conducted focusing on these themes as they relate to parents who have a child or children diagnosed with deafness.

### **Limitations**

This study is limited by the sample size and by the demographic similarities of the participants. The demographic similarities of the participants include race (Caucasian only) and household composition (two parent heterosexual households only). Additionally, all of the participants chose cochlear implants for their children and all participants were involved with Beginnings SC at the time of the interview. The size of the sample and the participant similarity limit the potential for applicability to all parents of children diagnosed with deafness. Limitations also exist due to the nature of the data collected as part of this research study. All interview data is based on parental self-report, and is therefore subjective and possibly influenced by the person of the researcher and the interactions between the researcher and the participant parents. Additionally, all interview data is interpreted by the researcher and is subject to bias and the researcher's own subjectivity.

### **Reflection and Conclusion**

The purpose for conducting this research study was to document the lived experiences of parents of children diagnosed with deafness and the meaning these parents made of their experiences. Unexpectedly, each parent interviewed for this study had

chosen cochlear implantation for his or her child or children. Prior to beginning this study, I had a bias against cochlear implantation and preconceived ideas regarding cochlear implants and their effectiveness as an assistive technology device. My preconceived ideas about cochlear implants were informed by conversations with members of the Deaf Community who are staunchly opposed to cochlear implantation, and who see it as a form of cultural genocide. Additionally, I have had personal and professional experiences with individuals who have been implanted and have not found success with the use of the cochlear implant as an assistive communication device.

Prior to beginning this research study, I was not opposed to cochlear implantation per se. I did, however, question the efficacy of cochlear implantation in allowing individuals diagnosed with deafness to function similarly to hearing individuals. As this study concludes, I find myself with a greater understanding of the possibilities available through cochlear implantation, and I have met families who have children who function similarly to their hearing peers. However, I do not believe cochlear implants are a "one size fits all" solution to deafness, nor do I believe cochlear implants themselves are a cure for deafness. I do not believe a family's choice to commit to cochlear implantation and the lengthy therapeutic process should be made lightly or without consideration for the family's ability to commit to the entirety of the therapeutic process.

During the course of this research study, I did not share my preconceived beliefs regarding cochlear implants with any of the parents. I attempted to be intentionally aware of my biases and pre-existing beliefs, and to bracket those biases and beliefs before engaging the parents in the interview process. My hope is that through the course of the interview process, these parents experienced a sense of empowerment as they had the

opportunity to share their struggles, successes, and strengths as they and their families have worked to address their child's or children's deafness. During the course of the interviews, I was amazed not only by the parents' dedication to their children's therapy and treatment, but also by the parents' desire to connect with other families in an effort to provide support, information, and a sense of community. This group of parents shared a wealth of information related to their cognitive, behavioral, and affective experiences, as well as the meaning they made of these experiences. Therefore, as counselor educators training the next generation of counselors and as counselors working with this population, it is our responsibility to use this information to lead us forward with scholarship and creativity as we continue to develop a greater understanding of this population and their strengths and needs.

## REFERENCES

- Bat-Chava, Y. (2000). Diversity of deaf identities. *American Annals of the Deaf*, 145, 420-428.
- Bevan, M. T. (2014). A method of phenomenological interviewing. *Qualitative Health Research*, 24, 136-144. doi: 10.1177/1049732313519710
- Bingham, A., Correa, V. I., & Huber, J. J. (2012). Mothers' voices: Coping with their children's initial disability diagnosis. *Infant Mental Health Journal*, 33, 372-385. doi: 10.1002/imhj.21341
- Bosteels, S., Van Hove, G., & Vandenbroeck, M. (2012). The roller-coaster of experiences: Becoming the parent of a deaf child. *Disability and Society*, 27, 983-996. doi: 10.1080/09687599.2012.705059
- Bristor, M. W. (1984). The birth of a handicapped child – a wholistic model for grieving. *Family Relations*, 33, 25-32.
- Byrne, M. M. (2001). Understanding life experiences through a phenomenological approach to research. *AORN Journal*, 73, 830-832.
- Creswell, J. W., Hanson, W. E., Plano Clark, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *The Counseling Psychologist*, 35, 236-264. doi: 10.1177/0011000006287390
- Decker, K. B., Vallotton, C. D., & Johnson, H. A. (2012). Parents' communication decision for children with hearing loss: Sources of information and influence. *American Annals of the Deaf*, 157, 326-339

