

A DESCRIPTIVE STUDY OF PARENT INVOLVEMENT IN EARLY
INTERVENTION FOR CHILDREN WHO ARE DEAF OR HARD OF HEARING AND
HAVE ADDITIONAL SPECIAL NEEDS

A dissertation presented to the faculty of the Graduate School of
Western Carolina University in partial fulfillment of the
Requirements for the degree of Doctor of Education.

By

Wendy Brooks Wieber

Co-Director: Dr. John C. Habel

Associate Professor

Department of Psychology

Co-Director: Dr. Bill Ogletree

Professor

Department of Communication Sciences and Disorders

Committee Members:

Dr. Cathy L. Grist, Department of Human Services

Dr. Terri Barrett, Lenoir-Rhyne University, Department of Education

June 2015

ACKNOWLEDGEMENTS

I would not have been able to complete this study without the support of many people. I gratefully acknowledge Dr. John Habel, who so thoughtfully co-chaired my dissertation committee and whose expertise with qualitative research was invaluable. I would also like to acknowledge Dr. Bill Ogletree, who co-chaired my committee and provided a complementary perspective. I am also grateful to my dissertation committee members, Dr. Cathy Grist and Dr. Terri Barrett. Since my research did not fit perfectly into any current department at Western Carolina University, this committee, representing the varied disciplines of psychology, communication sciences, early childhood education and deaf education created it's own perfectly balanced unit. I extend my special thanks to Dr. Kathleen Jorrisen for her unflagging optimism and encouragement.

I would like to thank all of the teachers of the deaf in the early intervention program for helping me recruit participants and to Ruth Anne Everett, director of the program. Extra thanks to Jenni Campagna, Roxanne Dearman and Mary Lou Wright for sharing their families with me. A very special thank you to Mandy Hice for always lending her support to me, including her help in my multitude of questions regarding the early intervention program. Thank you to Marcia Fort for her help with the North Carolina Early Hearing Detection and Intervention statistics. Thank you, Dr. Katherine Greysen for so carefully weeding my manuscript.

Finally, thanks to my dearest Elizabeth, who has supported me throughout with love, humor, editing, and some vital prodding.

DEDICATION

This study is dedicated to the parents of infants and toddlers with hearing loss and additional special needs, who took the time from their busy lives to participate in this study. I wish I could give more in return for your valuable assistance and heartfelt responses to my questions.

TABLE OF CONTENTS

	Page
List of Tables	8
List of Figures	9
Abstract	10
Chapter One: Introduction	12
Nature and Significance of the Problem	12
The Rationale for Very Early Intervention for Hearing Loss	13
Children Who Have Additional Special Needs	14
Purpose Statement.....	15
Research Questions	15
Theoretical Framework.....	16
Outline of Dissertation	19
Limitations	20
Delimitations.....	20
Definitions.....	21
Chapter Two: A Review of the Literature	27
Early Hearing Detection and Intervention Program: History	27
Early Hearing Detection and Intervention System Components & Timing	28
Age of Diagnosis.....	29
Congenital Hearing Loss and Additional Special Needs	30
Delay in Early Diagnosis and Intervention.....	31
History of Hearing Screening, Diagnosis and Intervention in North Carolina.....	33
History of Early Intervention for Deaf/Hard of Hearing	34
Purpose and Rationale for Early Intervention.....	36
Plasticity of the Infant Brain	36
Long Term Benefits of Early Intervention.....	38
Cost Savings of Early Identification and Intervention.....	39
Impact of Later Identification and Intervention.....	39
Early Hearing Detection and Intervention: Components and Timelines	41
Screening and Diagnostics	41
Tracking Pediatric Audiological Services and Early Intervention	42
Barriers to Early Diagnosis and Intervention.....	43
System Issues	43
Cost and reimbursement for audiology services.....	44
Family Risk Factors	45
The Confusion of Hearing Screening	46
Diagnosis of Hearing Loss: Reaction and Systems Issues.....	47
Complications in getting initial diagnosis.....	47
Surprise and disbelief.....	48
Family Responses to Early Intervention Practitioners.....	49
Dealing with Grief	50
Burden of Care.....	51

A Need for Family-Centered Intervention	52
Limitations of Existing Research.....	53
The Limits of Research in Families with Children with Hearing Loss and Additional Special Needs.....	54
Communication as a Fundamental Right.....	56
Family Participation in Early Intervention	57
Summary.....	57
Chapter Three: Methodology	59
Research Purpose and Questions	59
Paradigm and Assumptions.....	59
Research Design.....	60
Interview as the Primary Tool of the Study	61
Field Notes and Journaling	62
Identification and Recruitment of Participants	63
Purposeful Sampling.....	65
Description of Participants.....	66
Pilot.....	67
Incentive.....	67
Data Collection Procedures.....	68
Interview Procedures	68
Face-to-Face Interviews.....	70
Telephone Interviews.....	70
Methods and Procedures	71
Confidentiality	72
Ethical Considerations	72
Study Effects.....	73
Role of the Researcher	74
Chapter Four: Research Findings and Analysis.....	76
Data Analysis	76
Trustworthiness and Authenticity.....	78
Participants.....	80
Profiles of Families	85
Buffy, parent of Daphne	85
Jeannie and Lars, parents of Angus	86
Amara, parent of Jina.....	87
Erica Lynn, parent of Junior	87
Hannah, parent of Ryder.....	88
Peyton, parent of Callie.....	89
Jez, parent of Andrew	90
Giselle, parent of Sydney.....	90
Lainey, parent of Nikki	91
Themes in Parent Interviews.....	91
Learning Your Child Has a Hearing Loss.....	92
Initial Reaction.....	93
I cried	93
Other bad things could have gone wrong	94

The stress of receiving a diagnosis of hearing loss.....	95
Prioritizing Children’s Needs and Selecting Early Intervention.....	95
Hierarchy of Needs	96
Choosing the right therapies for my child.....	96
Getting in the Door	100
Working with early interventionists.....	104
The ups and downs of working with professionals.....	105
Early Intervention – Adjustments and Barriers	107
The Stressors of Having a Sick Child.....	107
Working mom	109
Professionals Who Don’t Help	110
She has a life!.....	111
Feeling judged and devalued	115
Does not listen to me.....	115
I can’t handle the unknown.....	117
Upsets my child.....	120
Financial Obstacles	121
Distance and Travel Needs	125
Having Professionals Come to the Home: A Mixed Review	126
Early Intervention – What Works.....	126
Positive Interactions with Professionals	127
Being heard and valued.....	127
Educates and provides information.....	128
Works well with their child.....	128
Seeing progress	130
Parents with Prior Experience.....	130
Faith	131
External Support	132
Financial Support	133
Advice from Parents	133
Advice to Professionals.....	133
Advice to Other Parents	135
Chapter Five: Discussion	138
Research Questions and Answers	138
Question 1: What are the Barriers to Early Intervention?.....	140
Delays in screening and diagnosis	141
Emotional overload and exhaustion.....	141
Adverse interactions with professionals	143
Insensitivity.....	143
Inability to provide information.....	144
Not listening.....	144
Costs.....	145
Question 2: What are the Positive Factors in Seeking Early Intervention?.....	146
Supportive interactions with professionals	146
Facilitated entry into EI	146

Response to needs	147
Caring attitude.....	147
Parental resilience	148
External and financial supports.....	148
Prioritizing needs	149
Strengths and Limitations of the Study.....	150
Recommendations for Future Research	152
Family Focused Research	152
Public Policy and the System of Service	153
Implications for Practice	154
What Parents Want Other Parents and Professionals to Know.....	154
Suggestions for Changes in the System of Care	155
Lessons I Learned	157
Conclusion	157
References.....	159
List of Appendices	178
Appendix A: Informed Consent.....	179
Appendix B: Interview Protocol	181
Appendix C: Your Child’s Needs	182
Appendix D: IRB Approval	183
Appendix E: Eligibility Definition for the NC Infant Toddler Program	185
Appendix F: A Sample of Parent Interview.....	188

LIST OF TABLES

Table	Page
1. Parent Participants (n=10) and Their Children (n=9)	83
2. Parent Prioritization of Child's Needs (n=10)	98
3. Factors Leading to Parents Seeking Early Intervention for Hearing Loss of Their Child (n=10)	104

LIST OF FIGURES

Figure	Page
1. Statements by Parents about Experiences with Professionals of Varied Disciplines.	106
2. Parents' Experiences with Obstacles and Positives in Early Intervention.....	139

ABSTRACT

A DESCRIPTIVE STUDY OF PARENT INVOLVEMENT IN EARLY
INTERVENTION FOR CHILDREN WHO ARE DEAF OR HARD OF HEARING AND
HAVE ADDITIONAL SPECIAL NEEDS

Wendy Brooks Wieber

Western Carolina University (June 2015)

Directors: John Habel and Bill Ogletree

Abundant studies have documented the benefits of early intervention in overcoming the detrimental effects of congenital hearing loss. This research has led to past and current recommendations by the Joint Commission on Infant Hearing on the timeliness of early intervention. Studies have focused on loss to follow-up for diagnosis and early intervention. The CDC (2015) estimated that of the infants diagnosed in 2013 with hearing loss, 36.8% were not documented as receiving early intervention. Most studies of these children and parents are substantially quantitative. Studies regarding barriers specific to families who have children with additional special needs are few. This study addressed a knowledge gap by exploring the lived experiences of 10 parents of 9 children in North Carolina who received early intervention for their child's hearing loss and other special needs. Through semi-structured interviews, parents spoke of making choices in early intervention when their child has competing special needs. Parents' adjustments to the diagnosis of hearing loss were complicated by stressors associated with their child's additional special needs and co-occurring ambiguity or delay in the diagnosis of hearing

loss. Families found strength in information, experience, faith and positive partnerships with professionals. Parents identified costs as obstacles to their children receiving early intervention services and a source of stress for parents. Financial support for hearing equipment and early intervention activities enhanced the family's ability to participate in their child's progress. Parents prioritized their child's needs for intervention in a hierarchy, which often placed hearing, speaking and communicating as a lower priority than other skills. Improved training in communication with parents about hearing loss across disciplines could help provide a critical mass of practitioners to inform parents' understanding of the impact of hearing loss. Educational and program materials for all providers could address this need. The inclusion of training in family-centered intervention and inter-professional training for educators and health providers is essential. Educational materials for parents tailored to hearing loss when a child has other special needs, could impact parents' understanding of hearing loss and early intervention.

CHAPTER ONE: INTRODUCTION

Nature and Significance of the Problem

In the United States, permanent congenital hearing loss (PCHL) is one of the most common groups of birth defects. According to the Centers for Disease Control and Prevention (CDC, 2015), the prevalence of diagnosed PCHL in 2013 was 1.5 per 1000 newborns nationally. The CDC also estimates that nearly one-quarter of children with hearing loss has one or more other developmental disabilities, such as cerebral palsy, intellectual disability or vision loss. Of those children who were diagnosed in 2013 (CDC, 2015), 36.8% were receiving no Early Intervention (EI) services, although 87.4% were documented as having been referred for EI.

North Carolina's Early Hearing Detection and Intervention (EHDI) Program has an excellent track record of getting infants screened, diagnosed and referred to Early Intervention Services so that, ultimately, these children can receive specialized services for hearing loss. The North Carolina Early Intervention Branch (NCEI) is a part of the N.C. Division of Public Health. It is the lead agency for the NC Infant-Toddler Program (ITP) providing service under the Individuals with Disabilities Education Act-Part C (IDEA) (Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004) for children ages 0-2 who have special needs. In NC, statistics through the state EHDI Program (2015) indicate that, in 2012 and 2013, 99.7 % of infants were screened (excluding infants who died or whose parents declined). Those screened by 1 month of age increased to 98% by 2013. Of those infants identified with permanent hearing loss, 84.7 % were enrolled in EI by 6 months of age in 2012. In 2013, this percentage dropped to 77.7 %. This is still better than the national average, but the remaining percentage,

those infants who are not receiving any documented EI by age 6-months, continues to be of concern.

The Rationale for Very Early Intervention for Hearing Loss

Studies that show early auditory deprivation changes the architecture of a child's developing brain indicate that auditory learning of spoken language becomes more difficult as the delay in receiving optimum amplification increases (Kuhl, Conboy, Padden, Nelson & Pruitt, 2005). Some studies suggest that the "window" for spoken language development through listening may be biologically determined by experience (Kuhl et al., 2005; Moeller, 2000; Watkin, McCann, Law, Mullee, Petrou, Stevenson, Worsfold, Yuen & Kennedy, 2007). The lack of auditory experience can, to extend the metaphor, close the window on spoken language development. The window cannot be fully reopened when the brain has already constructed a different architecture based on incomplete language, thus reducing the effectiveness of school-age interventions. Research also suggests that the sensitive period of spoken language acquisition can be made applicable to the acquisition of sign language (Allen, Letteri, Choi & Dang, 2014; Woolf, Want & Siegal 2002). This evidence supports promoting very early access to visual language for children whose families do not choose a listening and spoken language approach to communication. Studies of the brain have shown that babies who are native users of American Sign Language (ASL) show the same developmental trajectories for visually-based languages as hearing children do for sound-based languages (Petitto & Marentette, 1991; Petitto, Katerelos, Levy, Gauna, Tetreault & Ferraro, 2001). Studies of children who acquire visual language earlier indicate positive impact on a constellation of developmental outcomes (Allen et al., 2014).

Children Who Have Additional Special Needs

National and state statistics on infants who have hearing loss do not specifically classify those children who have additional special needs so there is no data on that subgroup of children receiving EI. There is little empirical information about the development of these children in the first few years of their lives. The information that does exist, shows greater gains in language ability for those children with additional special needs whose hearing loss was identified before 6 months of age compared with those who were identified later (Pipp-Siegel, Sedey, VanLeeuwen, & Yoshinaga-Itano, 2003). Quantitative measures alone fall short in describing the experience with EI of these children and their families. Because hearing loss is most often invisible, children who have hearing loss and additional special needs are at particular risk for missing out on critical language development “windows”. Other disabilities often require intense focus, often at the expense of auditory input of spoken language and/or visual input of signed language. Anecdotal reports by teachers of the deaf and hard of hearing (TOD) indicate that this group of families can be particularly difficult to enroll and engage in EI for hearing loss.

The supplement to the recommendations made in 2007 by the Joint Commission on Infant Hearing (American Academy of Pediatrics, JCIH) provides “comprehensive guidelines for early hearing detection and intervention (EHDI) programs on establishing strong early intervention (EI) systems with appropriate expertise to meet the needs of children who are deaf or hard of hearing (D/HH)” (JCIH, 2013, p. 171). Beyond recommendations that early intervention service coordinators and providers have professional qualifications, core knowledge and specialized skills in working with

children who are D/HH, the recommendations also address the needs of those children who have additional disabilities or special needs. The Commission's recommendation is clear: "Appropriate EI services should result in similar advantages for children who are D/HH with additional disabilities as for children who are D/HH only" (JCIH, 2013, p. 185). The Commission goes on to assert that "regardless of the primary disability...it is critical to recognize the primacy of communication for learning and the impact of communicative delays on other developmental domains" (p. 185).

Intervention for hearing loss when a child has additional special needs is a subject deserving of attention by professionals and families alike. Appropriate and early services for children with hearing loss and additional special needs are critical to long-term success with language and learning and the ethical responsibility of society. Rationale for the present study are provided with research questions.

Purpose Statement

The purpose of this study was to discover and describe both the barriers and the facilitating factors for parents that result in engagement with EI for their child's hearing loss when their child also has additional special needs. *Facilitating* or *positive* factors, as I defined them, are considered those that result in parents' choosing to receive and maintain EI specifically in relation to their child's hearing loss.

Research Questions

1. According to the parents of children with a hearing loss and additional special needs, what causes them to delay or to avoid participation with EI specifically to address hearing loss for their children?
2. According to the parents of children with a hearing loss and additional special

needs what information or interactions caused them to engage with EI for their children's hearing loss?

Additionally, I hoped parents might answer some of the following questions:

- How did parents experience the process of diagnosis of hearing loss?
- How did parents respond to their child's hearing loss in the context of additional special needs?
- How did the experience of learning about their child's hearing loss affect decision-making about engaging in early intervention?
- What types of barriers to participation in early intervention do parents talk about?
- What types of professional and informal supports did families find helpful?
- How did these supports help parents commit to EI for hearing loss?
- What do parents identify as positive and negative experiences with professionals and the early intervention system?
- What do parents of children who have hearing loss and additional special needs think important for other parents and professionals to know.

Theoretical Framework

A foundational aspect of this study rests in the literature of family support principles (Dunst, Boyd, Trivette, & Hamby, 2007; Dunst, Trivette, & Deal, 1988; Turnbull, Summers, Turnbull, Brotherson, Winton, Roberts, Stroup-Rentier, 2007) and in guidelines for family-centered services for early intervention through Part C of IDEA. EI programs in general and specialized programs for children who have hearing loss (HL) have become more family-centered over time, both in response to legislative mandate (IDEA-Part C) that requires use of a family systems model in intervention and due to

research into best practice. Dunst et al. (1988) foundational work in enabling and empowering families has informed EI's practice of service delivery as family-centered and focused on needs and supports identified by the family. The family and EI team drive development of goals and activities through the Individualized Family Service Plan (IFSP). Community resources are deemed most important in providing ongoing responsive support. Parent-practitioner relationships in EI can also be emotionally powerful and empowering for families. Understanding the dynamics of mental health, early intervention, and family support can "amplify [the practitioner's] helpfulness with families" (Foley & Hotchman, 2006, p. 29).

The literature discussed in following chapter provides underpinnings for why early support of families who have children with hearing loss is essential. Now that newborn hearing screening and early identification are almost universal, exploration of parent experiences with early intervention when their child has hearing loss and additional special needs is important. This study seeks to understand how parents experience their child's hearing loss in the context of additional needs and how they view and make choices in intervention. Toward that end, the study focuses on the very personal experiences of parents.

- A fundamental assumption of the researcher is the importance of communication as central to human interaction and a basic human right. This research proposes to give voice to families, so they, in turn, are empowered to give the gift of language to their children.
- Federal legislation regarding provision of services to children who have disabilities or are at risk for disability under Part C of the Individuals with

Disabilities Education Act, places families in the role of collaborator with professionals and establishes their primacy as the decision-makers regarding their children, especially through development of the Individualized Family Service Plan (IFSP). Brewer, McPherson, Magrab, & Hutchins (1989) describes family-centered care eloquently:

Family-centered care is the focus of the philosophy of care in which the pivotal role of the family is recognized and respected in the lives of children with special health needs. Within this philosophy is the idea that families should be supported in their natural care-giving and decision-making roles by building on their unique strengths as people and families. In this philosophy...parents and professional are seen as equals in a partnership committed to the development of optimal quality in the delivery of all levels of health care (p. 1055).

Identifying family-perceived barriers to choosing early intervention for their child's hearing loss and what situations most successfully do engage families in partnership with specialists in D/HH education can lead to earlier, more supportive and successful participation by families. Ultimately, early intervention for hearing loss allows for optimum brain development for learning spoken or visual language, enhances social, functional and academic outcomes and fulfills a basic human communicative need. For those children who have additional special needs beyond hearing loss, access to communication through vision or hearing may represent a critical opportunity to build positive interactions with caregivers, help reduce the burden of care and enhance the child's and family's ability to more fully participate in their community.

Outline of Dissertation

This dissertation is divided into five chapters and an appendix section. This first chapter provides a problem statement and rationale for the study, a purpose statement and research questions as well as the theoretical framework which guided the inquiry process. Also, limitations, delimitations and operational definitions are provided.

Chapter two presents review of the literature, which most appropriately informs this study and includes some history of NC programs and practice in relation to hearing loss. It also identifies gaps in current scholarly inquiry as well as discussing paradigms, assumptions and a conceptual framework of family-centered practice.

The third chapter describes the research design, interview protocol, methods and procedures, confidentiality, ethical concerns and validation strategies used to increase trustworthiness and authenticity. Participants are described briefly.

Chapter four presents and displays the data including more extensive descriptions of the participants and their children. Data include themes that emerged from interviews and direct quotes, which illustrate the themes. Parent perspectives are highlighted and new themes are identified and described.

The final chapter is a discussion of the results of the study: implications for theory development, practice, public policy, future research, and the strengths and limitations of the study, including a conclusion and a section on lessons learned. There will also be a list of the references used in all the chapters of this dissertation and appendices that include copies of the Internal Review Board approval from Western Carolina University (WCU), informed consent form, definitions of eligibility criteria for Part C of IDEA, the interview protocol, and the information form parents used to describe their child's needs

and interventions. There will also be a complete transcript of one interview.

Limitations

The study is limited by the small number of participants. Ten parents of 9 children participated in the interview process. Due to the small number of participants and the fact that participation was voluntary, parents' responses may not be fully representative of all families who have children with PCHL and additional special needs. In particular, they do not represent those who were lost to early intervention. Since all participants were selected from a western North Carolina population, there is geographic homogeneity. Participants were working with only three of the 16 statewide Children's Developmental Services Agencies (CDSA) in NC. Researcher bias is also a potential limitation. I have strong beliefs about the efficacy of early amplification for auditory stimulation to develop receptive and expressive spoken language. For families who choose visual language, I am equally passionate about the early introduction of a complete visual language and deep immersion in a community with which a child can engage in communication. Language and its consistent accessibility for the deaf or hard of hearing child in his or her community is, to this researcher, a fundamental right. Recognizing that this passion could alter family responses in the interview process, I planned to practice honest responses to questions, should they arise and quickly turn the interview back over to the families themselves. My life experience as the mother of a profoundly deaf child who is now an adult, gives me a real, but limited, perspective on the study population. The influence of my lived experience as a parent of a child with a PCHL may provide insight or create bias, possibly a combination.

Delimitations

The following delimitations bounded this study: This study focused only on families who had been in the North Carolina Early Sensory Support Program for Children who have Hearing Impairment (formerly called the North Carolina Early Intervention Program for Children who are Deaf or Hard of Hearing) for at least 4 months or transitioned out of the program within the last 4 months. The study only included parents whose children have a permanent diagnosed bilateral hearing loss that of mild or greater degree and at least one additional special need. An additional special need was defined using the NC Infant Toddler Program guidelines which included additional needs as congenital infection, genetic disorder, congenital anomaly, inborn errors of metabolism, visual impairment, gestational age less than 27 weeks, neonatal encephalopathy, intraventricular hemorrhage grade III or IV, or documented developmental delay (NC ITP, 2014). Participants were limited to those who are fluent in English to reduce barriers to mutual understanding. Participants had to be age 18 or older. Additionally, I purposefully went into each interview with little information about participants other than the child's special needs and the timing of birth, diagnosis, and referrals to the Infant Toddler Program and to the program for D/HH. I refrained from getting personal information from the teachers about these parents and children in order to be regarded as independent from the program for D/HH. I expected this would elicit more honest responses from the parents, particularly in relation D/HH issues as well as minimizing preconceptions about parents and children.

Definitions

Certain terms are used throughout this study and have specific meanings.

American Sign Language (ASL): The primary visual language used by deaf and hearing-impaired people in the United States and Canada. It contains all the components of a complete language.

Auditory Brainstem Response Test (ABR): Diagnostic hearing assessment measuring the response of the auditory nerve by monitoring the response of brainstem structures to auditory stimulations. The ABR provides reliable, objective information about the level of hearing. It is non-invasive and results are best obtained with the infant sleeping.

Auditory Neuropathy Spectrum Disorder (ANSD): Is a type of hearing loss which is characterized by a problem in the transmission of sound from the inner ear to the brain.

BEGINNINGS: for Parents of Children who are Deaf or Hard of Hearing, Inc. has served families as a non-profit organization, incorporated under the laws of NC since 1987. BEGINNINGS was established to provide emotional support and access to information as a central resource for families with deaf or hard of hearing children, age birth through 21.

Children's Developmental Services Agencies (CDSAs): Sixteen local Children's Developmental Services Agencies (CDSAs) are available in locations across NC to help families, caregivers, and professionals serve children with special needs through the Infant Toddler Program (ITP). The CDSAs offer or coordinate the following services for eligible infants and toddlers: Service Coordination, physical, occupational and speech-language therapies, family support, special instruction, and assistive technology.

Communication: refers to signed or spoken language.

Deaf/Hard of Hearing (D/HH): refers to any level of hearing acuity less than established norms, mild to profound, unilateral or bilateral. This terminology is meant to be inclusive of those who have permanent hearing loss, those who consider hearing loss a disability and those whose “hearing differences” give them pride and identity within the Deaf community.

Early Hearing Detection and Intervention Act of 2010 (HR. 1246, S. 3199):

Amends the Public Health Service Act to: (1) expand the newborn and infant hearing loss program to include diagnostic services among the services provided; and (2) require the Secretary of Health and Human Services (HHS), acting through the Administrator of the Health Resources and Services Administration, to assist in the recruitment, retention, education, and training of qualified personnel and health care providers to implement the program. Revises program purposes to include: (1) developing and monitoring the efficacy of statewide programs and systems for hearing screening of newborns and infants, prompt evaluation and diagnosis of children referred from screening programs, and appropriate education, audiological, and medical interventions for children identified with hearing loss; (2) developing efficient models to ensure that newborns and infants who are identified with a hearing loss through screening receive follow-up by a qualified healthcare provider; and (3) ensuring an adequate supply of qualified personnel to meet the screening, evaluation, and early intervention needs of children. Amends the definition of "early intervention" to require that families be given the opportunity to obtain the full range of appropriate early intervention services, educational and program placements, and other options for their child from highly qualified providers.

Requires the Secretary to establish a postdoctoral fellowship program to foster research and development in the area of early hearing detection and intervention.

Early Intervention (EI): are services given to very young children with special needs, from birth until the child turns age three. According to Part C of the Individuals with Disabilities Education Improvement Act (IDEA) of 2004, Early intervention is the process of providing services, education and support to young children who are deemed to have an established condition, those who are evaluated and deemed to have a diagnosed physical or mental condition (with a high probability of resulting in a developmental delay), an existing delay or a child who is at-risk of developing a delay or special need that may affect their development or impede their education. The purpose of early intervention is to lessen the effects of the disability or delay. Services are designed to identify and meet a child's needs in five developmental areas, including: physical development, cognitive development, communication, social or emotional development, and adaptive development. *Part B* refers to the section of IDEA under which children and youth (ages 3-21) receive special education and related services.

Early Intervention Service Coordinator (EISC): The EISC is assigned to families as they enter the Infant Toddler Program and provides case management services. Duties of the EISC include Individual Family Service Plan (IFSP) development, home visits, intervention planning, and coordinating, authorizing and monitoring of early intervention services according to federal law and state regulations.

Individuals with Disabilities Education Act (IDEA): This act ensures that all children with disabilities are entitled to a free appropriate public education to meet their

unique needs and prepare them for further education, employment, and independent living.

Loss to Follow-up (LFU): Refers to infants who were referred from their Newborn Hearing Screening and lost track of by the monitoring system. The loss to follow-up can occur at any of several steps in the process of the newborn hearing screening (NHS) and subsequent follow-up; between screening and outpatient rescreening, between final screening and diagnosis, and between diagnosis and the beginning of early intervention.

North Carolina Early Intervention Branch (NCEI): is a part of the N.C. Division of Public Health. It is the lead agency for the N.C. Infant-Toddler Program (ITP). The Infant-Toddler Program provides assistance and services for families and their children, birth to three who have special needs. Sixteen Children's Developmental Services Agencies (CDSAs) across North Carolina work with local service providers to support families in helping their children succeed.

Early Hearing Detection and Intervention (EHDI): Systems or programs that form a network of local and state agencies that provide screening, diagnosis and links to early intervention services for infants who are deaf and hard of hearing and their families.

Newborn Hearing Screening: Typically takes place in the birthing hospital prior to discharging the infant. Screening is quick and non-invasive, using Otoacoustic Emissions (OAE) screening or an Automated Auditory Brainstem Response (ABR) screener. If the infant “refers” or doesn’t pass in either ear, a follow-up screen is done later, once, and if “referred” again, the child is sent on for a full diagnostic workup which

includes a sleeping ABR and additional testing with an audiologist and an otolaryngologist.

Otolaryngologist: is an ear, nose and throat doctor (ENT).

Part B of IDEA: Governs how special education and related services are provided to children 3-21 years of age.

Part C of IDEA: a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, ages birth through age 2 years, and their families.

Permanent Congenital Hearing Loss: Refers to a hearing loss present at birth that will not resolve. It can include hereditary hearing loss or hearing loss due to other factors present either in-utero (prenatal) or at the time of birth.

Theory of Mind: Theory of mind is the capacity to form opinions about the cognitive state of others. It allows children to acquire more complicated socio-cognitive skills such as perspective-taking, collaboration, recursive thought, and metacognition.

Universal Newborn Hearing Screening Act (H.R. 1193 and S. 956): Incentive program passed by U.S. Congress in November of 1999 providing grants to state as inducement to implement hearing screening for all newborns, and to establish statewide tracking with linkages to early intervention services.

Universal Newborn Hearing Screening (UNHS) and Joint Committee on Infant Hearing, 2000: Policy and practice recommendations for performing hearing screening on every newborn, and for those referred, follow-up diagnostics, documentation and referral guidelines.

CHAPTER TWO: A REVIEW OF THE LITERATURE

Permanent congenital hearing loss (PCHL) is one of the most common groups of birth defects in the United States. According to the Centers for Disease Control and Prevention (CDC, 2013) the prevalence of diagnosed PCHL in 2013 was 1.5 per 1000 newborns nationally. White (2006) suggests that approximately 3 per 1,000 newborns in the US are born with a congenital hearing loss. Until recently, most children with congenital hearing loss were not identified until they were 2 to 3 years old (White, Forsman, Eichwald, & Muñoz, 2010). CDC national statistics show that in 2013, 87.4% of children diagnosed with hearing loss were documented as being referred for EI, yet only 63.2% were recorded as actually receiving Early Intervention services (EI).

Early Hearing Detection and Intervention Program: History

An enormous amount of energy and commitment helped fashion current Early Hearing Detection and Intervention (EHDI) programs. At the same time that companies were developing more accurate physiologic hearing screening equipment, the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services supported a 1989 demonstration project at Utah State University that helped 50 hospitals develop newborn hearing screening programs (Farrel, 2009). The Early Hearing Loss Detection, Diagnosis, and Intervention Act of 1997 (H.R. 2923) provided grant support to individual states to establish screening and intervention programs for newborns and infants with hearing loss. This legislation called for screening all newborn infants for hearing loss, follow-up diagnostic audiologic testing performed in a timely manner upon referral from the screening, linkage with community early intervention for infants diagnosed with hearing loss and establishment of public policy for the early identification

and intervention of newborns with hearing loss. This bill was last amended by the 111th Congress, retaining the essential aspects of early detection, diagnosis and treatment of hearing loss as the Early Hearing Detection and Intervention Act of 2010. The amended language calls for “screening, evaluation, diagnosis, and intervention programs and systems, and to assist in the recruitments, retention, education, and training of qualified personnel and health care providers” (S. 3199, 111th Cong. § 2-5 , 2010). The Joint Committee on Infant Hearing (JCIH, 2007, para 1) endorses the “goal of early hearing detection and intervention (EHDI) to maximize linguistic competence and literacy development for children who are deaf or hard of hearing” and goes on to assert that “without appropriate opportunities to learn language, these children will fall behind their hearing peers in communication, cognition, reading, and social-emotional development”.

Since 1994 there has been a significant increase in the number of infants who have their hearing screened at birth, reaching 97.90% by 2011 (Centers for Disease Control and Prevention [CDC, 2015]. Every state has an Early Hearing Detection and Intervention (EHDI) coordinator who coordinates statewide systems of care from screening through early intervention (White et al., 2010). Early intervention studies have documented improved outcomes for children who are identified and enrolled in early intervention before age 6 months using cross-sectional data at age 3 years (Yoshinaga-Itano & Sedey, 1998).

Early Hearing Detection and Intervention System Components & Timing

In order to ameliorate the social and educational impact of later identified/intervened hearing loss, the JCIH (2007) recommends screening all newborn infants within one month, diagnosing hearing loss within three months and fitting

amplification (if recommended) and begin early intervention within six months. Lack of improved developmental outcomes for certain early identified children may involve failure of follow-through by professionals or parents at any of the steps along the way, causing the child and family to be lost to early intervention. This streamlined process, although current best practice, places increased demands on parents and professionals to respond quickly to a new situation in a compressed time-line (Danhauser & Johnson, 2006).

Age of Diagnosis

Due to the successful growth of EHDI programs, the age of diagnosis for children with hearing loss has contracted dramatically in the past two decades, creating a different emotional scenario for families. Before 1990, children who were born with PCHL in the United States would typically not be identified until 2-3 years of age (Culpepper, 2003; Muñoz, Bradham, & Nelson, 2011). Parents and caregivers had time to begin to identify differences in their child and suspect hearing loss (Kurtzer-White & Luterman, 2003). The event of newborn hearing screening and objective medical tests can propel parents and caregivers towards a diagnosis when their child is still in the newborn stage, and for the group in this study, when their child may be facing medical crises.

Currently, according to Yoshinaga-Itano (2013), "some 98 or 99 percent of all children born in the United States are screened for hearing loss by age 1 month" (p. 1). For parents and caregivers, this compressed time-line presents an accelerated call for action to address their child's hearing loss. When infants have further health needs, this additional diagnosis may be overwhelming. Indeed, some analysis (Breen, 2009) suggests that focus on service delivery models of early intervention, the daily experience of

families “living with childhood disability and faced with negotiating the complexities of care do not easily correspond with the discourses of service delivery” (p. 18). Breen asserts that childhood disability remains institutionalized, but that the “institution” has shifted to the family, creating a burden that is a disabling force on the entire family. Green (2007) identifies a system that creates a social and economic burden that impacts the family in emotional ways beyond the grief of having a child who has a disability. The intersection of early intervention for hearing loss and the early intervention system for other disabilities, may, in a failure to provide essential and ongoing support, contribute to loss-to-follow-up for the hearing loss. Newborn hearing screening and a more coordinated EDHI system have reduced the number of infants who are lost to follow up and diagnosis, but there has been little focus on families who negotiate the EDHI system as well as the larger intervention system when their child has multiple special needs.

Congenital Hearing Loss and Additional Special Needs

The CDC estimates that nearly one-quarter of children with hearing loss have one or more other developmental disabilities, such as cerebral palsy, intellectual disability or vision loss. Others estimate a higher incidence of co-occurring disorders with hearing loss of as much as 30-40% (Gallaudet Research Institute, 2008; Chilosi, Comparini, Scusa, Berrettini, Forli, Battini, & Cioni, 2010). This point is illustrated in a Virginia study of 485 children with PCHL, where nearly one third (31.5%) of children with diagnosed hearing loss had one or more co-occurring birth defects (Chapman, Stampfel, Bodurtha, Dodson, Pandya, Lynch, & Kirby, 2011).

Sometimes hearing loss is a part of a named syndrome such as CHARGE, Waardenberg’s Syndrome or Treacher Collin’s Syndrome. Such syndromes are typically

identified at birth due to visible clusters of physical characteristics. Hearing loss at or around birth may also be the result of prematurity. Some estimates report hearing loss in 17-30% of premature infants (Lipkin, Davidson, Spivak, Straube, Rhines, & Chang, 2002). Cerebral Palsy, one of the most common results of prematurity, documented to affect as many as 10% of premature infants in a 2003 population (Vincer, Allen, Joseph, Stinson, Scott, & Wood, 2006) also has a high occurrence of concomitant hearing loss. A small portion of children have a type of hearing loss called *Auditory Neuropathy Spectrum Disorder* (ANSD), often also related to prematurity, which is characterized by normal peripheral hearing but, because of damage to the inner ear or hearing nerve, sound isn't organized in a way that the brain can understand (CDC, 2015). It can be difficult to determine actual hearing thresholds for infants who have ANSD since one of the hallmarks of ANSD is an abnormal or absent ABR, which is used as one measure of hearing before babies can give accurate behavioral responses to sound.

With the presence of cerebral palsy and other pressing medical and developmental issues a focus on hearing loss may seem secondary to other, more visible, needs. Dalzell and colleagues (2000) found that infants who were Neonatal Intensive Care Unit (NICU) graduates, were less likely to be fitted with hearing aids as quickly as babies from the well-baby nursery. Liu, Farrell, MacNeil, Stone, & Barfield (2008) report that loss to follow-up from diagnosis to early intervention services was significantly higher among infants weighing less than 2,500 grams at birth.

Delay in Early Diagnosis and Intervention

It is difficult to extract information specific to infants who have special needs in addition to hearing loss, but older data suggests that those babies who do have additional

special needs are among those who experience delay in complete diagnosis of hearing loss, fitting of amplification and early intervention. According to Dalzell et al. (2000), infants in New York State who were NICU graduates were less likely to be fitted with hearing aids as quickly as babies from the well-baby nursery. Infants who underwent surgery during the neonatal period also were more likely to have delayed follow-up or no follow-up (Folsom, Widen, Vohr, Cone-Wesson, Gorga, Sininger, & Norton, 2000). Other studies support the suspicion that infants who have more complex medical needs were more liable to have no follow-up or delayed intervention for their hearing loss. Child factors examined by studies included birth weight, race, gender, history of residency in the neonatal intensive care nursery (NICU) or transfer from regular nursery to NICU and neonatal surgery and ventilator status (Dauman, Roussey, Belot, Denoyelle, Roman, Gavilan-Cellié, ... Garabedian, 2009; Liu et al., 2008; Prince, Miyashiro, Weirather, & Heu, 2003; Shoup, Owen, Jackson, & Laptook, 2005). A recent epidemiological study of 193 children across eight states examined timeliness of diagnosis and intervention (Holte, Walker, Oleson, Spratford, Moeller, Roush, ... Tomblin, 2012). This study addressed barriers to timely follow-up through analysis of family and child characteristics such as socioeconomic status (SES) and degree of hearing loss, as well as specific reasons cited by parents for delays to follow-up diagnosis and intervention. This group found that higher SES, measured by mother's educational level, was associated with earlier confirmation of hearing loss and hearing aid fitting, but not related to age of enrollment in early intervention services. The authors surmised that this might be a consequence of federal legislation requiring prompt referral to early intervention systems. Another factor that the authors identify has having changed since

the implementation of Universal Newborn Hearing Screening (UNHS) is delay due to milder hearing loss. According to the results of this study, degree of hearing loss was not a factor in delay. Factors this research group identified as most predictive of delay of diagnosis were lower educational level of the mother, multiple rescreening prior to referral for diagnostics, delay in referral by family physician due to lack of information about hearing loss, excessive wait times for appointments and delays due to the child's medical conditions. These researchers conclude that many of the families in the study did access care within the recommended timelines and that barriers might be best address through "improved systems, services, and educational efforts" (p. 169).

History of Hearing Screening, Diagnosis and Intervention in North Carolina

In 1999, North Carolina (NC) enacted legislation requiring the screening of all newborn infants for hearing loss as part of a comprehensive statewide effort to achieve early hearing detection and intervention (EHDI). This law requires physiologic screening prior to hospital discharge unless declined by the parents or precluded by medical complications. Those children who have medical complications are tracked and all efforts are made to screen them before they are discharged. Results are then reported to the North Carolina State Laboratory for Public Health.

NC's Early Hearing Detection and Intervention Program has an excellent track record of getting infants screened, diagnosed and referred to Early Intervention Services (Part C of IDEA), which is also known as the Infant Toddler Program (ITP). In NC, statistics through the EHDI Program (2015) indicate that in 2012 and 2013 99.7 % of newborn babies were screened (excluding infants who died or whose parents declined). Those screened by 1 month of age increased to 98% by 2013. Of those infants identified

with permanent hearing loss, 84.7 % were enrolled in EI by 6 months of age in 2012. In 2013, this percentage dropped to 77.7 %. This percentage is still greater than the national average but that remaining percentage, those infants who are not receiving early intervention by age 6-months, is of concern because of the significant long-term effects of unmanaged hearing loss.

History of Early Intervention for Deaf /Hard of Hearing

Before 2000, young children who were identified as D/HH in North Carolina received early intervention and pre-school services until age 5 and, in some cases, until age 6 through the Department of Health and Human Services (DHHS) Program for Children who are D/HH. This program served children until kindergarten entry, although federal and state policy stated that public school programs—Part B—were responsible for children age 3 and older. Beginning with the 2001-2002 school year, North Carolina public schools began assuming responsibility for serving children upon their third birthday and all preschool classrooms for youngsters who were D/HH through DHHS were closed. When these classrooms were closed, the early intervention target population was reduced to 0-2 year olds and the existing teaching staff, teachers of the deaf (TOD) and speech and language pathologists (SLPs), became itinerant. Beginning 2011, the program moved from under Department of Health and Human Services to management through the Office Of Early Learning (OES) Sensory Support Program, which is part of the Department of Public Instruction (DPI). Current interventionists are teachers of the deaf, most dually certified in early childhood education and deaf education, the majority with advanced degrees and all with Infant Toddler Family Specialist certification. A significant number of these interventionists are also Nationally Board Certified educators.