- DesGeorges, J. (2003). Family perceptions of early hearing, detection, and intervention systems: Listening to and learning from families. *Mental Retardation and Developmental Disabilities*, 9, 89-93. doi: 10.1002/mrdd.10064
- Dilthey, W. (1985). *Poetry and experience. Selected Works, Vol. V*. Princeton, NJ: Princeton University Press.
- Eleweke, C. J. & Rodda, M. (2000). Factors contributing to parents' selection of a communication mode to use with their deaf children. *American Annals of the Deaf*, 145, 375-383.
- Feher-Prout, T. (1996). Stress and coping in families with deaf children. *Journal of Deaf Studies and Deaf Education*, 1, 155-166.
- Folkman, S. & Moskowitz, J. T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, 55, 745-774. doi: 10.1146/annurev.psych.55.090902.141456
- Freeman, B., Dieterich, C. A., & Rak, C. (2002). The struggle for language: Perspectives and practices of urban parents with children who are deaf or hard of hearing. *American Annals of the Deaf*, 147, 37-44.
- Glaser, B. & Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative research. New York: Aldine Publishing Company.
- Glesne, C. (2011). *Becoming qualitative researchers: An introduction* (4th ed.). Boston, MA: Pearson Education.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough?: An experiment with data saturation and variability. *Field Methods*, 18, 59-82. doi: 10.1177/1525822X05279903
- Harnett, A. & Tierney, E. (2009). Convention of hope – communicating positive, realistic

- messages to families at the time of a child's diagnosis with disabilities. *British Journal of Learning Disabilities*, 37, 257-264. doi: 10.1111/j.1468-3156.2009.00580.x
- Husserl, E. (1970). *The crisis of European sciences and transcendental phenomenology: An introduction to phenomenological philosophy* (D. Carr, Trans). Evanston, IL: Northwestern University Press.
- Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004).
- Jackson, C. W., Traub, R. J., & Turnbull, A. p. (2008). Parents' experiences with childhood deafness: Implications for family-centered services. *Communication Disorders Quarterly*, 29, 82-98. doi: 10.1177/1525740108314865
- Jackson, C. W. & Turnbull, A. (2004). Impact of deafness on family life: A review of the literature. *Topics in Early Childhood Special Education*, 24, 15-29.
- Jones, A. (2001). A condensed history of the phenomenology: The first and second phases from Franz Brentano to Hans-Georg Gadamer. *Nurse Researcher*, 8, 65-75.
- Koch, T. (1999). An interpretive research process: Revisiting phenomenological and hermeneutical approaches. *Nurse Researcher*, 6, 20-34.
- 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
- Leybaert, J. & D'Hondt, M. (2003). Neurolinguistic development in deaf children: The effect of early language experience. *International Journal of Audiology*, 42, S34-S40.
- Lonergan, B. (2003). *Method in theology* (2nd ed.). Toronto: University of



- Toronto Press.
- Luckner, J. L. & Velaski, A. (2004). Healthy families of children who are deaf. *American Annals of the Deaf*, 149, 324-335.
- Luterman, D. (2004). Counseling families of children with hearing loss and special needs. *The Volta Review*, 104, 215-220.
- Mason, J. (2002). *Qualitative researching* (2nd ed.). London: Sage.
- Moeller, M. P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics*, 106, 1-9.
- Opirhory, G. & Peters, G. A. (1982). Counseling intervention strategies for families with the less than perfect newborn. *The Personnel and Guidance Journal*, 60, 451-455.
- Patrick-Ott, A. & Ladd, L. D. (2010). The blending of Boss' concept of ambiguous loss and Olshansky's concept of chronic sorrow: A case study of a family with a child who has significant disabilities. *Journal of Creativity in Mental Health*, 5, 74-86.  
doi: 10.1080/15401381003627327
- Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Perry, D. J. (2013). Transcendental method for research with human subjects: A transformative phenomenology for the human sciences. *Field Methods*, 25, 262-282. doi: 10.1177/1525822X12467105
- Prescott, M. R. & Hulnick, H. R. (1979). Counseling parents of handicapped children: An empathic approach. *The Personnel and Guidance Journal*, 58, 263-266.
- Pringle, J., Hendry, C., & McLafferty, E. (2011). Phenomenological approaches: Challenges and choices. *Nurse Researcher*, 18, 7-18.

- Reio, Jr., T. G. & Fornes, S. L. (2011). Learning and adaptation after diagnosis: The role of parent education. *New Directions for Adult and Continuing Education*, 2011, 53-61. doi: 10.1002/ace.431
- Seidman, I. (2013). *Interviewing as qualitative research* (4th ed.). New York, NY: Teachers College Press.
- Senghas, R. J. & Monaghan, L. (2002). Signs of their times: Deaf communities and the culture of language. *Annual Review of Anthropology*, 31, 69-97. doi: 10.1146/annurev.anthro.31.020402.101302
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method and research*. London: Sage Publications
- Snell, S. A. & Rosen, K. H. (1997). Parents of special needs children mastering the job of parenting. *Contemporary Family Therapy*, 19, 425-442.
- Storbeck, C. & Calvert-Evers, J. (2008). Towards integrated practices in early detection of and intervention for deaf and hard of hearing children. *American Annals of the Deaf*, 153, 314-321.
- Taylor, D. C. (1982). Counseling the parents of handicapped children. *British Medical Journal*, 284, 1027-1028.
- Turnbull, A. P., & Turnbull, H. R. (2001). *Families, professionals, and exceptionality: Collaborating for empowerment* (4th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: State University of New York Press.
- Wilgosh, L. & Scorgie, K. (2006). Theoretical model for conceptualizing cross-cultural

- applications and intervention strategies for parents of children with disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 211-218.
- Woolfson, L. (2004). Family well-being and disabled children: A psychosocial model of disability-related child behaviour problems. *British Journal of Health Psychology*, 9, 1-13.
- Yoshinaga-Itano, C., Sedley, A. L., Coulter, D. K., & Mehl, A. L. (1998). Language of early- and later-identified children with hearing loss. *Pediatrics*, 102, 1161-1171.
- Ziolko, M. E. (1991). Counseling parents of children with disabilities: A review of the literature and implications for practice. *Journal of Rehabilitation*, 57, 29-34.