These interventionists have various specialties such as strong American Sign Language (ASL) skills, cued speech skill, Listening and Spoken Language Specialist (LSLS) (formerly Certified Auditory Verbal Therapist) and certification in working with deaf-blind students. The program, although its name has changed several times, continues to provide free early intervention for children who have any type or degree of permanent hearing loss. Another substantial change occurred in 2011 when children who had hearing loss as their only identified need were not permitted to receive early intervention for hearing loss through this program, without also enrolling in the Infant Toddler Program through DHHS. An additional change to this referral process began in 2013 when children identified with hearing loss through the EHDI program were mandated to go through the portal of the Children's Developmental Services Agency (ITP) without contact with an educator from the early intervention program for hearing loss. These families then needed to choose to continue with enrollment through the ITP, meet with a service coordinator to review a "menu" of providers, one of which included the current program for early intervention for hearing impairment, without necessarily receiving any education about the impact of congenital hearing loss on child development. Beginning in 2014, the newly named Early Sensory Support Program also began billing to Medicaid for services to families whose children had Medicaid insurance. As of early 2015, the program did not bill to private insurance companies. The impact of these changes has not, to my knowledge, been investigated, but enrollment in the ITP by 6 months of age for those infants diagnosed with hearing loss, steadily on the rise since the beginning of UNHS, dropped, for the first time, by 7%, from 2012 to 2013 (NC EHDI, 2015). The total number of infants and toddlers enrolled in the Early Sensory Support Program for

Deaf and Hard of Hearing in January of 2014, the month before I wrote to Teachers of the Deaf to recruit participants, was 404 children statewide. During that month, 25 children were referred to the program. The average age of referral was 7.72 months, with a range of 1 month to 30 months.

Purpose and Rationale for Early Intervention

A foundational assumption regarding EI programs is that they provide a benefit to families who have children with diagnosed disabilities. The Individuals with Disabilities Education Act (IDEA) Part C provides to infants and toddlers with disabilities (birth-2) and their families early intervention services to:

- Enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay
- Enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities
- Provide, to the maximum extent appropriate, services in the child's natural environments, including the home and community settings in which children with disabilities participate. (Foley & Hochman, 2006, p. 95)

Early Intervention (EI) refers to services given to very young children with special needs, from birth until the child turns three. The rationale is that these services, provided early, can address delays in development in hopes that the child will have the greatest opportunity to reach his or her fullest potential. Early intervention specific to hearing loss has benefits clearly established through empirical evidence.

Plasticity of the Infant Brain

Research has consistently demonstrated that children born with permanent congenital hearing loss (PCHL) are more likely to suffer from disordered or delayed language development when they experience language deprivation during the critical sensitive period their first year of life (Kuhl et al., 2005; Sharma, Dorman, & Kral, 2005). Moreover, there is a language-learning decline in ability and efficiency when neural pathways are not established during this sensitive period. Madell and Flexer (2011) suggest that identification and treatment of newborn hearing loss should be considered a “neurodevelopmental emergency”. When families do not respond to this emergency, infant brain development is compromised. Carol Flexer (2012) explains:

Neuroplasticity is greatest during the first 3 ½ years of life; the younger the infant, the greater the neuroplasticity. Rapid infant brain growth requires prompt intervention, typically including amplification and a program to promote auditory skill development. In the absence of sound, the brain re-organizes itself to receive input from other senses, primarily vision; this process is called “crossmodal re-organization” and it reduces auditory neural capacity. Early amplification or implantation stimulates a brain that has not yet been reorganized, allowing the brain to be more receptive to auditory input resulting in greater auditory capacity. (Summary section, para. 1)

The architecture of the infant brain is best established during this period of greatest plasticity (Kuhl, 2004). Current brain imaging techniques support the theory that there are sensitive periods for the development of auditory and language skills (Sharma, Nash, & Dorman, 2009). Early neural commitment to a native language may predict better language skills later (Kuhl et al., 2005). Studies of deaf late signers showed deficits

in Theory of Mind understanding relative to deaf native signers or hearing controls, highlighting the need for very early language experience for those children whose families opt for visual language (Woolfe, Want, & Siegal, 2002). A large 3-year study of preschool-aged deaf children used an accelerated longitudinal design, and found positive effects of early sign language on literacy, social and cognitive skill (Allen et al., 2014). Language skill is necessary for reading comprehension, which is foundational to educational achievement. Young children with language impairment are more likely to demonstrate later reading disabilities (Catts, 1993; Geers, 2003). Implication of this research is borne out by achievement averages of students who are D/HH who receive early and later intervention for hearing loss.

Long Term Benefits of Early Intervention

Review of current studies from developed countries documents long-term benefits to universal hearing screening and intervention (Pimperton & Kennedy, 2012). Furthermore, Pimperton and Kennedy's synthesis of this current research highlights that "more consistent evidence provided for links between early intervention and positive language outcomes" (p. 651). Substantial inquiry indicates that babies who are identified with hearing loss and receive early intervention beginning by six months of age achieve language development more aligned with typically hearing infants and significantly better than other, later identified children with hearing loss (Pimperton & Kennedy, 2012; Yoshinaga-Itano, 2004; Yoshinaga-Itano, 2003; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). This benefit extends to those infants who have cognitive skills ranging from quotients of 20-80. They too demonstrated significantly better language scores than later-identified children with additional special needs when they were early identified and

received timely EI services (Pipp-Siegel et al. 2003). The potential benefits of early screening, diagnosis and intervention are diminished when babies and their families do not participate in early intervention. EI services targeting hearing loss is the ultimate purpose and goal of newborn hearing screening, assessment, and diagnosis.

Cost Savings of Early Identification and Intervention

Cost savings to society were documented in a 1993 study by Johnson, Mauk, Takekawa, Simon, Sia, & Blackwell which posited that when children who have hearing loss are not identified and do not receive early intervention, special education for a child with hearing loss can cost schools an additional \$420,000, with a potential lifetime cost of approximately \$1 million per individual. A later study (Mohr, Feldman, Dunbar, McConkey-Robbins, Niparko, Rittenhouse, & Skinner, 2000) presents a similar estimate of lifetime costs for those with prelingual onset deafness; exceeding \$1 million. Conclusions drawn by this group indicate that interventions aimed at children, “such as early identification and/or aggressive medical intervention, may have substantial payback” (p. 1130). General savings to families and society as well as clear educational cost savings continue to be documented (Grosse & Ross, 2006). Research also suggests that early identification and intervention by six months of age for children who have hearing loss promotes measureable gains in language development (Yoshinaga-Itano, 2003). Moreover, parental involvement and the child’s age at initiation of intervention, significantly predicts language outcomes (Moeller, 2000).

Impact of Later Identification and Intervention

Before 1990, children who were born with PCHL in the United States would typically not be identified until 2-3 years of age (Culpepper, 2003; Muñoz, Bradham, &

Nelson, 2011; Mace, Wallace, Whan, & Stelmachowicz, 1991). Young men and women who have hearing loss have, in the past, graduated with diplomas from high schools at rates considerably lower than peers who have typical hearing (Schildroth, Rawlings, & Allen, 1991). A 1989 study of students who were deaf in transition from school to work conducted by the Center of Assessment and Demographic Studies at Gallaudet University, documented that only an average of 50 percent of students with hearing loss who were leaving high school graduated with a diploma (Allen, Rawlings, & Schildroth, 1989). In contrast, census data for the general population for the same year show a graduation rate of 81 percent (U.S. Bureau of the Census, 1997). In 1991, a considerable number of students with hearing loss were still graduating from high schools throughout the nation with third- to fourth-grade reading levels (Bowe, 1991). The Annual Survey of Deaf and Hard of Hearing Children and Youth, conducted by the Center for Assessment and Demographic Studies, found that only one-fourth of students with hearing loss who enter postsecondary institutions read at fifth-grade level or above (Allen, 1994).

Nevertheless, with timely and skilled early identification and intervention, children who have diagnosed permanent hearing loss and who have no additional disability have an 80% probability of language development in the low average level in their first 5 years of life (Yoshinaga-Itano, Coutler, & Thompson, 2001). Reading, writing and phonological processing skill in youngsters who received early intervention and early amplification has been increasing since the advent of newborn hearing screening and other technological advances (Geers & Hayes, 2011). However, even for those children who are not diagnosed and intervened with in the recommended time frame, “family participation can help to compensate for the deleterious effect of late management on language (Watkin et

al., 2007, Results section, para. 6).

Early Hearing Detection and Intervention: Components and Timelines

In order to ameliorate the social and educational impact of later identified/intervened hearing loss, the JCIH (2007) recommends screening all newborn infants within the first month of birth, leading to diagnosis of hearing loss within 3 months. The third step in this 1-3-6 month program is to complete all diagnostic evaluations and begin intervention by at least 6 months of age. Lack of improved developmental outcomes for certain early identified children may involve failure of follow-through by professionals or parents at any of the steps along the way, causing the child and family to be lost to early intervention.

Danhauer, Johnson, Finnegan, Hansen, Lamb, Lopez, ... Williams (2006) identified the components of an EDHI program, and Danhauer and Johnson (2006) also clarified five levels of compliance in their study of a newborn hearing screening program: Inpatient screening in the birthing hospital, outpatient rescreen, diagnosis of hearing loss, treatment by an otolaryngologist, and finally, follow-up treatment by an audiologist and commencement of aural habilitation/early intervention.

Screening and Diagnostics

The effective components of a successful EDHI program follow a coordinated sequence (Danhauer et al., 2006). The first step is Newborn Hearing Screening (NBHS). This program requires clear communication among NBHS stakeholders and hospital professionals who are able to provide parents with clear explanations of the screening process and the need for follow-up. The second component is an effective and efficient referral process. This would include local pediatric audiology services that recognize the

need for timely follow-up and clear communication and who are willing and able to test very young children. This also involves other participating physicians, especially in the child's medical home. This study found that many of the vital team members such as otolaryngologists, audiologists and pediatricians, were insufficiently cross-trained regarding their own specialties and additionally had scant accurate information about current EI systems, technology and recommendations for best practice for children who have hearing loss (Danhauer et al., 2006). Medical providers' lack of knowledge of the EDHI system can impact a family's willingness to participate.

Failures in parental compliance and loss of infants from the system due to follow-up may relate to how involved participating physicians were in the program and how persuasive they were in making their recommendations to parents for obtaining follow-up audiological services in a timely manner (p. 34).

White (2006) also suggests that lack of coordination between EDHI programs, Part C programs and medical providers causes children to miss out on the proven benefits of early identification and intervention. Many of the medical providers most likely to be involved in the care of young children who have hearing loss, indicated through a survey, a lack of understanding of advances in the field and how these advances affect timelines for services for these children. The Joint Committee on Infant Hearing (JCIH, 2007) noted a shortage of professionals with skills in pediatrics and hearing loss.

Tracking Pediatric Audiological Services and Early Intervention

The third step in the model is a system or database that is seamless, has essential information and is easy to use to assure that infants are reliably tracked. A coordinated child-find and referral system is fundamental to a smooth EHDI system (White, 2006). A

fourth and essential component is the willing support by local audiology/ENT practices as well as their current expertise in pediatric care. The fifth essential level rests with early intervention programs that are in place and ready to work with parents and their children. This fifth step represents a shift from medical providers to therapists and educational providers. There is “increased need for collaboration with other service providers from both private and public agencies, and the increased need for consistency among providers who may have differing views of service delivery” (Malone, Easterbrooks, & Gallagher, 2005, p 2). As a family moves through these five levels, family support remains essential.

The journey a family goes through upon the discovery of a child with hearing loss very soon takes a departure from the typical “medical model” of treatment for a condition or disability. DesGeorges (2003) speaks of the additional knowledge families must develop when they have a child who is deaf or hard of hearing (D/HH), “while the medical component of the experience must rightly be addressed, there is a vast amount of information and knowledge families need in order to make effective choices for the child who is D/HH” (p. 90). The bewildering amount of information that families are expected to process can be compounded by additional needs of the child and family.

Barriers to Early Diagnosis and Intervention

Barriers to early diagnosis and intervention exist in the EHDI system, including professional practitioners and their abilities to communicate with and support families through initial diagnosis. There are also barriers related to family characteristics and perceptions. Any combination of factors, systemic and personal, can create obstacles to early diagnosis and intervention.

System Issues

In 2006, a national evaluation by Mathematica Policy Research, Inc. reported that a severe lack of qualified audiologists to provide diagnostic evaluations, a lack of appropriate equipment, and a lack of knowledge among health care providers about the importance and urgency of follow-up testing were factors contributing to the poor follow-up rates of diagnostic evaluations (Shulman, Beculides, Saltzman, Ireys, White, & Forsman, 2010). Possible points of loss or barriers to early intervention for children who have hearing loss have also been suggested by the American Speech–Language–Hearing Association (ASHA) in their technical report of 2008. These barriers include health care personnel, family education, coordination among service providers, funding, proximity to resources, and family issues and profiles.

Cost and reimbursement for audiology services. Anecdotal reports by early intervention practitioners indicate that Medicaid reimbursement rates are low for hearing services for children and that some ENT / audiology practices refuse to serve or limit services to children who have hearing loss. Poor reimbursement of audiology services was documented by JCIH (2007). McManus, Hayden and Fox (2001) evaluated Medicaid reimbursement for hearing services for children and found:

Overall, Medicaid fees for hearing services were low and state variation in payment amounts was significant. We found that the majority of audiologic fees were in the bottom third of Medicaid rates. The extent to which such low Medicaid fees contribute to restricted access to audiology providers and services is an issue that requires additional study (Conclusions section, para. 2).

Muñoz and colleagues (2015) surveyed parents of children with hearing loss born between 2007 and 2010 and found that the top three challenges parent reported in relation

to hearing aids were (1) paying for hearing aids, (2) accepting the need for hearing aids, and (3) wait time for an appointment. Recently, according to the American Speech and Language Association (2013), 20 states have passed laws requiring insurance companies to cover hearing aid costs for children, however requirements vary by state for ages covered, amount covered, time periods and provider qualifications. In North Carolina, effective January 2011, health plans were required to provide coverage for one hearing aid per hearing-impaired ear up to two thousand five hundred dollars (\$2,500) per hearing aid every 36 months for covered children under age 22 years (b). Deductible, coinsurance and other limitations apply to this legal mandate. However, beginning January 1, 2008 the "EHDI Initial Hearing Aid Program" took an additional step to support early intervention by pledging to fund newly diagnosed infant and toddler's first hearing aids, ear molds, batteries, care kit and dispensing fees for those children who were not eligible for Medicaid. It will also pay the difference if the family has insurance that covers a portion of the cost.

(<http://www.ncnewbornhearing.org/files/EHDIInitialHearingAidProgram.pdf>)

Indeed, after surveying physicians and otolaryngologists potentially involved in Early Hearing Detection and Intervention Programs (EHIDPs), Danhauer et al. (2006) found that "in many parts of the United States, UNHSPs and the necessary community infrastructure for effective follow-up are nonexistent or just emerging" (p. 34). Buy-in for local audiology/ENT practices is essential and the only way to assure this is through creating fair and prompt reimbursement systems statewide (Danhauer et al, 2006).

Family Risk Factors

Influences such as changing emotional responses to diagnosis and intervention within the broad EI system are more difficult to describe and document, but are included in the literature. A number of measureable family characteristics have been identified that may create barriers to parent participation in early intervention (EI) programs. A longitudinal study of a California Early Start Program suggests, “family risk factors exert a significant effect on loss to care” (Giannoni & Cass, 2010, p. 194). In this study, risk factors for loss-to-care included mother’s age and educational levels, Medi-Cal ineligibility and lack of transportation. Similar results were found by Kavanagh, Smith, Golden, Tate and Hinkle in their 1991 study of parents of pediatric patients of regional otologic–communication clinic. Families themselves documented family risk factors for non-attendance of appointments, and parental age and education were shown to be major predictors of clinic attendance. Transportation was a compounding factor related to parental age.

The Confusion of Hearing Screening

Due to Universal Newborn Hearing Screening, the discovery of congenital hearing loss occurs much earlier in a child’s life. There is a compressed timescale between birth and identification and the family may discover the hearing loss during the initial bonding period with the child. Early Intervention then can occur as early as the first month of life. This process may alter family responses to the situation. Young and Tattersall (2007) outline these changes and present results from an interview study of 45 parents whose infants were identified as deaf/hh through the Newborn Hearing Screening Programme in England. They caution careful tailoring of “parent-professional encounters

in the changed condition of early identification” as “the long-term patterns of parental adjustment in light of UNHS remain almost totally unknown” (p. 218).

Diagnosis of Hearing Loss: Reaction and Systems Issues

Even though EHDI promotes speedy screening, diagnosis, amplification (if recommended) and intervention, there can be barriers to the steps after screening takes place. As previously noted (Danhauer et al., 2006), family physicians’ lack of knowledge of implication of hearing loss and critical timelines can impede diagnosis of hearing loss. In DesGeorges’ 2003 study of family perceptions of the EHDI system, parents did identify a barrier created by uninformed pediatricians. One mother said, “the pain is not my daughter’s diagnosis, but it is the language opportunity she lost during those 11 months between when I first asked the family doctor for help and when I cornered the ENT into finally diagnosing her” (p. 91). Many families “thought there was too much of a delay from the initial screening to the time when diagnostic tests were performed. Some parents said providers often downplayed the need for timely follow-up testing” (Arnold, Davis, Humiston, Bocchini, Joseph, Bass, ... Forsman, 2006, p. S344). The fact that primary healthcare providers are unaware of many of the improvements in early intervention services for this population is not surprising given how rapidly the field has changed (White, 2006). Improved and increased information to medical home providers regarding working with families whose child may have a hearing difference, is an area in which positive change and support for families can occur (DesGeorges, 2003).

Complications in getting initial diagnosis. Family characteristics that may put a family at additional risk for missing out on EI have been identified through the literature. Liu, Farrell, MacNeil, Stone, & Barfield (2008) found that “infants born to women who

were racial or ethnic minorities, had public insurance, or smoked during pregnancy were at higher risk of become lost to follow-up on the use of audiologic evaluation services” (p. e341). Provision of educational materials in the native language of parents was also identified as a need by parents (Arnold et al., 2006). If previously identified barriers to participation in early intervention apply to families who have children with hearing loss, transportation and lack of insurance (Kavanagh et al., 1991) could also be a barrier to this step in the process which requires visiting an ENT and audiologist, for diagnosis and hearing aid fitting. In NC there are few practices that focus exclusively on pediatric patients so travel to these may be at quite a distance for families. Often repeat visits are necessary for the complete diagnosis necessary for hearing aid fitting.

Surprise and disbelief. The great majority of parents have no reason to suspect hearing loss even when their infant is born with special needs. Hearing loss is most often an invisible condition. Young and Tattersall (2005) in their study of parent perspectives of the Universal Newborn Hearing Screening process in England, evaluated the screening process and its consequences for intervention from the perspective of parents. One of the issues parents identified as most discomfiting was that screening is inconclusive. Messages provided by the screeners were often just as inconclusive (p. 142). At least one couple in this study expressed distrust of audiology in general because screening could not provide a concrete diagnosis for their child. Young and Tattersall conclude, “it is important to *check* the meanings parents attribute to an inconclusive screen result or to an eventual referral for audiological assessment” (p. 144). Which professional communicates and checks understanding and how skillfully she or he does it is a key question in every setting in which newborn screening takes place. Parents’ understanding

of the recommended steps impacts their willingness to participate in those steps. Indeed, parents report that knowledge is important and that they want information about developmental milestones of listening, speech and language. Additionally, “several parents indicated that parents needed to receive the message about the need for diagnostic testing more than once because they might experience denial at first” (Arnold et al., 2006, p. S345).

Family Responses to Early Intervention Practitioners

The Joint Committee on Infant Hearing (JCIH, 2007) recommends that early intervention for children who have hearing loss be provided by professionals who have expertise in the field of hearing loss. The strength of this final intervention level depends partially on higher education systems to train practitioners whose skills keep pace of a rapidly changing field: hearing testing and technology, best practice in early intervention, parent education, communication methodologies, as well as essential family support techniques. At least one study strongly suggests that University training programs have failed to adequately train graduates “to meet the developmental, communicative and educational needs of children who are deaf or hard of hearing” (Wilson, Nevins, & Houston, 2010, p.232). Well-prepared professionals are essential components in the final step of the EHDI program. Providing both university pre-service programs and ongoing in-service professional development can meet the need for “knowledgeable and skilled professionals” to guide families in their child’s development (Wilson et al., p. 245). “A cadre of trained providers is needed to deliver these services” (Malone et al., 2005, p. 29). Many questions surround the issue of trained providers and parent access to these providers. This area deserves study both nationwide and in NC where one program has

historically employed and monitored trained specialists in the field of educating infants and toddlers who have hearing loss.

Guiding families may be most successful when practitioners are able to frame their knowledge and expertise in family-centered practices. Ingber and Dromi's study of family-centered practice in EI for children who have hearing loss (2010) suggests that there is a gap between theory and actual practice of family-centeredness. Professionals' attitudes towards parents are a critical variable in predicting parental involvement. Thus, there is a need to "provide professionals with appropriate training and support to ensure that they will acquire the knowledge and ability necessary to further enhance parental involvement" (Ingber & Dromi, 2010, p. 68). This may involve ensuring that training in family-centered practice is a required component of professional training.

Dealing with Grief

Family-centered practice draws on the ability of practitioners to guide and empower families through crises. Anecdotal reports suggest that practitioners believe that many families who decline services or exit EI programs after enrollment, may do so due to grief or denial. Kurtzer-White and Luterman (2003) suggest that families may have difficulty coping with their child's hearing loss due to the ambiguity and invisibility of hearing loss as one factor. Other factors that create stress for families include technical information about hearing loss that is complex and a broad range of decisions that families are asked to make regarding sensory devices, modality and communication choices. When a child has additional health or developmental needs, the parents and caregivers may choose to focus their energies on that which can be seen; feeding, mobility, and health related issues. The event of such early identification of a disability

that is “invisible” warrants thorough study so that professionals can discover how to support families who may experience the grief of having a “less than perfect newborn” (Opirhory & Peters, 1982, p. 451).

Burden of Care

Breen’s (2009) analysis of the assumptions regarding family-centered intervention in the Australian system can be brought to bear upon similar systems in the US. Breen sees family-centered care as a shift of caring responsibility, both time and financial burden, to the family, often with limited professional and financial supports. She notes that the concept of chronic sorrow is problematic as it tends to ignore the social, economic and cultural impact of caring for a child who has special needs. Green (2007) sees that the emphasis placed on the emotional stress of having a child with special needs may keep researchers from examining the negative economic issues and dearth of financial supports for these ongoing needs. She notes that traditional scholarship has tended to “focus on the individual, emotional burdens of having a child with a disability rather than the burden imposed by negative public attitudes toward disability and inadequate support for the expensive and time consuming task of caring for a child with special needs” (p. 151). She categorizes the emotional components of distress over having a child with special needs as a “Subjective Burden”. However, the socio-structural constraints, which include financial issues, dealing with social stigma of having a child with a disability, impact on parental ability to work, on ability to participate in recreational activities, impact on family and marriage are an “Objective Burden”. Green’s (2007) research points to the greater impact that the Objective Burden has on parents and the ways that these socio-structural constraints can increase the Subjective

Burden resulting in feelings of distress, grief and anger. Her findings, through interview and survey of families, suggest that improvements to the system of care for parents of children who have disabilities could be made through “consistent, effective and continuing assistance with the pragmatics of caregiving” (p. 161). When considering this research in relation to children who have hearing loss and additional disabilities, families who experience a greater objective burden, leading to more distress, might be less able to add one more layer of attention to the crushing demands of caregiving.

A Need for Family-Centered Intervention

Early intervention programs (EIPs) in general and early intervention programs for children who are D/HH have become more family-centered over time, both in response to legislative mandate in IDEA Part-C that requires use of a family systems model in intervention and due to research into best practice. Dunst, Trivette and Deal’s (1988) foundational work in enabling and empowering families has informed early intervention practice of service delivery as family-centered and focused on needs and supports identified by the family. The family and EI team drive development of goals and activities through Individualized Family Service Plans (IFSP). Community resources are deemed most important in providing ongoing responsive support. Parent-practitioner relationships in EI can also be emotionally powerful and empowering for families. Understanding the dynamics of mental health, early intervention, and family support can “amplify [the practitioner’s] helpfulness with families” (Foley & Hotchman, 2006, p. 29). The use of a meta-analytic structural equation model (MASEM) investigation of family-systems intervention practices showed the positive role such practices have in ensuring

that resources and supports can function as intended to promote learning and development (Trivette, Dunst, & Hamby, 2010).

At the same time that the focus of EI shifted from a medical model to a family-centered and community resource based model, new findings and recommendations have emerged about the need for very early, intense and family based intervention for children who have hearing loss and whose parents choose spoken language and listening as their chosen language modality (JCIH, 2007; Yoshinaga-Itano, 2003). In response, professionals also focus on promoting and supporting the use of necessary medical interventions such as hearing aids and cochlear implants. Studies of cortical reorganization as early as the first year of life (Sharma et al., 2009) demonstrate the need for very early and appropriate amplification in order for the child to construct an auditory brain that will function as effectively as same-age peers in processing sound necessary for recognizing and developing spoken language. This current research (Dorman, Sharma, Gilley, Martin, & Roland, 2007) highlights the need for early and speedy pediatric audiological intervention; for some children, medical / surgical audiological intervention in the form of cochlear implantation and for practitioners to be well trained in family-centered, evidence-based early intervention services (Wilson et al., 2010). Professionals must address family support at each step along the way within a combined medical, educational and family care model if JCIH timelines are to be met.

Limitations of Existing Research

Existing research abundantly supports early hearing detection and intervention as a valuable to children, families and society. There are rich data reinforcing early identification and intervention in promoting children's success with language and

literacy. There is ample and ongoing quantitative research on the EDHI systems leading to a call for nationwide standardization of data, definitions and reporting (Mason, Gaffney, Green and Grosse, 2008). However, as Luterman (2004) suggests, “the subject of children with hearing loss and special needs and the impact of the additional disabilities on families is severely under-researched” (p. 220). A starting-point for research by a deaf-educator is in giving parents’ experiences “voice” in order to identify themes and, if possible, to develop supports and future training to better engage with these families in intervention for their children’s hearing loss.

The Limits of Research in Families with Children with Hearing Loss and Additional Special Needs

Families whose children have hearing loss and additional special needs may face competing issues or choices after diagnosis. The literature has identified family characteristics, systemic barrier points to hearing intervention, funding issues, personnel and legal issues that can impact families’ ability or willingness to engage in early intervention for their child’s hearing loss (American Speech and Language Association, ASHA, 2008) and provides systemic recommendations for improvement (Hoffman, Muñoz, Bradham, & Nelson, 2011). Much of the research focuses on synthesis of Early Hearing Detection and Intervention (EDHI) data collected nationally through hospitals and surveys of families’ experiences and perspectives on the impact of early diagnosis of hearing loss (Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007). These studies include some families who have children with additional special needs (Larsen, Muñoz, DesGeorges, Nelson, & Kennedy, 2012), but there has been little focus on families’ perspectives when their child has more than one disability or health issue. Other than

studies of the benefits of cochlear implants for multiply involved children (Berrettini, Forli, Genovese, Santarelli, Arslan, Chilosi, & Cipriani, 2008; Bertram, 2004; Wiley, Jahnke, Meinzen-Derr, & Choo, 2005), there has been scant exploration of the perspectives of this subset of families whose children have other disabilities or health issues along with hearing loss.

A gap exists in the literature regarding factors in engagement with early intervention for hearing loss for the specific group of families who have infants with additional health or developmental needs. The majority of scholarship has examined family characteristics of loss to follow-up using quantitative data gathered through the Centers for Disease Control (CDC) and Early Hearing Detection and Intervention (EDHI) data by state systems. This qualitative study hopes to interpret families' responses to their children's hearing losses in the context of their additional special needs through their personal narratives and the meanings they bring to them.

Although children with co-occurring birth defects or health issues may be identified with hearing issues earlier than their healthy counterparts and referred to Part C of IDEA for early intervention earlier, actual intervention specific to their hearing loss is often delayed for both amplification fitting and use or education about the impact of hearing loss (Dalzell et al, 2000). This may result in lack of access to communication for these children, either auditory or visual, which in turn affects the synchrony of individual development and family communicative interactions. Low language skills impact both functional development, how a child is able to communicate with important people in the environment, and future academic achievement (Dorman et al., 2007; Kuhl et al., 2005; Moeller, 2000; Yoshinaga-Itano, 2003; Yoshinaga-Itano & Sedley, 1999).

The literature identifies characteristics of families who are lost to diagnosis or lost to follow-up (ASHA, 2008; Dalzell et al., 2000; Hoffman et al., 2011; Liu et al., 2008) as well as issues with the EDHI system that impact decision-making as families progress through screening and diagnosis of hearing loss (Danhauser et al., 2006). Screening and diagnosis are the first steps on the pathway to early intervention for hearing loss. Although Early Intervention Programs have become more family-centered and family-driven, identification of hearing loss occurs within a medical model of otolaryngology and audiology, with clearly delineated timelines for screening to diagnosis to hearing aid fitting to early intervention (Joint Committee on Infant Hearing, 2007). The critical developmental reasons for these recommendations have been previously outlined (Dorman et al., 2007; Flexer, 2012; Kuhl et al., 2005; Moeller, 2000; Yoshinaga-Itano, 2003; Yoshinaga-Itano & Sedley, 1999). Nevertheless, family experiences of screening and diagnosis in those months after childbirth may not fit neatly into the recommended timelines, particularly when a child has additional needs that require family response. Family grief experiences (Foley, 2006) and family support systems do not have clearly defined timelines and may clash with more rigid medical survival needs.

When families are able to reflect on their experiences in the timing of choosing early intervention for their child who has a hearing loss, they can provide information about barriers to intervention and the factors that resulted in the choice to become involved in early intervention. This information can assist professionals in becoming more flexible, family-centered and able to balance the drive of the physical necessities of life with the responsive care of a family support and empowerment approach.

Communication as a Fundamental Right

One common element of deaf children's bills of rights is recognition of the "basic human need for a child to be able to communicate freely with others" (NAD).

Ethical issues surround the right of children to access communication either through audition or vision. According to the National Association of the Deaf's (NAD) website, several states have created laws known as *deaf children's bill of rights*. In turn, some state public school systems responded by developing individual communication plans to be used with each deaf and hard of hearing child along with his or her Individualized Education Plans (IEPs) to ensure that children's language and communication needs are met through their educational program. Early Intervention can provide the foundation for language and communication development within the family.

Family Participation in Early Intervention

Family participation is considered an essential element of sound early intervention practices (Dunst et al., 1988). Inclusion of the parents/caregivers in early intervention has a strong correlation with parent satisfactions and feeling of self-efficacy related to their child's intervention (Dunst et al., 2007). Early identification and intervention is also shown to provide the best opportunity for reducing the extent of child language delay while also reducing stress-reactions of families (Pipp-Siegel, Blair, Deas, Pressman, & Yoshingago-Itano, 2000; Carney & Moeller, 1998).

Summary

There are many potential barriers, both systemic and individual, to parent participation in a program for their child's hearing loss when the child has additional special needs. It is essential to discover optimal supports for families who have children who are identified at birth and who have hearing loss and additional needs, so the impact

of hearing loss is not overlooked or purposefully set aside. Parent's voices can contribute to the identification of needed supports. Family variables intersect in complex ways with intervention system and professional provider variables (Gavidia-Payne & Stoneman, 1997). Ongoing and quality family participation in early intervention depends on the perception and support of each family's specific needs in relation to the steps families take through the EHDI system. Swift identification of these needs can inform practitioners on ways to provide a more easily accessed, aligned, empowering and seamless early intervention system.

CHAPTER THREE: METHODOLOGY

This chapter describes the methodology used throughout the study. Following a review of the research purpose and questions, the chapter describes the study's research design, participants, data collection procedures, and data analysis procedures. The chapter concludes with a discussion of the researcher's role in the study.

Research Purpose and Questions

The purpose of this study is to describe how parents of children who have hearing loss and additional special needs experience early intervention. It specifically seeks to develop an understanding of how parents respond to their child's hearing loss in the context of their other needs and how parents work with early intervention.

The following research questions guided this study:

1. According to the parents of children with a hearing loss and additional special needs, what causes them to delay or to avoid participation with early intervention (specifically to address hearing loss) for their children?
2. According to the parents of children with a hearing loss and additional special needs, what information or interactions caused them to engage with early intervention for their children's hearing loss?

Parents' accounts of their responses to the diagnosis of their child's hearing loss as well as their positive and negative interactions with professionals in the field of early intervention help inform the study. Parents also share their decision-making processes for early intervention and any additional guidance they have for other parents and professionals regarding the early intervention experience.

Paradigm and Assumptions

This study will take family-centered principles into the research by inviting parents/caregivers to tell their stories, including how they came to accept the invitation to partner with the early intervention program for their children's hearing losses. The Early Childhood Technical Assistance Center (ECTA, 2013) speaks of family centered principles on its website; "Core to family-centered services is sensitivity and respect for the culture and values of individual family members and each family's ecology, as members define the people, activities and beliefs important to them". Descriptors that are found in the literature of family-centered principles include *strengths-based, family systems, family support, family-driven, empowerment, proactive service delivery, competency focused, partnerships, collaborative relationships*. Listening to what parents share about their experiences with a child who has hearing loss and additional special needs can help identify themes of how families make decisions specific to this situation, how they prioritize child and family needs, and inform practitioners on ways to best support families and children who have multiple health and developmental needs.

Research Design

Families themselves possess some of the answers to the questions generated from the research problem and if not able to provide direct answers, families, in telling their stories, assist in making meaning of their own experiences in ways that can inform others in similar circumstances along with the professionals who hope to work with them. Thus, a qualitative, interpretivist approach is most logical. The interpretivist approach assumes that reality is socially constructed and that the "variables are complex, interwoven and difficult to measure" (Glesne, 2011, p. 9). Additionally, Glesne suggests that the researcher role may be personal and empathic. Guba and Lincoln (1994) identify the

constructivist “voice” of the researcher as that of a “passionate participant” and a facilitator of multi-voice reconstruction and meaning-making (p. 112).

In this research, individual family reconstructions of their decision-making processes, their responses to their child’s diagnoses and reports of family interactions with professionals coalesce around certain themes. However, this meaning-making can be useful to the families themselves, to those who work in the field of early intervention, especially in relation to the meaning for action and further steps (Guba & Lincoln, 1994). Pre-determined themes do not constrain the study as they may detract from emerging themes and could “represent an attempt to gain power in their use” (Charmaz, 2000). Themes in the literature strongly focus on quantitative demographics. This research is qualitative and will focus on family-identified themes. Although the approach of this study is essentially grounded theory, it is not from an objectivist perspective, which could be too didactic, but as suggested previously, constructivist, interpretivist, and emergent, emancipatory and interactive. Families were asked to tell their stories and my intent is to convey, through listening, respect and recognition that families make competent decisions about the intervention process for their children that are “correct” for them.

Interview as the Primary Tool of the Study

The method of exploration is parent interview. Parents’ and caregivers’ stories of their experiences are at the heart of finding engaging ways to support them in their efforts to create the positive outcomes for their children. A review of the literature indicates there is no established interview protocol that would provide the information sought through this study, the experience of choosing early intervention for a child who has hearing loss along with additional special needs. Thus, loosely guiding questions inspired

from the various sources (Desjardin, 2005; Enns, 2009; Matthijs, Loots, Mouvet, Van Herreweghe, Hardonk, Van Hove, ... Leigh, 2011; National Center for Special Education Accountability Monitoring, 2005; Wainscott, 2010) were specifically designed to focus on parental experience of barriers and facilitators to early intervention for hearing loss. Wainscott (2010) as part of her dissertation, created a helpful Likert scale for parents to identify the degree of their concern on “ impact of hearing loss” on a variety of categories such as language development, parenting, childcare, bonding, school success, etc. (p. 3, Appendix D). This was useful in considering how to explore family priorities in relation to a child’s additional special needs. Enns’ (2009) *VL2 Early Education Longitudinal Study Parent Questionnaire*, was quite lengthy at almost 20 pages, and covered detailed respondent and child information, including extensive demographic data. The questionnaire also included hearing device questions, effect of different types of therapy and/or language modalities on child achievement, child behavior and literacy, school adjustment and beliefs about deaf education. Clearly designed for students older than the target population of this research, the section on beliefs about deaf education and outcomes led me to consider asking similar targeted questions about family response to hearing loss, however, a more open-ended format has been chosen to capture what most fluently emerges from parents regarding their child’s circumstances.

Field Notes and Journaling

I took brief field notes to capture nuances of the interview so that additional non-verbal meanings could be constructed in concert with the recorded linguistic meanings. In addition, I kept a field diary of memos with reflections and impressions of interviews to create an audit trail and to capture the detail, nuances, visceral responses and decision-

making process of the data collection as well as identify procedural, theoretical and coding issues. These field notes became part of a reflective journal to describe my feelings about conducting research in this area of study. The journal serves as one way to “bracket” biases she identifies (Tufford & Newman, 2012). According to Morrow and Smith (2000), the use of a reflective journal adds rigor to qualitative inquiry, as the investigator is able to record her reactions, assumptions, expectations and biases about the research process. Although bracketing can be a method to diminish the effect of researcher preconceptions related to a study by “putting one’s own assumptions and understandings in abeyance” so that the phenomena can be more clearly seen (Rolls & Relf, 2006, p. 290), bracketing can also positively take into account the relationship between the researcher and the phenomena. Tufford and Newman (2010) suggest it can facilitate deeper levels of reflection across all stages of a study. Fischer (2009) asserts that “being in touch with data through one’s own life, being affected by data, and attending to associations are all tools in qualitative research” (p. 587). Field notes and the researcher’s journal provide additional data for analysis.

Identification and Recruitment of Participants

After approval from Western Carolina University’s Institutional Review Board and director of the North Carolina Early Sensory Support Program for Hearing Impaired Children from which participants were recruited, I contacted early intervention teachers of the deaf (TOD) with the program in February of 2014. I explained the purpose of the study and the criteria for participation. Participants in the study were parents of infants and toddlers who had been diagnosed with permanent bilateral hearing impairment (hearing loss in both ears) and at least one additional special need. Participants were 18

years of age or older. The degree of child's hearing loss for parental inclusion in the research was a mild bilateral loss or greater; that is at least 26 decibels or greater according to the conventions of Pure Tone Averaging (PTA) of thresholds at 500 Hz, 1000 Hz and 2000 Hz. In the case of Auditory Neuropathy Spectrum Disorder (ANS), since PTA is not accurate, bilateral abnormal or absent Auditory Brainstem Responses qualified participants for this study. An additional special need is defined using the NC Infant Toddler Program eligibility guidelines (appendix E) including such additional needs as congenital infection, genetic disorder, congenital anomaly, inborn errors of metabolism, visual impairment, gestational age less than 27 weeks, neonatal encephalopathy, intraventricular hemorrhage grade III or IV, or documented developmental delay (NC ITP, 2014). Families had to have been working with a parent-infant deaf educator for at least 4 months, and were either currently working with an educator or had transitioned out of the infant toddler program within the last 4 months due to the child attaining the age of three. The rationale for these parameters is that families and caregivers needed at least 4 months of experience working with a parent-infant educator to fully reflect on their choice to participate in early intervention. The upper cut off was designed to include parents in the study who could reflect on their experience from the perspective of having transitioned out of the program. Additionally, these families were still in contact with their early intervention teacher. Thus, the upper age limit for inclusion for a parent is when their child has reached 40-months of age and the youngest child could be no younger than four months.

I e-mailed teachers a chart that allowed them to list potential participants by number without personal identifying information but including each child's various

disabilities and timing between birth, diagnosis of hearing loss and beginning of early intervention for hearing loss. Upon receipt of these recommended participants, I selected, by each child's designated number, 16 possible participants from five teachers and asked those teachers to present the informed consent materials to these potential parent participants. These materials included the actual consent form (appendix A), the interview protocol (appendix B) and the form Your Child's Needs (Appendix C) in which parents prioritized their child's interventions and listed current services by frequency. Teachers were given the materials to hand-deliver to selected families at their homes. The informed consent outlined the purpose of study, protocol, interview questions, ways to ask questions of researcher and explained my interest in this topic as well as academic and employment affiliations. Teachers then returned signed informed consent forms to me and at that point I was able to directly contact parents. At this initial contact, families were offered opportunities to ask questions and continue with scheduling an interview or withdrawing their permissions.

Purposeful Sampling

I used purposeful sampling, as described by Patton (2002) to select potential participants. I was most interested in differing times of entry to early intervention for hearing loss, so I examined cases in which early intervention varied by the length of time between a child's initial hearing screening referral and the beginning of their participation in early intervention for their child's hearing loss. I also hoped for some geographical variety and diversity in other disabilities and race or ethnicity. Initially I identified 16 students from five different teachers in the western third of North Carolina. These teachers provided families with the recruitment materials including informed consent.

Additional family members who had not previously read and signed the Informed Consent were welcome to interview individually only after they read and signed the informed consent material and confirmed understanding of the study. Family choice in the communication mode or language in use with their child was not part of the selection process nor was hearing aid or cochlear implant use. This is a theme in deaf education that has long been contentious and was purposefully removed as a focus in this study. Families who were not fluent in spoken English or American Sign Language were excluded from the study since the use of an interpreter would create an additional barrier to understanding.

Description of Participants

I received signed informed consent from 11 parents but was only able to successfully schedule 9 interviews. One family moved and could not be located. Another of the 11 children exceeded the upper age limit by the time I was able to speak with the mother. One of the nine scheduled interviews doubled when each parent participated individually in an interview. In this study, nine parents were the biological parents of the children and one parent adopted her daughter after having fostered her. All parents lived in the western third of North Carolina. Six families lived in urban or suburban areas and three lived in rural areas. Only two races were represented; four parents were Black and six were White. Ages of the focus children ranged from 14-months to 38-months. Pseudonyms were used for all of the participants, some selected by the parents themselves. Chapter four begins with more descriptive portrayals of the participants, however, it should be noted that I went into each interview with little information about these parents from their teachers of the deaf. This was purposeful so that I could

minimize preconceptions.