## APPENDIX A – DEMOGRAPHIC INFORMATION FORM

Interview #:

Parent Pseudonym:

Mother / Father

Parent Age:

Educational Level:

Employment:

Ethnicity:

Children in Family:

Family Income:

<\$14,000	\$14,000-\$25,000	\$25,000-\$35,000	\$35,000-\$45,000
\$45,000-\$55,000	\$55,000-\$65,000	\$65,000-\$75,000	>\$75,000

Type of Family:	<b>Two Parents</b>	<b>Single Mother</b>	<b>Single Father</b>
-----------------	--------------------	----------------------	----------------------

Location in South Carolina:

Community Type:	<b>Urban</b>	<b>Suburban</b>	<b>Rural</b>
Community Size:	<b>Small</b>	<b>Medium</b>	<b>Large</b>

Number in Family who are Deaf:

Child's Age:

Child's Age at Diagnosis:

Child's Sex:

Hearing Loss of Child:	<b>Moderate</b>	<b>Severe</b>	<b>Profound</b>
------------------------	-----------------	---------------	-----------------

Communication Method:

Sensory Device:

## APPENDIX B – INVITATION LETTER

Study Title: A Phenomenological Study of the Experiences of Parents of a Child or Children Diagnosed with Deafness

Dear \_\_\_\_\_,

My name is David Leach. I am a doctoral candidate in the Educational Studies Department at the University of South Carolina. I am conducting a research study as part of the requirements of my degree in Counselor Education and Supervision, and I would like to invite you to participate.

I am studying the experiences of parents who have a child or children diagnosed with deafness. If you decide to participate, you will be asked to meet with me for an interview about your experiences. In particular, you will be asked questions about your ongoing experiences as the parent of a child or children diagnosed with deafness, and the meaning you make of those experiences. The meeting will take place at a mutually agreed upon time and place, and should last about 60 minutes. The interview will be audio and videotaped so that I can accurately reflect on what is discussed. The tapes will only be reviewed by members of the research team who will transcribe and analyze them. They will then be destroyed.

You may feel uncomfortable answering some of the questions. You do not have to answer any questions that you do not wish to. Although you probably won't benefit directly from participating in this study, we hope that others in the community/society in

general will benefit by a deeper understanding of the experiences of parents of a child or children diagnosed with deafness.

Participation is confidential. Study information will be kept in a secure location at the University of South Carolina. The results of the study may be published or presented at professional meetings, but your identity will not be revealed. So, please do not write your name or other identifying information on any of the study materials.

Taking part in the study is your decision. You do not have to be in this study if you do not want to. You may also quit being in the study at any time or decide not to answer any question you are not comfortable answering.

We will be happy to answer any questions you have about the study. You may contact me at 843.209.2845 or leachd@email.sc.edu or my faculty advisor, Dr. Joshua Gold at 803.777.1936 or josgold@mailbox.sc.edu if you have study related questions or problems. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at 803-777-7095.

Thank you for your consideration. I will call you within the next week to see whether you are willing to participate.

With kind regards,

(Signature)

David Leach, MRC, CRC, LPCI

Wardlaw College

843.209.2845

leachd@email.sc.edu

## APPENDIX C – PRE-INTERVIEW SCRIPT

### A Phenomenological Study of the Experiences of Parents of a Child or Children Diagnosed with Deafness

My name is David Leach and I am conducting this study for my doctoral dissertation. I am a Ph.D. candidate at the University of South Carolina. This study is being conducted in order to gain a deeper understanding of the experiences of parents who have a child or children diagnosed with deafness and the meaning these parents make of their experiences. This information may prove valuable to professionals and service providers who work with these children and their families. You are being asked to participate because you are the parent of a child or children diagnosed with deafness. This interview is voluntary and your responses are anonymous and confidential. You do not have to answer any question or questions you do not want to answer. This interview is being recorded, so that I will be able to accurately reflect on the information you share during the interview. The interview will take approximately one hour. You may contact me regarding questions about this research or the IRB manager at USC regarding your rights as a participant. What questions do you have before we begin?

## APPENDIX D – INTERVIEW QUESTIONS

1. Can you tell me about the time when you became aware of your child's deafness?
2. Can you tell me about any significant questions or concerns you have had since your child's diagnosis and how you have sought out answers to the questions/concerns?
3. Can you tell me about any conclusions you have reached about being the parent of a child diagnosed with deafness?
4. Can you tell me about any decisions you have made since becoming the parent of a child diagnosed with deafness that stand out to you or seem important?
5. How has this experience influenced your development as a parent?