Pilot

I planned to pilot the interview questions with two families with whom I was working as their Teacher of the Deaf. These families met the participant criteria guidelines but in both cases, the infants became critically ill, experienced intensive hospitalization, preventing parents from participating prior to the beginning of the actual recruited interviews. In my journal, I wrote that, “although I have almost a quarter of a century of experience asking other parents about their experiences with their children, that process still always involves adjusting, as a dancer with a new partner, to their rhythm. I always hope to find the core graces of respect and integrity, that allows a person to safely and without regret, open her heart.” Professional distance and objectivity is not possible in a study of this sort, but the act of sharing may give voice to a group that can feel or may actually be marginalized or at least minimally represented in the literature.

Although unable to pilot the study, I was still able to use my prior experience as a parent and interventionist in the “interactive” aspects of drawing out family stories (Green, 2003). The shared aspect of parenting a child who has a disability were scripted into my initial request for participation, but limited in expression during the interviews, with only occasional spontaneous comments by the researcher so as to follow Seidman’s (2013) dictum, “listen more, talk less” (p. 81).

Incentive

Patton (2002) suggested that researchers show how we value participants’ contributions by offering something of value in exchange. As an incentive to participate

in the study, I offered each participant a \$25 gift card to either Wal-Mart or Amazon. Parents could choose which card at the end of the interview. In face-to face-interviews, I handed it to them. In the case of phone interviews, I mailed the chosen card to them with a brief note.

Data Collection Procedures

Each participant engaged in an individual interview. I created the interview protocol in order to address specific questions about parent's experiences. Due to time constraints, I conducted one interview, which attempted to include all the components of his three-interview approach (Seidman, 2013). The initial questions were designed to elicit the history of the child's diagnoses and the parent's reconstruction of the experience of learning that their child has hearing loss. I also hoped to glean details of the participant's present lived experience regarding their child's special needs and their ongoing interactions with professionals. Questions also encouraged parents to "reflect on the meaning of their experience" (Seidman, p. 22).

Interview Procedures

One in-depth, semi-structured interview consisting of six questions was conducted with each participating parent (Appendix B). Before beginning the six-question interview protocol, parents were asked to identify and organize by priority their child's special needs along with information about the number of children in the family, and information about their child's current therapies and schedule. Although a standard interview protocol guided the interviews, parents often shared more than asked and I, as researcher, encouraged them to talk. All interviews were scheduled on dates, at times, and in locations that balanced the convenience, preferences, and comfort of participants

against the progress of the study. Face-to-face interviews were conducted with 5 parents and phone interviews were conducted with 5 parents.

Originally, the face-to-face interview mode was selected as preferred. However, as the project progressed into the fall and winter seasons, more participants chose phone interviews. This may have been due to approaching holidays or due to the fact that the latter participants' schedules made them more difficult to connect with even though they had already consented to participate. I looked to the current literature comparing telephone and face-to-face qualitative interviewing modes for guidance. As a researcher, it is important to know if the quality of data collected by telephone is comparable to that collected in face-to-face interviews. In a study that led to comparing telephone and face-to-face interviews, Sturges and Hanrahan (2004) compared transcripts each and found no significant differences in the interviews. In fact, they suggest that phone interviews may reduce embarrassment involved in responding to emotionally loaded questions leading to greater likelihood of participation in an interview. Trier-Bieniek contended that being "interviewed over the phone may result in more honest data" (2012, p. 630) and suggested that people are now more accustomed to 'virtual' communication. Sensitive information may be shared more easily over the phone and Trier-Bieniek saw phone interviewing as a participant-centered, feminist mode because of the safety and control provided to the participants. For these parents of young children, the phone allowed flexibility. Indeed, one phone interview in my study occurred in several stages as the mother left work, picked up one child from one pre-school and then two more children from childcare. (I did make sure that she was using a hand-free device while in the car). Another mother had forgotten the interview time and I was able to reach her at church,

where she was happy to chat. In this study, the participants seemed equally involved on the phone and at home. The ability to build rapport was perhaps more likely to occur when participants led in choosing the method of interview. Some participants may have been relieved not to have one more home visitor since that can involve making the home and oneself presentable. At least one respondent cried several times during the phone interview, but she was able to collect herself and continue. I don't know if the phone helped her be more willing to participate or if it allowed her to share feelings she might have been too constrained to share face-to-face. Creswell (2008) did note that the use of a telephone deprives the researcher of seeing non-verbal communication.

Face-to-Face Interviews

Among the face-to-face interviews, four were conducted at participants' homes and a single interview was conducted at a MacDonald's play area, per parent request, with her son playing while we talked. This particular interview was unique in that the mother had already answered all of the interview questions in a written format. I nevertheless, continued with a verbal interview, which provided additional information.

Telephone Interviews

Telephone interviews were conducted with five participants who either expressed a preference for that format or who were unavailable for face-to-face interviews. All interviews were audio-recorded using a Sony IC recorder to ensure the accuracy of data collection (Kvale & Brinkmann, 2009). Participants were reminded of the recording instrument in both face-to-face interviews and phone interviews, and were told exactly when the recording instrument was being turned on and off. Some discussion occurred before the device was turned on and some afterwards, mostly in the form of introductions

and pleasantries. I noted any comments in the margins of the protocol and these comments were in some cases used in this research.

Methods and Procedures.

Interviews were recorded with an unobtrusive voice-activated Sony digital recorder. Parents were told when the device was turned on and off. I took brief field notes to capture nuances of behavior and my thoughts during the interviews so that important ideas were not lost. I described my impressions and added detail after the interviews. These field notes became part of a reflective journal to express my feelings about conducting research in this area of study. The journal served as one way to “bracket” biases I identified (Tufford & Newman, 2010).

According to Morrow and Smith (2000), the use of a reflective journal adds rigor to qualitative inquiry, as the investigator is able to record her reactions, assumptions, expectations and biases about the research process. Although bracketing can be a method to diminish the effect of researcher preconceptions related to a study by “putting one’s own assumptions and understandings in abeyance” so that the phenomena can be more clearly seen (Rolls & Relf, 2006, p. 290), bracketing can also positively take into account the relationship between the researcher and the phenomena. Tufford and Newman (2010) suggest it can facilitate deeper levels of reflection across all stages of a study. Fischer (2009) asserts that “being in touch with data through one’s own life, being affected by data, and attending to associations are all tools in qualitative research” (p. 587). Field notes and the researcher’s journal provide additional data for analysis; notes on participant behavior, identification of emerging themes, researcher reactions to the

interviews, notes about the environments and about parent interactions with children form “thick description” (Geertz, 1988).

Confidentiality

Computer, audio and paper files were labeled using the fictitious names, some chosen by parents and some by the researcher. Recordings were used to create transcripts of the interview for coding and data analysis. The digital recordings and transcripts of interview recording are kept in a locked file cabinet away from any information that would identify the participant. Upon acceptance of this dissertation/publication, the digital recordings, initially maintained in a locked cabinet, will be destroyed after 12 months. The recording will not be used for publication or broadcast at any time. Setting a password protected all computer files, which were saved in my personal computer to which I have sole access.

Ethical Considerations

I informed all participants of the purpose of the research and let them know that, although no real names will be used, there may be a possibility that their anonymity may not be maintained. Each family member was assigned a pseudonym for confidentiality, yet these “names” assisted in writing rich descriptions of families, their situations and their perceptions. Since the subject of the interviews was emotionally charged for families, I provided some resources to families who showed interest after the interviews. These resources included local contacts for The Family Support Network of North Carolina, Local Parent Support Groups, Parent Advocates through the EHDI program and regional numbers for BEGINNINGS for Parents who have Children who are Deaf or Hard of Hearing. These resources provide both professional and trained parent-

to-parent support for parents who have children with special needs and hearing loss. When I was unsure of local resources, I asked the family's assigned teacher of the deaf to help with further resources.

Study Effects

I expected to learn from this study. While I learned, I valued these parents and was changed by the stories they shared. Taking off my "teacher of the deaf" hat and opening myself to these families' experiences, gave me new perspective on early intervention. As the parent of a late-diagnosed child who is deaf, learning about the experience of multiple very early diagnoses altered my appreciation of what parents may experience in the first months of their infant's lives. Families involved in the study may also have benefited from telling their stories (Green, 2003; Romanoff, 2001). Their decision-making processes, made more transparent through their own reflection, may help them in with future decision-making and empowerment as well as providing valuable information to other families who face similar circumstances of having a child with two or more special needs.

The primary audiences for this study include professionals in the fields of audiology, teachers of the deaf, early intervention service providers, early childhood special educators, neonatologists, pediatricians, otolaryngologists and speech and language pathologists. There are also implications for improvement in professional training programs as they address the needs of professionals in practicing positive ways of engaging with families who have very young children who have special needs. Early Hearing Detection and Intervention Programs (EHDI) may benefit from parents' perspectives. Through this process, the researcher discovered additional self-awareness as

a parent and as a professional (Green, 2003).

Role of the Researcher

This researcher hoped to gain rapport with families and her experience as a parent of a profoundly deaf child assisted with affinity. Yet, I was aware that my previous experience as a teacher and a parent of a deaf child, did inform the perspectives I brought to the current study. It was necessary for me to acknowledge and bracket my experiences (Creswell, 2008). Researcher bias may compromise reliability in any qualitative study (Hill et al., 2005); therefore, I made an effort to remain open to where parents took the interviews. Because the researcher is the primary data collection instrument in qualitative research (Creswell, 2008; Kvale & Brinkmann, 2009), it is important that she acknowledge biases and assumptions that may affect her understanding of data and interpretation of its meaning. My greatest bias is founded in the research on infant toddler brain architecture and the need for early language input for optimum child development.

During analysis I became so immersed in parent stories that I felt I lived them. Glesne (2011) suggests that the researcher role may be personal and empathic. However, the researcher also understands that care should be taken to assure that hers are not the only lenses through which to perceive each parent and caregiver experience, and that parent/caregiver voices are given authentic representation.

Lincoln and Guba (2000) identify the constructivist “voice” of the researcher as that of a “passionate participant”, and as a facilitator of multi-voice reconstruction and meaning-making (p. 166). The interview questions were designed to be open-ended in order to gain understanding and facilitate the expression of many meanings ascribed by

participants. It is my humble hope that this study does justice to the parents who kindly shared brief yet concentrated glimpses of their lives.

CHAPTER FOUR: RESEARCH FINDINGS AND ANALYSIS

The purpose of this study was to discover and describe both the barriers and the facilitating factors for parents that result in engagement with early intervention (EI) for their child's hearing loss when their child also has additional special needs. Parent experiences were explored through semi-structured interview. Parents identified barriers and supports to participation in early intervention for hearing loss, as well as all areas of early intervention. This integrated approach mirrors the intent of early intervention, where providers from various disciplines join with the family to form an Individualized Family Service Plan (IFSP) to address each family's needs in a cohesive, family-driven process.

Data Analysis

The data analyzed for this study included participants' demographic information, information provided by parents regarding Your Child's Needs (appendix A), responses to the interview questions (appendix B) as well as notes on my perceptions during and after the interview. All interviews were transcribed to documents using the Microsoft Word for Mac (2011) program and upon completion, were printed to paper for initial analysis. Phenomenology calls for rigorous reading and rereading of transcribed interview data, to uncover the essence of the phenomenon being examined (Giorgi, 2002; Hein & Austin, 2001). Each interview and its accompanying written reflection were read in full at least four times, so that I could familiarize myself as much as possible with the participants and the data they generated. In addition, the field notes I compiled were consulted frequently, to aid in the recall of what I was thinking during interviews. Because most field notes were taken in the margins of the protocol that I used as my

interview guide (Appendix B) or in the Your Child's Needs form (Appendix C) that I reviewed with each parent, I was often able to elaborate on particular parts of the verbal responses.

I initially hand-coded each transcription, highlighting what seemed most emotionally impactful for families and what were causative factors by which parents made decisions and evaluated their situations. Miles and Huberman (as cited in Creswell, 2008) observed that qualitative data analysis is an adaptive, iterative process designed to promote discovery. Additional themes emerged through repeated immersion with the data and resulted in the use of additional codes. After the initial hand coding I then loaded all interview transcripts into NVivo for Mac (2014), a computer qualitative data analysis program. Using NVivo, I was able to identify additional themes through word searches and to organize ideas into thematic "nodes". After the NVivo analysis, I returned to hand-coding once again. Additional themes and patterns emerged subjectively, with my perceptions influenced by my own personal past experiences and responses to parent narratives. I coded in various ways and distilled or "crystalized" (Richardson, 2000) to those themes that seemed most in need of being voiced.

One purpose of qualitative research is to "make sense of actions, narratives, and the ways they intersect" (Glesne, 2011, p. 1). If one can understand and explain participant meaning (Morrow & Smith, 2000), one has gained important insight into human issues. More specifically, Creswell (2008) defines qualitative research as an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem.

The main questions in this study were addressed to and answered by parents through their descriptions of their experiences in interviews. The time frame for completing this project was 14 months. The proposal was submitted for IRB approval in the spring of 2014. Contacts and permissions were made during July and interviews occurred between August and December of 2014.

Trustworthiness and Authenticity

In qualitative research that assumes meaning is socially constructed, it is difficult to ensure truth, accuracy or validity. Nevertheless, it is important to address trustworthiness and authenticity. This study focused on parent perceptions leading to participation in early intervention. The use of their own words in “rich, thick, description... allows the reader to enter the research context” and, according to Creswell, as summarized by Glesne (2011, p.49) contributes to trustworthiness.

Use of peer review and debriefing with a trusted colleague was utilized to obtain external reflection and input on the study. Additionally, I wrote reflective notes to understand the self as the researcher, the self as the teacher of the deaf and the self as a parent of deaf child. These multiple selves perceive families through different lenses and interact with them from different understandings. Journal writing is a method of inquiry and synthesis as well as autobiographical narrative. Identification of these many selves need to be on paper because “I know they are affecting what/how I lay claim to know” (Richardson, 2000, p. 941).

The initial questions in the study design guided the research but also served only as “boundaries around the study without unduly constraining it” (Marshall & Rossmon, 1999, p. 40). Analysis yielded several broad themes:

- Parent (and family) adjustment to the diagnosis of hearing loss, including patterns of responses/emotions, as well as factors for how they prioritized their child's needs,
- Identifying difficult adjustments or barriers to seeking, engaging, and remaining in early intervention,
- Identifying common reinforcers or positive supports that aided parents and families in staying engaged in early intervention, and
- Ideas and recommendations from parents for suggested improvements in accessing early intervention moving forward, for both professionals and system issues, as well as parents of newly-diagnosed infants with hearing loss and additional special needs.

Parents interviewed demonstrated various personal characteristics and described experiences that reinforced their participation in early intervention, as well as experiences that inhibited them but did not preclude them from participating in early intervention. Families also mentioned external resources, such as finances and family support as factors that were either helpful in the overall intervention process or obstructed it.

When given the opportunity to address what parents most wanted professionals and other parents to know, all participants had heartfelt messages. Three parents addressed their final comments directly to professionals about such topics as the need for information, the influence of professional attitudes and practice and the politics of negotiating the early intervention system. Four parents chose to share their feelings and perspectives with other parents as their audience. Three parents addressed both professionals and other parents. Throughout the interviews, parents identified additional

resources that helped or hindered their abilities to continue with major life pursuits such as work or activities with their other children. Parents also specifically spoke about medical insurance that either supported or denied provision of therapies, equipment or educational settings that they felt were important to promote their child's progress.

Participants

Participants were parents of nine children, who were ages 14 months to 38 months and had hearing loss and a variety of additional special needs. Table 1, below, provides information about the parents and children. Pseudonyms are used instead of their actual names, and any name used in this study, including those in Tables and Figures, should be considered pseudonyms instead of subjects' real names. This is done as a means to protect individual identities. All parents were biological parents with the exception of one mother, Lainey, who first fostered Nikki and then later adopted her when she was a 2-year-old. Therefore, all those interviewed are termed parents. Lainey was the only parent interviewed who was raising a child by herself. She has three biological children who are now grown and no longer live at home. All but one of the children had siblings. Of the eight children with siblings, all but one were the youngest children in the family.

Nine of the interviewed parents were female and one was male. Angus' father, Lars, home because it was a school holiday, consented to an interview after I interviewed Angus' mother, Jeannie. When early intervention teachers made referrals for this study, all names listed as contacts were the mothers, in these cases, the parent most likely to be coordinating early intervention services. The mothers who worked full-time jobs still took the time to speak with me, although these interviews were more likely to occur by

phone. Interviews were equally divided between face-to-face and phone interviews and decided by preference of the parent.

Because two parents from one family were interviewed, the number of parents in the study is 10 and the number of children is nine. The number is specified for different types of data. Parent participants were only from two identified races: six White parents and four Black parents. The parents all lived in Western North Carolina. In terms of rural or urban, three families were from rural areas, and the other six families were from suburban or urban areas. Whether or not the child had Medicaid insurance emerged as an unexpected topic. Of the nine children whose parents participated in the study, four received Medicaid and the remainder had private insurance, requiring them to pay out-of-pocket for deductibles or services.

In order to be included in the study, children had to have received early intervention for hearing loss for at least four months. All but one of the children, Junior, were still receiving intervention for hearing loss at the time of the interview. Junior had attained his third birthday in the last two months and therefor transitioned from Part C services with the Infant Toddler Program to Part B services, under the umbrella of his Local Education Agency (LEA).

Another criterion for this study was the child had to have a hearing loss and at least one other medical or special needs diagnosis. Sometimes the critical nature of the child's other special needs was a barrier to timely diagnosis. Of the nine children in this study, five children had their hearing loss diagnosed within three months, the timeline recommended by the Joint Commission on Infant Hearing (JCIH, 2000), and four children were diagnosed after three months of age. Other than hearing loss, children had a

variety of additional special needs and known medical diagnoses, listed, under their pseudonyms, in Table 1, along with demographic information and pseudonyms for parents and children in this study.

Table 1*Parent Participants (n=10) and Their Children (n=9)*

Parent(s)	Child (gender)	Age of Child At Interview	# of other siblings in the home	Race: White (W)/ Black (B)	Child has Medicaid : Yes/No	Time Elapsed from		Child's HL Dx (+ detail) & Other Medical Dx or Special Needs
						Birth to HL Dx	HL Dx to EIHL	
Buffy	Daphne (f)	30 months	1	W	Y	6 months	1 month	Mild-Mod HL (Bilateral - Aided); Holoprosencephaly, Hydrocephalous w/ shunt, Visually Impaired, G-tube for feeding
Jeannie & Lars	Angus (m)	16 months	3	W	Y	2 months	2 months	Mild HL (Bilateral - Aided) Down Syndrome
Amara	Jina (f)	14 months	2	B	Y	1 month	1 month	Mod-Severe HL (Bilateral - Aided) CMV Motor Delays Visually Impaired
Erica Lynn	Junior (m)	38 months	2	W	N	8 months	1 month	Bilateral ANSD Mod-Sev HL (Bilateral -Aided) Strabismus & Hyperopia Sensory Processing Disorder

Table 1 - continued

Parent(s)	Child (gender)	Age of Child At Interview	# of other siblings in the home	Race: White (W)/ Black (B)	Child has Medicaid: Yes/No	Time Elapsed from		Child's HL Dx (+ detail) & Other Medical Dx or Special Needs
						Birth to HL Dx	HL Dx to EIHL	
Hannah	Ryder (m)	19 months	0	W	N	2 months	1 month	Left-Profound HL, Right-Moderate HL, Recent CI surgery L side CMV, CP G-tube for feeding
Peyton	Callie (f)	16 months	4	B	N	2 months	2 months	ANSD, Hearing loss (unaided per audiologist); Vision Loss, Motor Delays, G-tube for feeding
Jez	Andrew (m)	30 months	2	W	N	6 months	1 month	ANSD Fluctuating Bilateral HL (Aided); Chronic Lung Disease, G-tube for feeding
Giselle	Sydney (f)	30 months	2	B	N	2 months	2 months	Mod/Severe Bilateral HL (Aided); Premature Twin Developmental Delay Failure to Thrive
Lainey	Nikki (f)	34 months	0	B	Y	24 months	2 months	Mild HL (Bilateral – Aided) Arthrogryposis, Scoliosis, Camptodactyly Motor Delay G-tube for feeding

Table 1 - *continued***Acronym Key to Table 1**

ASND Auditory Neuropathy Spectrum Disorder

CI Cochlear Implant

CMV Cytomegalovirus

CP Cerebral Palsy

Dx Diagnosis

EIHL Early Intervention for Hearing Loss

G-tube Gastrostomy (feeding) Tube

HL Hearing Loss

NICU Neonatal Intensive Care Unit

Profiles of Families

The following profiles complement Table 1 and are presented in the same order. Each profile is based on what I learned about the families from their teachers, what parents directly told me and what I observed during my conversations with them. Race and socioeconomic status were not intentionally singled out as focus for this research; however, since these two factors can significantly influence both experience and perception, I include the race of the participants and whether or not their child qualified for Medicaid. The only two races represented were Black and White. There were no instances where couples were not of the same race. There was only one single parent in the study.

Buff, parent of Daphne. Buffy and her husband live in an old farmhouse down in a hollow far out in the country. This family is White. Buffy is a young mother who

stays home with her two daughters. Daphne, the older, is two-and-a-half and Sissy is 10 months old. Buffy gets up early in the morning to make breakfast for her husband who goes to work around 6 am. Then, she and the girls sometimes go back to bed before Daphne's therapists start arriving at 9 am. Buffy said she and her husband would like to have another baby and hope it will be a boy. Daphne has a diagnosis of holoprosencephaly, a complex congenital brain malformation. She has a shunt due to hydrocephalous, is fed through a g-tube, is visually impaired and has a mild to moderate bilateral hearing loss. She has hearing aids. She is currently working on rolling over and holding her head up. She has Medicaid insurance. Buffy schedules all the visiting therapists and teachers Monday through Thursday so Daphne has "a long weekend". She likes therapists to come in the morning because Daphne started having seizures recently and she is happier in the morning. Buffy says that Daphne is a "daddy's girl" and loves it when he comes home from work in the afternoon. Her attitude towards Daphne's special needs was "that's the way God wanted her to be."

Jeannie and Lars, parents of Angus. This family lives outside of a large city in a modest home in a suburban neighborhood. They are White and they have four children. Angus is the baby in the family. He now has Medicaid insurance. He is 16-months old and has Down Syndrome with a mild bilateral hearing loss. He wears hearing aids. Both parents reported that keeping the hearing aids on is a frustration. Jeannie has homeschooled the older children for the past 10 years. This fall, the two younger ones went to public school for the first time. The older daughter, a high school senior, continues with a home-school program because she is so independent. Jeannie was composed and somewhat shy when we started the interview. I got the feeling that she had

really enjoyed teaching her children and was sad to give it up due to the therapy schedule with Angus. Lars is a high school English teacher who said he also has two extra jobs to try to make ends meet. Finances are a stated concern for the family and Lars works very long hours. He was off on the day of the interview because it was a state holiday. He returned from an outing with the older children just as Jeannie and I were finishing the interview. He consented to an interview and joined us. Jeannie became much livelier when Lars joined us and during this second interview, and during Lar's interview they had several tangential conversations about hearing aids, Angus not sleeping through the night and their church community.

Amara, parent of Jina. Amara and Jina live outside of a city in an apartment complex. There are two older school-aged children in the family and Jina's father lives with them. Amara says she has lots of family support. This family is Black and Jina has Medicaid. Amara got sick when she was pregnant with Jina and was prenatally diagnosed with Cytomegalovirus (CMV). This is a common infection that is usually harmless, but can cause long-term problems for infants who are infected before birth. Jina has gross motor delays and feeding issues. She will be getting glasses soon and has a moderate to severe bilateral hearing loss. She wears hearing aids, but Amara reports it is a struggle to keep them on and wonders how it will be when she adds glasses. Amara was upset that doctors were unable or unwilling to give her information and support about CMV while she was pregnant with Jina. She searched for information while pregnant and joined an on-line support group.

Erica Lynn, parent of Junior. Erica Lynn and her husband live out in the country in a home in the mountains near a national forest. This family is White and their

son, Junior, does not have Medicaid. Junior's father is a pastor of a church and Erica Lynn stays home with the three children. She says all the children pretend that they are "preachers". She wanted to meet at a McDonalds because she was in town for a doctor's appointment for Junior. She said her house was a mess and there were also bees in the walls. She spoke so quickly at times that her narrative was like a stream of consciousness story. She talked about her youth when her family traveled the mountains performing bluegrass music. Junior, who has a bilateral hearing loss called Auditory Neuropathy Spectrum Disorder (ANSD) diagnosed as moderate to severe and he wears hearing aids. He is over age three and he recently transitioned out of the early intervention program. He was a sick premature baby delivered C-section due to placenta abruptus. He has strabismus and hyperopia and sensory integration issues. Erica Lynn was the only parent who read all the informed consent materials before our interview. She wrote out all her answers to the interview protocol that she initially received. She said in her strong southern accent, "I always wanted to be a writer, but I'm terrible at punctuation. What goes where, this that and the other". I also recorded her discussion of each question. When I thanked her for sharing so much, she said "I'm over the top!"

Hannah, parent of Ryder. Hannah and her husband live outside a large city in a modest suburban home. This family is White and Ryder did not have Medicaid insurance. Ryder is a first child and the only one at the time of the interview. Although Ryder did not pass his hearing screening, he appeared to be healthy baby, but then ended up in the hospital at three months with an extremely compromised immune system and a deadly blood infection. He was placed in a coma while the doctors tried to figure out what was going on and save him. At this time, he was diagnosed with CMV. Since then he has been

diagnosed with cerebral palsy (CP) and bilateral progressive hearing loss. He had recently received a left cochlear implant and had to stay in the hospital longer than expected due to post-surgical breathing difficulties. At the time of the interview, his incision was still healing so the implant had not yet been activated. Hannah and her husband have extended family support. Family members sometimes join in for therapy sessions. Hannah was somewhat shy in the interview, but had strong opinions about needed supports for middle-income families. Hannah, an educator, is one of the mothers who said she was unable to work due to her son's needs and his therapy schedule.

Peyton, parent of Callie. Peyton's family lives in a suburban home in a bedroom community to a large city. She and her husband have four older school-aged children. This family is Black and Callie had Medicaid insurance. Callie was diagnosed with Auditory Neuropathy Spectrum Disorder (ANSD) and has low vision, motor delays and needs a g-tube for feeding. Peyton said that they stopped putting hearing aids on Callie because the audiologist couldn't adequately set them. As Peyton explained it, the audiologist thought the hearing aids needed to be more powerful, but was afraid to set them that high. She spoke very softly about how she never expected a child of hers to have such complex issues. She said she was going to go to a different neurologist with Callie, hoping that another one would have a more positive outlook for her. As the interview progressed and I asked if there was more she wanted people to know, she apologized saying "...there are no words...let me see if I can (long pause) ...I can't think of any one complete thought. This is crazy". She was very reflective and talked about how she had really learned to empathize with those who have family members with special needs.

Jez, parent of Andrew. Jez and her husband and three children live out in the country. Jez is a registered nurse. This family is White. Andrew originally had Medicaid insurance and then shifted to private insurance. Jez had lots to say about her experience of the differences in availability of services with and without Medicaid. Since Jez often works night shifts, Andrew's father and grandfather also juggle their schedules to help care for Andrew, who is 30-months old. He was born prematurely at 26 weeks gestation after Jez's water broke at 24 weeks. Jez said he was so sick that they didn't think they would bring him home. Andrew has hearing loss due to ANSD, chronic lung disease and has a g-tube for feeding. He was not yet "free-walking". Jez had a strong sense of humor and a feisty attitude. She also has a hearing loss of unknown origin and wears hearing aids. Andrew calls his mother's and his hearing aids their "ears".

Giselle, parent of Sydney. Giselle and her family live in an upscale subdivision of well-built homes in a large city. This family is Black and Sydney does not have Medicaid insurance. Giselle is an occupational therapist in early intervention. Her husband, originally from Haiti, is a pediatrician. They have worked in New York and in Washington DC and Giselle drew on that experience in discussion. There are three children in the family. Sydney and her twin brother are the younger and were premature. Sydney was very small for gestational age and continues to struggle to gain weight. She has a bilateral hearing loss that is moderate to severe and developmental delays. She wears hearing aids. The family is very busy or as Giselle put it, "in survival mode". Both parents work and the children are in childcare and then have afterschool care at home. Giselle and I conducted this interview in three segments, by phone (hands-free on her end) as Giselle left work and picked children up from their various settings.

Lainey, parent of Nikki. Lainey and Nikki live in an apartment outside of a large city. This family is Black. Nikki has Medicaid insurance. Lainey works in a school cafeteria, but also went back to school to learn medical transcription. Lainey has three grown biological children who are no longer at home. She was first Nikki's foster-parent starting when Nikki was under a year old and then legally adopted her when she was two years old. Nikki has arthrogaposis, scoliosis, camitozactyly and a mild bilateral hearing loss. She has a g-tube but also now eats by mouth. She wears bilateral hearing aids. She is two and a half. Her greatest challenges are mobility and fine motor skills. She has trouble bending. She is able to walk now after lots of therapy. Lainey talked a lot about her team, working together and putting the child first. Lainey was the most joyful parent I spoke with. She frequently expressed her pride in Nikki's accomplishments and her delight at watching her make progress. She said, "This little girl I got, is very smart"! Nikki's diagnosis of hearing loss came when she was about two years old, according to Lainey, but she thought maybe she had not passed her newborn hearing screening and the information got lost somehow. She said she is so happy watching Nikki grow up; "Nikki is my blessed child".

Themes in Parent Interviews

After coding and analyzing the data, parental responses, experiences, and attitudes were distilled into four primary, but broad themes:

- 1) Parent (and family) adjustment to the diagnosis of hearing loss, including patterns of responses, clarity of diagnosis as well as factors of how parents prioritized their child's needs,
- 2) Identifying difficult adjustments or barriers to seeking, engaging, and

remaining in early intervention,

- 3) Identifying common reinforcers or positive supports that aided parents and families in staying engaged in early intervention, and
- 4) Ideas and recommendations from parents for suggested improvements in accessing early intervention moving forward, for both professionals and system issues, as well as parents of newly-diagnosed infants with hearing loss and additional special needs.

Learning Your Child Has a Hearing Loss

The Joint Commission on Infant Hearing (JCIH) recommends for newborn hearing screening, diagnosis and intervention follows a “1-3-6” format; screening by one month of age, diagnosis by age three months and early intervention by six months (American Academy of Pediatrics, Joint Commission on Infant Hearing, 2007). The JCIH asserts the ultimate goal of screening and diagnosis is to provide early intervention as quickly as possible for children who have special needs. Five of the children in this study met JCIH guidelines for timing of diagnosis and intervention, with intervention beginning by the time the child was six months of age. The remaining four children did not meet the guidelines, and the ages at which intervention began ranged from seven months to 26 months. Nikki was not identified until age two, so she did not begin early intervention until she was 26 months old. Lainey was not sure about the results of Nikki’s newborn hearing screen, as she was not yet her parent, so there is a possibility that her hearing loss was progressive. If it was not a progressive hearing loss, Nikki was lost to follow-up and diagnosis for almost two years.

The timing between diagnosis and beginning early intervention for hearing loss

was, on average, only 1.4 months. The Hearing Link in North Carolina, part of the Early Hearing Detection and Intervention Program, was quite effective at getting these children referred to the Early Intervention System in a timely manner. All of the children were referred from diagnosis to early intervention and began intervention for hearing loss within one to two months. The greatest delays occurred between birth and diagnosis.

Initial Reaction

The first formal interview question specifically addressed parent's thoughts and feelings when their child's hearing loss was confirmed. Results from the data show a range of reactions, from parents being overwhelmed by grief to those who were just interested in learning more about hearing loss.

I cried. Negative feelings reported by parents included "shocked," "sad," "hurt" and "angry." Hannah said, "It was completely devastating." Lainey confessed, "I cried. It was like she had so much other stuff going on with her that I felt bad that she had to deal with that too." Erica Lynn said that her husband was "in denial" while she worried about learning sign language "just in case". Two mothers reported immediately worrying that they would have to learn sign language. Erica Lynn stated, "I thought, I quit doing plays because I can't remember my lines. How in the world am I going to learn sign language?" Jeannie reports a similar thought, "Oh, we are going to have to learn sign language. That was my first worry. Cause it seemed like a lot - learning a new language." Six of the parents interviewed reported strong feelings of sorrow or shock when finding out about their child's hearing loss. Several, like Hannah, spoke of the confusion and how "everything got dumped on me at once, so I had to process a lot in a very short amount of time." Four parents report not remembering events clearly due to all that was happening

with their babies. Jeannie said, “it’s hard for me to remember... we came home with oxygen and stuff so ... the first six months is just kind of a blur.” Peyton said, “everything was just happening so fast and I just wasn’t ready. I was still kind of like in shock and all these people were calling me.”

Other bad things could have gone wrong. Four parents reported the diagnosis of hearing loss didn’t cause a strong negative reaction for them. In most of these cases the baby was either quite sick or had a syndrome that had other physical components. Jez said, “It wasn’t a big deal for me ... we never thought we would actually bring him home from the hospital.” Buffy said that “it wasn’t as bad as finding out that she needed a shunt ... other bad things could have gone wrong.” Lars, the only father interviewed, said this about the diagnosis of his son’s hearing loss:

It was a minor blow because when you have a child with Down Syndrome and you make it through the first months without any...of the other birth defects that would go along with that chromosomal disorder. You are kind of waiting for another shoe to drop, and if it was hearing loss, it was ok...we’re good. If that’s as bad as it’s going to be, we can deal with that pretty well.

Giselle said that she and her husband were not too concerned about Sydney’s hearing loss. She and her husband both had professional experience with young children’s health and development. As an occupational therapist married to a pediatrician, Giselle expressed curiosity and interest in learning more. She said that they were “surprised, mostly. We were not devastated at all. We knew very little about hearing loss, so we had lots to learn in that area.” This parent expressed that she and her husband saw

Sydney's diagnosis of hearing loss as an opportunity to learn more about a special need that they hadn't encountered much in their professional lives.

The stress of receiving a diagnosis of hearing loss. Parents of typical newborns share tales of exhaustion during the weeks after a normal birth. For the parents whose babies were hospitalized, hearing screening occurs after the child is stabilized and when the child's age is adequate for the parameters built into the automated screening equipment. When the babies were referred from hearing screening, they were often sent to a pediatric audiologist and otolaryngologist or ear, nose and throat doctor (ENT) for diagnosis at another site. Screening for hearing loss occurs in birthing hospitals, but many hospitals are not able to perform actual diagnostics, which most often includes an auditory brainstem evoked response test (ABR) for which children need to be sleeping or sedated. For some of the parents, these diagnosing specialists, audiologists and ENTs were quite a distance away and families may have had to bring oxygen or feeding tube bolus to the hearing testing, spend the night or driven long distances at an expense. Buffy said that Daphne "had to be in the NICU for 32 days". "She failed every single hearing test that they did...about a month to two months after she got out, she had to do another one" which did confirm hearing loss. Buffy was actually talking about initial screenings, which lead to the later diagnostic testing. The diagnosis of hearing loss occurred for Daphne and the other children after their graduation from the NICU or PICU, most often making hearing loss one of the last special needs that was confirmed. It is only after confirmation of hearing loss, that a child is referred for services and intervention for hearing loss.

Prioritizing Children's Needs and Selecting Early Intervention

Hierarchy of Needs

Diagnostic confirmation of hearing loss may come after other services to the family such as physical therapy or nutrition and feeding services are already underway. In some instances the IFSP team has already initially conferred with the family and written goals.

Prior to interview, nine mothers completed the questionnaire called Your Child's Needs (Appendix C), which included the parents prioritizing the most critical interventions they thought were needed for their children. In other words, were parents most concerned about receiving intervention to help with hearing or communication, or were they more concerned about getting interventions and therapies for their children's other special needs? Of the nine mothers polled, only one mother rated Hearing/Speaking/Communicating" as her child's primary need for early intervention. The other eight mothers listed their children's other medical and therapy needs as a higher priority for early intervention. These higher-prioritized interventions included physical therapy, occupational therapy, nursing, nutrition, vision services, and language facilitation.

Choosing the right therapies for my child. As parents faced the intense, multiple, or unresolved special needs of their babies, families were able to manage and prioritize these needs. In some cases, the needs were either clearly identified, which helped parents better identify what they could do to help, or the special needs actually resolved, as in the case of severe feeding issues for two families. I originally designed the brief form, Your Child's Needs (Appendix C) to provide basic information about each child's special needs, each child's placement among siblings, sibling's special needs and

frequencies and types of interventions. The form was provided to the families by their early intervention teachers of the deaf as part of their Informed Consent packet during recruitment. None of the parents had already filled in the form prior to the interview so we talked about it as much as each parent wanted to.

All of the families in the study had been receiving early intervention for their children's hearing loss for at least a year. The average length of time each child had been receiving EI specific to hearing loss was 18 months with a range of 12 months to 26 months. Most of the families had other early intervention services, such as physical therapy, that began prior to or at the same time as those for hearing loss. When asked to prioritize their children's special needs, all of the parents had at least some experience with more than one intervention. This helped inform their identification of their priorities.

Only one parent, Erica Lynn identified "hearing/speaking/communicating" as the number one need for her child, Junior. This child was also the oldest child in the study at thirty-eight months. Gross motor skills and feeding are more noticeable issues for younger children and language needs not as obvious until a child is older. Three parents identified gross motor skills as the number one priority and two identified feeding as paramount. Three other parents identified as utmost the following issues: a medical issue (child's shunt), vision and fine motor skills. Hearing, speaking or communicating was rated as number two for three families. Feeding was also rated as number two for three families.

As noted earlier, when asked to organize their child's special needs, parents provided the following ratings beginning with 1st as the most essential for intervention. The number of needs parents listed for each child varies from 2 to 5 needs (Table 2).

Table 2*Parent Prioritization of Child's Needs (n=10)*

Type of Therapy	1 st	2 nd	3 rd	4 th	5 th	Notes & Quotes
Gross Motor Skills Physical Therapy (PT)	3	2	1	0	0	"If you can walk around and work in your environment to get what you need, then...yeah, that comes before his hearing." "Physical therapy is the main one right now because she still can't lift up her head and she doesn't roll or do nothing
Feeding (SLP, OT, Nutritionist)	2	3	1	1	0	For at least one family feeding went from #1 concern to least concern. "Failure to thrive" was an issue that many of the children experienced-"I guess that would be the most critical because if you don't eat, you die". "For us, at that time, the priority was not her hearing and listening, our priority was she's not gaining weight, she's losing weight." "I can't say now that's the first thing because she's eating fine on her own now".
Hearing, Speaking, Communicating (HI Intervention)	1	3	3	2	0	Only one parent rated hearing as #1 priority. This child was the oldest in study and had ANSD. Hearing ability was this mother's greatest unanswered question.
Medical issues (shunt eg.)	1	0	0	0	0	Only one child had a shunt due to hydrocephalous- this was the primary concern for this mother although she rated Gross Motor skills (Physical Therapy) as a great need due to child's inability to lift her head or roll over.
Vision (VI Intervention)	1	1	0	2	1	
Fine Motor Skills Occupational (Therapy - OT)	1	1	1	1	0	

Each parent had a clear highest priority for her or his child; however, one mother,

Giselle, talked her way through the form and moved hearing, speaking and communicating into second place making feeding her first priority. Giselle qualified her decision by stating that “hearing is not her only need” and that she didn’t want her daughter, Sydney ending up in the hospital with a g-tube because they didn’t focus on her feeding issues. Giselle mentioned friction between her and the Teacher of the Deaf due to her priorities, “I think the difficulty was meshing priorities...we recognized that we could work on hearing, but it wasn’t going to help if Sydney was in the hospital with a g-tube because she wasn’t getting enough nutrition.”

The abilities of parents to prioritize needs and schedule visitors and appointments were clear and appeared to be satisfying to parents, both from how they focused on their ratings and comments. This satisfaction may have been the result of parents feeling some measure of control over circumstances. Two parents expressed satisfaction at the process of filling in the chart. “I think ranking them was helpful. To show...where we are,” expressed Peyton. As she filled in the chart, Buffy articulated her own awareness of her skill at managing scheduling when I commented on how neatly she had arranged Daphne’s schedule. When her daughter Daphne first came home from the hospital, she said had several interventionists visiting every day. She gradually moved all providers into a Monday through Thursday schedule, mostly mornings, when Daphne was better able to respond to therapy and so she can play with her father when he gets home from work in the afternoon. She said, “I don’t have anyone come on Fridays...I give her a three-day-weekend.” When I suggested she was good at coordinating everyone, “Have to be” she said, laughing.

The question “think of the time when you first chose to work with an early intervention teacher for deaf and hard of hearing children” was often met with a long pause or a blank look. Families did address this topic to the best of their abilities, but the overall impression was that the time of diagnosis was a time of bewilderment. Hannah said “My first thought was probably (pause) “What?” Parents answered this question in a variety of ways, but most answers addressed either *how* they connected with early intervention for their child’s hearing loss or *why* they chose the service. Jeannie said, “We were just guided in that direction.” Amara said, “I just wanted her to have everything.”

Getting in the Door

Guidance by professionals played a critical part in making the connection with intervention for hearing loss. Audiologists, ENTs and the Early Childhood Service Coordinator (EISC) through the Children’s Developmental Services Agency (CDSA) facilitated the connection with the Teacher for the Deaf (TOD). Buffy said that the “hearing doctor said it and they had it set up for us and then (service coordinator) kinda found something for us around here and stuff. And that’s just how we got into the program. Just through doctors and connections”. Jeannie said “we were just guided in that direction from the hospital”. Hannah said something similar, indicating that a high level of guidance provided her link to a Teacher of the Deaf for Ryder.

It was kind of thrust at us, which was nice because I had no idea of the programs out there or where to even begin with this. And you know our pediatric audiologist just went ahead and set us up with that and I was actually kind of

skeptical at first, I'm like, what is this, people will be coming in my home I mean I just....this was just a whole new arena for me.

Lainey described a visit from Nikki's service coordinator and someone else from the CDSA, "they came they explained everything about the services and things that were put in place". Erica Lynn tried to remember the sequence of events and described a visit from the service coordinator who provided a menu of services.

I can't remember how I even got started with them. I think I had a phone call and then they showed up one day...and said "ok, this is what we provide...would you like to have any of these services?" They explained each one. And that's when I was [she makes gurgling sounds and rolls her eyes] in my head about "my gosh, what next?"... you know, but then I said yes to (TOD) and I don't think they gave me too many options at that point. It was mostly that. I did have a lady from BEGINNINGS come later.

The Teacher of the Deaf was already involved with the family when the advocate from BEGINNINGS visited. Erica Lynn spoke very highly of the advocate from BEGINNINGS who told a personal story about her own son who has hearing loss:

She was able to give....he's 20 something now, he's probably getting closer to 30 now, but, same exact thing and she gave me examples of how he would speak and how he would get frustrated and how much better he did and how he is now as an older person making his own choices. That made me...that probably was the most effective thing that I went through with anyone because this woman knowed exactly...because she had a son who....and she was able to give me examples.

Even though it was a short brief example, it just put so much in my head that I was able to look ahead and be ok with it.

Peyton told a similar story about her encounter with the educator from BEGINNINGS. She directly stated that the quality of this visit lead to her willingness to entertain the idea of visits from the Teacher of the Deaf:

Well, I had a really, really wonderful lady come to my house. We sat and had a long conversation. She told me her personal story and it gave me hope. I walked away from that conversation with the hope that at some point I will be able to communicate with her and she in turn would be able to communicate with me. So that's kind of where the ball got rolling.

Two additional parents focused on the need to be able to communicate competently as part of their reasoning behind choosing early intervention for hearing loss. Jez said that Andrew “needs to be able to communicate. That’s paramount. You can’t get anywhere in this world if you cannot communicate”. Lars specifically said that the Teacher of the Deaf told them they needed early intervention because “she was stressing very much seventeen and how he’s going to be talking at seventeen and that the clarity is going to be determined now and that seems pretty significant.” Amara specifically said she just wanted everything that could help Jina. Amara said, laughing, “I told them I wanted everything. Anything that could help her...I wanted it all!” Lainey said she chose early intervention for hearing loss “because I wanted what was best for my child. I started working with (Teacher of the Deaf) shortly after I found out that Nikki had hearing loss”.

In three parents' descriptions, the connection with the Teacher of the Deaf either "just got set up" was "set up for us" or was "thrust at us". The other seven described actively choosing this specific intervention for a variety of reasons. The ability to communicate was mentioned by four parents as the driving need for early intervention for hearing loss. Wanting "everything" or "the best" for their children was how two parents described this choice. One parent stood out as having a more informed sense of choice in the matter. Giselle and her husband, each involved with early intervention in two other states prior to coming to NC, brought more critical experience about early intervention to their decision-making process:

We needed help understanding hearing loss. I understand early intervention, but my expertise is in the motor area. My husband, as a pediatrician, knows the medical piece. This was something new for us so we needed help. I knew the teacher of the deaf from [a different public school and county in NC] and we thought about enlisting her help because we felt that in the schools, anyway, services were good there. We also considered going back to DC. Because of Gallaudet and the Kendall School, we knew that the services would be excellent there in regard to hearing loss. But, [Teacher of the Deaf] came to us and she is very knowledgeable about hearing loss.

Table 3 classifies how each parent described their memory of how or why they began early intervention for hearing loss for their child. Each of the 10 parents responded.

Table 3

Factors Leading to Parents Seeking Early Intervention for Hearing Loss of Their Child

(n = 10)

Early Intervention was “Set Up” By Professional(s)	Parents Selected Early Intervention On Their Own Accord		
	Parents Saw Need For Child To Learn Communication	Parents Said They Wanted The Best Of Everything For Child	Parents Wanted To Learn About Hearing Loss
3	4	2	1

Although almost a third of the parents remember intervention for hearing loss occurring without much conscious choice on their parts, that doesn't necessarily mean that they were unhappy with the services. The three parents who said that intervention for hearing loss was set up for them were still working with an early intervention teacher of the deaf. Daphne received a home visit from the TOD every other week and had been for 23 months at the time of the interview. Angus and Ryder received weekly visits and had been for 14 and 16 months respectively. Two of these mothers also made spontaneous positive comments about the teacher of the deaf. The only negative comment about a deaf educator was made by Giselle, who most consciously weighed her choices for all interventions, even to the point of considering moving out of state. She felt that the TOD didn't understand Giselle's family priorities. Giselle also balanced her negative comment with a positive one indicating that the TOD was quite knowledgeable about hearing loss.

Working with early interventionists. An additional focus of the study was on analyzing parent responses to professional practice in the field of early intervention, particularly in relation to hearing loss, to help inform practitioners of what parents identify as being most and least helpful, productive and engaging.

All of the parents who were interviewed spoke of contacts with professionals either in interaction with their children or with themselves as parents. Some of the stories of encounters with medical professionals occurred prenatally or in the neonatal period when the children were still in the NICU, at the hospital or in other medical centers and offices and during the first few months of the child's life. Those were the months when health and diagnostic issues were at the forefront. These foundational interactions took place outside the home and were not as frequent as the home-visits by teachers, therapists and service coordinators.

Buffy specifically asked that I stay after the interview to meet Daphne's physical therapist, Sally. She indicated that this therapist was most important to the family, and the special need she identified as the most critically requiring intervention was physical therapy. She expressed a sense of continuity with Sally, saying, "she's been with us the longest, Sally has. She's been with Daphne pretty much since the NICU."

The ups and downs of working with professionals. During each of the interviews, parents had several interactions and impressions from working with many professionals – not just early interventionists, but providers from all realms of healthcare and early education. Each parent was directly asked to talk about particular instances in which an early intervention service went particularly well or did not go well. Figure 1 shows the number of positive and negative impressions made by families per interdisciplinary professional. The majority of responses were from questions four and five in the Interview Protocol (Appendix B) where parents were asked to talk about most and least helpful intervention experiences. Spontaneous comments about professional interactions that occurred at other times in the interviews were catalogued as *more*

positive or *more* negative, using key words such as “helped, was patient, connected, told me, listened” for positive flags and “didn’t listen, tell me or do” what I asked or needed or seemed to be “judging” for negative flags. In cataloguing these comments about parent interactions with providers by professional affiliation, medical providers and SLPs received the most negative comments. Medical providers also received the fewest positive comments. Families speak more about medical visits early on than later on in their child’s lives, so interactions when their child was very sick or being initially diagnosed may carry a greater burden of negative associations.

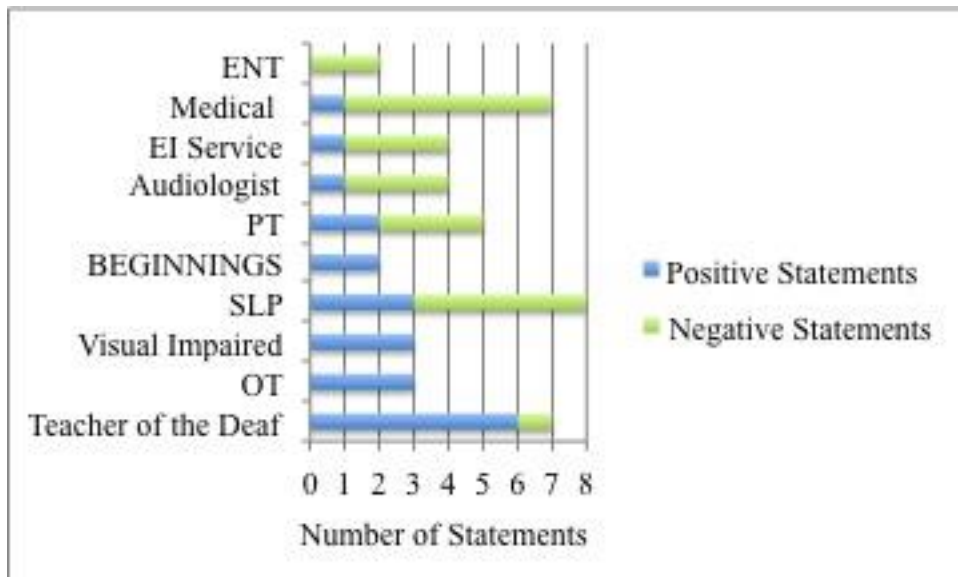


Figure 1. Statements by parents about experiences with professionals of varied disciplines.

Three types of providers stand out as having all positive comments; OTs, Visual Impaired teachers and the parent advocates from BEGINNINGS. The advocate from BEGINNINGS typically visits once around the time of the child’s diagnosis with hearing loss and then again at transition time, so their visits, although representing just one occasion for each comment, stood out as extremely constructive. The two very positive

comments by parents mentioned hope, understanding, and an encouraging glimpse into the future.

Teachers of the Deaf (TOD) also received very positive statements, with only one negative expressed by Giselle in relation to feeling pushed by the TOD to view hearing loss as a priority when the family felt otherwise. Positive comments centered around the teacher sharing information, being a “tremendous professional” and the value of “one on one instruction”. Erica Lynn mentioned several times that the TOD who visited with her and Junior became “a friend.”

Early Intervention – Adjustments and Barriers

Throughout the interviews with parents, it became clear that there were many “good” things about early intervention and treatments their children were receiving; however, there were also some difficult adjustments and barriers when trying to get treatment for their child.

The Stressors of Having a Sick Child

The stress of having a hospitalized and fragile child is compounded when parents are staying at the hospital with a sick baby, going back and forth to care for siblings, and/or trying to keep a job. Six families in this study had other children to care for while dealing with a sick newborn in the Neonatal Intensive Care Unit (NICU). Peyton and her husband had four older children to care for and Lars and Jeannie had three older ones. Four parents had two other children at home. Jez’s son, Andrew, spent five months in the hospital, moving from the NICU to the hospital’s pediatric “step-down care” when his medical needs became less intense. Jez spoke of feeling judged by the staff because she went back and forth to home and couldn’t always be there. She said, “Andrew is not my

only child. I have two other children and I have to work *-have to work-* and my husband has to work. I didn't have the luxury of staying at Ronald McDonald House."

All but one of the children in the study spent time in the NICU. The one who did not, Ryder, went home after what was considered a typical birth, but almost died when he was three months old. He spent time in the Pediatric Intensive Care Unit (PICU). His mother, Hannah, spoke of the ordeal of his stay in the intensive care unit in an induced coma on a ventilator while the doctors tried to diagnose his illness. He had a devastating blood infection due to a suppressed immune system secondary to cytomegalovirus (CMV).

Only three mothers did not have other siblings to care for at the time their child who had special needs was born; Buffy, Hannah and Lainey. Buffy and Hannah had no other children at the time the little ones in this study were born. Not only are Lainey's older children grown, but also she was not yet Nikki's foster mother at her birth. Most of the parents spoke of the time of diagnosis as confusing and "blurry". Jeannie said that her little boy, Angus, spent six weeks in the NICU because of prematurity and Down Syndrome. He came home with oxygen and when asked to talk about how she responded to his diagnosis, Jeannie frankly admitted, "the first six months is kind of a blur".

Jez, in recounting the months that Andrew was in the NICU, said that she just couldn't have stayed at Ronald McDonald house near the hospital because of her other children. Lars spoke about two competing issues: the difficulty of having a large family and the help other children provide: "If it's the last of a series of children its really a challenge. You can't ditch the other three. You can't sacrifice their lifestyle to such an extent." Lars also commended Angus's older siblings saying, "I think with the kids he

gets something different; a wider variety of sounds. I think it's a lot easier when it's the youngest. We've got three that are able to interact and they are not shy about it at all". Peyton, mother of 5, felt the drain of having a big family. "Of course you know I have 4 other children who are all in school. It's definitely been a trying time". She talked about the effect on her entire family, "It's really been an eye-opening experience for all of us and it's definitely been an adjustment to our family." She added, "And I kind of feel bad that I can't all the time give attention that one might need But between my husband and me, we do what we can do." When asked if she had been able to find any parent support groups, Peyton said, "I haven't had the opportunity because I have so many other things going on you know with the kids. I have not been able to reach out to any type of parent groups..."

Giselle and her husband finely balanced their three children's needs; "Sydney's needs are very important, but the other children have needs as well and we, as parents, want to meet all of our children's needs." She and her husband clearly had thought about how to best maintain stability for all of their children.

Then we had her brothers to manage. So we had to come to the realization that yes we do have a child with special needs, hearing is not her only special need but we also do have two other children in this house who also need attention. And so we finally got to the point where we were just, we will do what we can do, and um, that's it.

Working mom. Three mothers specifically said that they had to stop working. Hannah said, "I can't work because I'm at home with Ryder. He has all these therapists coming in and so many special needs that I can't work." Jeannie, who had been

homeschooling her older children for 10 years, decided to send two of her children to public school so she had time for therapies with Angus and his various appointments. Homeschooling was both her cherished work and an issue that affected two other children in the family. Peyton flatly stated, “It’s gotten to the point where I can’t work”.

Jez was able to keep working, in part, due to her husband and her father helping with the children and the fact that they had different shifts. Lainey was quite assertive with her employer and carved out time for therapy sessions with Nikki. She said, “my supervisor still works with me because she knows I have a medically fragile child. I feel like if no employer don’t understand that, that the problem lies with them and not with the family.” Her “team” was also acutely responsive to her scheduling needs.

Nevertheless, the fact that three of the nine mothers stated that they could no longer work, while only two spoke about what they needed to do to keep working, indicates the intense pressure on parents.

Professionals Who Don’t Help.

A recurrent theme in the interviews was hearing from parents the level of insolence some professionals projected when talking about or working with their child. Whereas professionals may have thought their comments were constructive, parents recounting of the events indicate that they responded with feelings of hurt, anger, and shame. These feelings, in turn, led them to distrust some professionals, often bleeding over into defensiveness or caution with other professionals as well. Parents value their child’s life and when they feel that professionals don’t value their child they perceive it as a negative experience. One of the first issues two families needed to face was the perceived encouragement from physicians and family to terminate the pregnancy.

She has a life! Buffy and her husband found out when Buffy was 14 weeks pregnant that Daphne had hydrocephalous and structural brain differences. Buffy spontaneously brought up this topic during the most open-ended interview question when asked what else she would like to share with professionals and other families. Buffy talked about how her doctors and her parents encouraged her to terminate the pregnancy:

Everyone was wanting us to abort the pregnancy and everything...and we just, we heard the heartbeatshe has a life...so we didn't, we just kept faith. When she was born, they only gave her a 20% chance of living past a week and now she's almost 2 so we are really grateful that all the little stuff, like the hearing and vision, is just part of who she is. She has everything she needs, the longer we can keep her.....

Buffy and her husband began the pregnancy with their first child with a sense that this baby's life was not valued by professionals and family members. Buffy indicated that her parents "came around" after Daphne was born, but they "moved off" and don't live nearby. The most consistent professional in Buffy and Daphne's lives was the physical therapist, Sally. She began working with the family immediately after Daphne came home from the hospital and was still with her at age 2. Although Buffy didn't overtly praise Sally, she did identify her as the therapist in the most positive early intervention event. Buffy also said that Sally had changed her schedule with Daphne several times to accommodate Daphne's changing needs. Most telling was that she specifically asked me to "wait around a little longer" so I could "meet Sally...she's been with us the longest". When I met Sally, Buffy introduced her and let Sally know that she had said good things about her to me.

Jeannie and Lars faced a similar situation in which their baby's life seemed devalued by professionals and the community. An ultrasound at 16 weeks gestation showed soft signs of Down Syndrome for Angus. Jeannie said that when they met with the geneticist "I felt like she felt we were dumb to continue. You know it was um, it was... a messed-up person, why would you continue..." the pregnancy. She mentioned pressure from another doctor during one of these prenatal visits.

He was the oldest one there. I would have thought he was in his early 70's and he had this look on his face and he said, "don't you already have three children?" You know and it was from that angle.

Lars, Angus' father, expressed a similar sense that professionals didn't value either Angus' life or the family's clearly stated choice to continue their pregnancy with Angus. He wondered how younger parents who had less experience might feel about what he perceived as a push to terminate from both the community and the medical profession:

I think a lot of them start to look at you like, you know, if you had a million dollars in the bank maybe this would be a wise decision to keep the child, but otherwise, its going to be such a horrible burden on you financially and its going to be a terrible burden of time with the other children if you have him and we kept hearing, "do you have any other kids"? And even today, people will ask me "Did you know? Did you know that he had Down Syndrome?" Like, "I'm surprised you had him if you already knew". It's the oddest thing in the world but I think that probably there's a law... I know I mean when we were sitting in the meeting with the geneticist, that um, she had a different perspective than I did, and the

geneticist herself looked like she was due the following week...she was huge.

But, you know, when you are carrying a child and someone is asking you if you are sure you want to keep it, uh, I guess that they have to ask, but it seemed like an interesting question at the time cause I don't know how many people might walk out of there going "gosh, I wonder".

Lars commented about how other parents, those younger or less experienced, might respond to being asked if they want to keep their baby.

You know when you are carrying a child, and again, we had the advantage of we knew people who had children who had Down Syndrome and we knew what wonderful children they were and this is not going to end your life but be a wonderful addition to it. So, you know, it was a lot easier. If it's your first child and they are young parents, its probably going to be overwhelming. Cause you have a lot of people telling you just how much its going to change your life.

These two families were the only ones whose babies' prenatal diagnoses came early enough in the pregnancies to be presented with the choice of terminating. Both families perceived the discussion less as offering a choice and more as encouragement to terminate. They felt this from the medical profession and within their own personal communities.

Hannah and her son, Ryder, worked with a PT assistant for therapy. According to what Hannah said, the PTA has a nephew who has cerebral palsy whom she talks about, drawing comparisons between Ryder and her nephew. Hannah thought maybe she did it to try to assure Hannah that she understood cerebral palsy or Hannah's situation, but it

seemed to have the opposite effect of alarming Hannah while refocusing the conversation on her own nephew.

Ryder has cerebral palsy too, and she'll tell us about how badly (her nephew) was made fun of at school because of his cerebral palsy and I just don't know why she tells me that because obviously that's a big concern for me... him going to school and being with other students. And she'll say stuff like that or she'll get irritated with Ryder. Her attitude is different than the other therapists. Sometimes she makes kind of insensitive comments that I really...she has no idea that she's making....she just doesn't have children in this situation so she just doesn't understand...so when the PT is really negative, it really gets me down and when I get down then I don't end up working with him as much as I should...so if they can be encouraging that makes such a difference.

Peyton made this compelling statement about the importance of encouragement. She emphasized that she felt she didn't work with her son as much when his therapists said discouraging things. Moreover, she stressed that parents are good at reading how much professionals care about them:

We can tell how invested they are in our child and how much they care and that just makes all the difference in our whole mind set. I mean if it wasn't for [speech therapist] I really think I would be despairing. But she has just been so encouraging. Any time I start to get down, I just think of her and I think of things she has said and that gets me going. And that is my biggest thing to therapists. If they can just realize how important they are just mentally for us, to keep us parents going. If they can just realize how weighty their words are.

Feeling judged and devalued. All of the parents who were interviewed made remarks that indicated they had a keen sense of who valued their child and who didn't.

Jez stated:

I just really wish that people would not frown on people who have disabilities. Just because they're not a perfect person in society it doesn't make them any less of a person. It doesn't mean they have less to contribute. But that's not something we can change. I have felt that from therapists.... and I have even felt that from the people at the hospital.

Erica Lynn confessed that she felt as if everyone was looking at her and appraising her child when she brought Junior in for hearing testing. She describes her feelings while in waiting room at a large hospital:

Then the audiologist out there one of them she come out she's thinking "we are not going to do too good with this one". I mean that was the first thought in her head cause he was screaming, he was unhappy, everyone was looking ...so just to go to a doctor's office with a child that's screaming, that's uncomfortable enough, I mean that's hard, very stressful. So we was already like *ahhhh* out of our heads, stressed-out...

Does not listen to me. When parents described times that intervention was least helpful or didn't go well, three mothers spoke about therapists either not listening to them or making comments that indicated that they appeared oblivious to the parent's wants or needs. Jez said that her son's speech therapist did not listen to the recommendations that Jez made from direct experience with her own child's feeding preferences and challenges.

And she wouldn't listen to you. I mean I would try to give her input, and she would not...it was just what she wanted to do.... When I finally got him so he would feed off the bottle, if she saw that he was taking his bottle really well, she wanted to take the nipple and dip it in applesauce and then stick it in his mouth. And I asked her...I said "I really wish you would not do that because I finally got him to like this and if you trick him and try to pull over something like that it's going to make it where I can't feed him with a bottle any more." Well, sure enough, she poked it in his mouth and he projectile-vomited everywhere. And it took me a day and half to where he would take a bottle from me again.

Hannah simply said that her son's therapist "doesn't understand" and makes insensitive comments that hurt and worry her. Giselle indicated that there was some friction with Sydney's Teacher of the Deaf. Giselle felt she did not listen to her family's main concerns.

I don't think it was so much the service as it was the approach. It was the parent educator services. And I think it was just more so the expectation of being what we needed to do as a family and what (Teacher of the Deaf) perceived as being the big priority. And for us at that time the priority was not her hearing and listening. Our priority was she's not gaining weight, she's losing weight, so all around the priority was that we needed to put weight on her. But there was this big push that we needed to do this and we needed to do more of that, and we were like that's not even a priority for us. So I think the difficulty was meshing priorities.

Parents also described when doctors didn't listen to them. Amara, who repeatedly

and to no avail, asked doctors to help her understand how CMV might affect her baby while she was still pregnant with her, also had difficulty being heard after Jina was born.

Once she got to like eight or nine months she started choking really bad, and started...she chokes on her saliva, and I was telling the doctors and they was saying it was because she was teething ...and I was like “no, this isn’t just teething”. So they finally did the test and found out that she was aspirating when she was drinking.

I can’t handle the unknown. Jez, Amara, Peyton and Erica Lynn each expressed frustration at ambiguous diagnoses or lack of information about their child’s needs. Erica Lynn had ongoing concerns about lack of information regarding her child’s hearing loss. She repeatedly said, “I can’t handle the unknown.” Her son, Junior, has ANSD, which is marked by fluctuating hearing ability. His diagnosis, not confirmed until he was eight months old, was complicated by the fact that his type of hearing loss cannot be accurately measured with objective electrophysiological hearing tests.

It is not uncommon for a child to be referred from their hearing screening or rescreening and then go to local ENTs and audiologists for diagnostics. Junior started his diagnostic experience closer to home and was referred on to several different audiologists before arriving at a large pediatric hospital practice that successfully diagnosed him. Erica Lynn describes several hearing tests that were questionable in her mind, “the hospital’s machines were messed up so when they finally attempted to take his hearing test, one failed and the other one passed. But they weren’t sure, so they recommended we go to [name of bigger hospital].” Then, at this subsequent visit, he “screamed and fought the whole time and the attachments kept falling off”. Erica Lynn felt she hadn’t known

what to do at this visit. She said, “They really didn’t recommend what I should have done to better prepared him...”. For their following visit to an even larger hospital with pediatric audiologists, she specifically requested information. She said that after asking, “I knew what to do. I talked to them and asked what do we need to do?” With the information provided about how to prepare for ABR testing, she and her husband got a hotel room near the hospital, spent the night there and “deprived him of food, we deprived him of sleep...I mean we suffered.” Ultimately, the family learned that their eight-month old had a hearing loss that is called Auditory Neuropathy Spectrum Disorder (ANSD). This was a late and traumatic diagnosis that did ultimately lead to early intervention for hearing loss a month later, when Junior was nine months old.

Erica Lynn described her response after finding out that her son had ANSD and vision problems, both of which were diagnosed with no clear prognosis, felt helpless.

I was just so heartbroken. But it was for his future (beginning to cry again) it wasn’t for the moment. It was for his future because I didn’t know. And like I said, I’m OCD too, and if I’m not prepared for tomorrow, I may not make it today. If I’m not prepared for tomorrow I’m not gonna make it through my day.

The inability to make a clear diagnosis in a timely fashion caused several families to move to different audiology practices. Erica Lynn, Giselle and Jez moved from local audiologists to the larger practices that had pediatric ENTs and Audiologists. All made positive comments about these moves.

Amara went to her doctor for the flu while she was pregnant and tested positive for CMV:

She was like “I’m gonna get you tested for CMV”. So they ordered the test and it

came back positive so they moved me to the high risk section of the doctors' office, which wasn't any different...but I just wish there was just another way they would have just went about it, period. Like I didn't, they didn't explain anything... they just handed me a print off saying some of the things it could do or what it was and how you got it, but that was it.

Amara was told to wait and see. "They said you won't know nothing until you...we can't tell you nothing, you just gotta wait till you have her to see." She was so concerned that she did her own research on-line about the effects of CMV, but had no real support while she waited and worried. Afterwards, she found that the doctors had known that Jina's cranial ultrasound did show effects of the CMV but the doctor never shared that information with Amara:

And they had seen the bleeding on her brain from an ultrasound they had done, but I didn't find out about it until the day that they were doing my C-section when he came in and asked me about it...and I was like "well what?" He was like "I can't really tell you because I'm not the one that gave the ultrasound"...I was like "well but you're the doctor and you read the ultrasound".

Amara stressed that she did ask questions and repeatedly pursued answers throughout her pregnancy but was only given a printout about CMV.

But just explain to the patient the whole you know...what could happen. Don't just say "wait till you know"...let them know all the side effects and anything like give them a support number. I was terrified cause I went on line myself and was googling everything and you're looking at all this stuff about kids with feeding tubes and dying and all this stuff and ...it was hard. Like you don't have any

support they didn't give you any, you know, just give some kind of information. Amara, when asked what she wanted professional to know, emphasized the intense need for information that she, as a parent, had about her child's condition.

Upsets my child. When asked about times that early intervention didn't go well, Peyton described a feeding session that didn't go well. Her empathetic connection with her daughter is palpable:

The speech therapist was out and she was trying to feed Callie and Callie wasn't very cooperative that particular day. Callie chokes a lot. And this particular day she couldn't seem to feed Callie, because she was choking so much. At that point I just kind of stopped the feeding all together because it wasn't helping Callie and of course you know how you feel when you choke. She was just doing it constantly. So I just kind of stopped it. So that was probably the worst experience we've had.

Two parents describe specific instances in which they stopped working with a therapist due to the way that professional worked with their child. Jez mentioned that she "critiqued "the people her son worked with and "the ones he didn't work really good with, I took away"!

A case in point, was Andrew's speech therapist:

His speech therapist, who was supposed to help with speech and feeding, she kept trying to force a cup on him. And I kept telling her, "don't push...don't force him into a cup like that...don't hold it up to his mouth and make him try to drink out of it, it's not going to work." Well, to this day, and that was almost a year ago, to this day, he won't put a cup anywhere near him.

Peyton, whose daughter, Callie, has neurological complications, briefly mentioned that she is no longer seeing Callie's original neurologist. She made an appointment with another neurologist "to see if she has a better outlook than the guy she was going to".

Financial Obstacles

Giselle's little girl did not qualify for Medicaid and she addressed the impact that this has on childcare and provision of services in her area. She specifically mentioned a lack of the "therapeutic" childcare centers that she was familiar with in another state where she and her family had previously lived and worked:

The way early intervention was funded is that if your child is in the early intervention program and they had an IFSP and they had services, you did not pay for daycare. And so, that in and of itself was a plus. So there was no barrier to children with disabilities having access to other children who did not have disabilities. So that was one thing but the other thing is that I recognize that I could have gotten, if there was a center like Kendall, not with children where children who are deaf or hard of hearing were housed, but where they were supported and their families were supported, I feel it would be a better system. They needed to provide comprehensive services for the entire family. And so, with that, sometimes here the system seems very disconnected. Like you know, (here) deaf and hard of hearing and vision services did not originally fall under infant-toddler services, whereas in DC, that's part of the Infant-Toddler Program. We have our vision specialists and we have our specialists in deaf or hard of hearing....Now that they've merged and they are working together it's a little

more comprehensive or cohesive. But even still, just when we are looking for resources and asking people, we realize that it's piecemeal. We have to ask the right person to give us the right information because not everyone knows.

In addition to the impact work demands for families, insurance emerged as an important support or barrier to early intervention services. All of the parents who brought up financial issues had private insurance. Hannah pointed out the disparity between those who qualified for Medicaid and those who do not.

My husband works, but he makes too much to get Medicaid or disability benefits or anything like that. So I guess that's our biggest concern is just the money.

We're on a sliding fee scale, which is great, but apparently several years ago, it was free, everybody was free until they were 3 years old.

Lars talked about the overwhelming bills they received after Angus got out of the hospital and the anxiety they faced worrying about how to pay them.

...this deals strictly with money and this is an aspect that cannot be ignored...we were starting to get hit. I mean any kind of extra care ...but I think it was the hospital we were in they didn't mention to us anything about Medicaid. We had to hear it from a friend and they said "oh no no, he should qualify 100% for Medicaid". And we had to chase them around for a while. ...they were not helpful. I would say that probably for a lot of young parents, man, that would be hard. They might go for months without having a clue that a lot of these bills should be taken care of. They really are taken care of, retroactively; they take it all the way back to the beginning, but we were pulling our hair out wondering, whoooo, how we going to do this?

Hannah said, “sometimes I feel like he’s just not getting everything he needs because we just can’t afford it.” She specifically mentioned that Ryder needed “a sit-to-stander and our insurance denied it. But if we were on Medicaid, they provide that. I just wish there was something more for families in our situation.”

Giselle said, “We were paying out of pocket for everything. No one had told us about the program that funds the first set of hearing aids and covers ear molds and batteries. We just needed information and the audiologist at (name of facility) provided that for us in a very professional and comprehensive way”.

Erica Lynn, whose son, Junior, had transitioned from Early Intervention to the Public Schools, spoke of her insurance issues.

We have had private insurance the whole time. We then and still have a high deductible plan. For instance we had to borrow money from a family member to purchase Junior’s hearing aids, which was over one thousand dollars just to finish off our deductible. Still a better number than being over \$3000 full price for the set. Then for some weird reason our insurance turned around and paid what we had already paid and instead of refunding us the money, the hospital applied it to one of Junior’s big bills from his ABR testing, which was great. Honestly, in the short run of all that, and the people there at the hospital also made the comment, we would almost have been better off without the insurance. With certain fundings and programs, Junior could have gotten a one-time funding to have paid for his hearing aids, and help with bills.

A new law in NC (North Carolina Gen. Stat. §58-3-285) has instructed insurance companies to cover at least a portion of the cost of childrens’ hearing aids, but certain

companies with out of state corporate offices, do not necessarily have to comply. As Erica Lynn says, “why do they pay for something they say they don't pay and then don't pay enough”. She did say that Junior’s Teacher of the Deaf and “our CDSA worker worked considerably hard and done a lot of research and phone calls and carried a lot of that headache for me when I couldn’t have done it all by myself.” She concludes her commentary on insurance and the financial burden of having a child with special needs.

Whether or not a family has insurance, there is a lot of paperwork, worry, and headache with the money part of the whole deal, because there is a very considerable amount of money involved. The impact that financially having a child with hearing loss is almost unbearable. Before we talked about emotions because of the child itself, but when you add the financial part and insurance to the mix, wow! That's a part of it I really work hard to not overly stress myself with.

Jeze, whose child was on Medicaid and then under a private plan, was able to compare provision of services under Medicaid and under private insurance:

When he was on Medicaid, there were so many people, so many people coming out here they were blowing the hinges off the door. I can definitely tell a difference between when he had Medicaid and when he didn't. I can definitely tell a big difference because it's like nobody wants to come out.

Only one parent really focused on financial and care aspects of the distant future. Lars spoke of his concerns about financial and daily living support for Angus as he and his wife age.

The one thing that I do think about, you know, because he does have Down

Syndrome, and probably every parent who does, is if he outlives us, because very often it's the result of the parents are over 40, they're beyond 40, and they are thinking that maybe they will die before the child does...that's something that pops up, um and you are thinking of providing financially and whose going to be taking care of my child after I'm gone cause they may need that type of care and attention forever. That's daunting. Eventually you'll think about that and maybe it'll take a year and suddenly it dawns on you and you start adding up the years and we might not be around that long.

Distance and Travel Needs

Living in a rural area compounds the issues with providers as there are fewer available therapists in remote areas and travel is not reimbursed by insurance or Medicaid. When families did have to travel to appointments, distance, expense and competing family needs sometimes got in the way. Erica Lynn, who does live in a rural area, talked about missing appointments when Junior was little.

He was supposed to go up to a year. Well I was out here and had an emergency with my mother-in-law and couldn't make it to the appointment. I never made another appointment. I mean insurance was paying, we was paying out of pocket. That was hard too.

Additional expense is a huge disincentive to pack a fussy baby into a car and drive for long hours to a specialist. Erica Lynn described the expenses.

You add up deductibles, gas, food sometimes a place to stay, which the Ronald McDonald house being a free place was the best thing ever invented, but sometimes if you have to get a room, that alone is a lot of money.

Having Professionals Come to the Home: A Mixed Review

Some parents had concerns about home-visits. Erica Lynn said, “the first thought that came through my mind was a strange person coming to my house once a week and with my little one ‘how am I gonna keep this house clean?’ ...that was the first thing”. But most of the families expressed relief that they did not need to travel to providers.

Hannah was initially uncertain:

I was actually kind of skeptical at first, I’m like, what is this, people will be coming in my home I mean I just...this was just a whole new arena for me that I just hadn’t experienced so I was kind of skeptical at first, but then you know, once everybody started coming out and we realized how helpful and what a wonderful blessing it was for them to be coming in our home every week.

When asked about people coming to her house to provide services, Jeannie said “that was great!” and told about when she was a child having to travel with her mother to her brother’s many appointments. Her husband, Lars, also said that one of the factors that makes early intervention services go well is that it comes to them; “It comes to us, for one thing. We are not going anywhere which I don’t think that we would be able to fit a whole lot of that in...it would be very difficult”. Jeannie and Lars were not in a rural area and lived closer to providers than most families interviewed, but their family needs made travel difficult.

Early Intervention – What Works

While parents expressed their frustrations and stressors in dealing with their child’s hearing loss and working with professionals in the community, they were also quick to point out what *did* work well in their experiences.

Positive Interactions with Professionals

Erica Lynn had reservations about working with a teacher of the deaf, saying, “the first thought that came through my mind was a strange person coming to my house once a week” and that having a teacher weekly involved keeping the house clean and was “a responsibility. And it’s going to be long term.” Nevertheless, she accepted early intervention. By the time Junior aged out of early intervention, Erica looked back at the experience positively:

We had fun, it helped Junior, and we made a great friend. Even though I had all these negative thoughts from the beginning, I never knew our teacher as a stranger. I would have cleaned our whole 2 ½ acres off for her, cause she was well worth it.

Erica Lynn also provided written answers to the questions in the interview protocol. This is what she wrote about her son’s teacher of the deaf. She underlined some parts for emphasis, “I would not have done as well on my own and Junior may not be who he is today with his good abilities without our teacher, our friend that we truly miss”.

Being heard and valued. Hannah related that Ryder’s SLP, who is also trained as a Deaf Educator, is trusted because “it’s obvious that she cares about him...that he is her main focus when she is here.”

Parents often mentioned how their providers met their expressed needs, particularly when it came to scheduling visits. Buffy explained how the PT, Sally, changed her schedule to accommodate Daphne’s changing moods after she began having seizures. She also said, “everything’s just kind of working and if things didn’t we work

we just kind of sat down and figured out another time”. Lainey also spoke of her team as being very responsive.

When they would come was based around my work schedule. I had to get them in when the times I got off work. So I could make sure I could get Nikki when she needed to be there so I could be there with her while she was going through the therapy so if there was anything I needed to know, anything I could be working on with her I would be there and I would know the things I needed to do to incorporate it in her life so she could learn it more. *From me. Because I'm the caregiver!* (Her voiced emphasis is italicized to reflect her tone)

Educates and provides information. Hannah spoke very highly of the education provided by her son's SLP. “And just everything that she has taught us...I don't think we could have a better person. She is so knowledgeable, she is just an angel.” Erica Lynn, whose son, Junior, was initially cautious with the teacher of the deaf, said, he finally accepted “his teacher” but that “even before that, (TOD) helped me. She taught me...”. Erica Lynn also spoke of how Junior's TOD and case manager worked together to find information for her about funding Junior's hearing aids: They “worked considerably hard and done a lot of research and phone calls and carried a lot of that headache for me when I couldn't have done it all by myself.”

Works well with their child. Lainey, who expressed positive views of her daughter, Nikki and shared her pride in their IFSP “team”, saw the benefits of hard work in physical therapy sessions.

Most of the time it was hard seeing Nikki trying to do things. And maybe sometimes I might have thought she was getting pushed a little too hard. But I

knew she had to do it. And I knew she could do it. But just to see your child get frustrated and aggravated because, you know what I'm saying, because she didn't feel like she could do it. So my most aggravating part was seeing my baby struggle. But it made me happy and joyful when she did it. So all the hard work and the struggling I had to see her go through, it paid off.

Peyton spoke highly of Callie's vision teacher and mentioned a specific session where Callie showed intentionality when this teacher used an engaging ipad application:

And this particular one she has is the xylophone. It's really bright. It's really loud. So Callie would essentially reach out and hear that every time she reached out she would hear it. So (interventionist's name) would try it on different angles she put it on the side of her instead of directly in front just to see if it was an intentional thing that she was reaching for it and Cally would find it to her side. I mean, like I said, she's most of the time stretched out in front of her, but she would find it by her side. It was really, really awesome. I was almost in tears. But that particular session that day had to be for me the greatest thing that happened since she's been born.

Three mothers specifically mentioned the patience of therapists in sessions that were shared as being helpful. Jez said that Andrew's OT was "very patient and she took her cues from Andrew. She wasn't trying to...she would push him to a point, but she'd let Andrew lead." Hannah spoke of her son's SLP, "She is compassionate and that she is trying to help him and she seems like she just understands him. And it's obvious that she cares about him. That he is her main focus when she is here." Erica Lynn talked about how patient Junior's teacher of the deaf was in waiting for his acceptance:

and then one day, (TOD) come and he was just sittin', kinda quiet like he is now, just looking off into space and just watching her talk and wondering "...ok does she have a bag with good stuff in it ...I'm waiting for what (teacher) may have".....and she come out and I think she had a new song or something that day and she had to take off with things...I mean it like if you have to wait on Junior you may get nothing done. She took off with it and he just all of a sudden latched on to her...went and jumped in her lap and sit with her and from then on he finally accepted (teacher) ok this is who you are and this is what you make me do and I'm gonna do it. So, and then they become best friends.

Seeing progress. "Compared to where he was this time last year or two years ago, he's doing extremely well." Jez was able to look back and see that Andrew had made progress. Lainey mentioned progress in relation to a difficult session with a therapist, but portrayed the difficulty as being worth it. "When she was on the walker and she wasn't on the walker any more, she was walking on her own, we had to start with new goals." For Peyton, seeing Callie make a clear choice by reaching for the xylophone on the i-pad was "the greatest thing that had happened since she was born". Amara mentioned the milestone of Jina sitting as real progress, "I think seeing her starting to sit up is really when I you know seen it being a lot of help". Seeing progress gave families hope and allowed them to set new goals.

Parents with Prior Experience

Lars and Jeannie each had prior teaching experience. Lars teaches high school "and there are exceptional children all over campus and there must be seven children and

young adults with Down Syndrome that are on campus that I routinely bump into.”

Jeannie had homeschooled their older three children for the past 10 years. They also had friends and people in their church who had children with Down Syndrome. Lars mentioned directly experiencing what “wonderful children” they are prior to Angus’s birth. Lars attributed the experience he already has as a parent and a teacher in helping him appreciate Angus for himself. Lars said, “ I don’t look at him and think ‘child with Down Syndrome’ or ‘child with hearing impairment’. It’s just Angus and that’s what he does and he’ll just be different like the other three are different.”

Giselle and her husband each work with very young children; Giselle in early intervention as an OT and her husband as a pediatrician. Giselle specifically mentioned that, “I understand early intervention”. Jez works as a nurse and Lainey went to school in a medical-related field during the time that she began to foster Nikki. First time parents like Hannah and parents whose experiences do not directly inform their ability to deal with their child’s special needs describe feelings of being overwhelmed as they tried to cope with their new and unexpected circumstances. Peyton expressed this feeling when she explained, “I didn’t even know prior to this that this thing even existed. ...I didn’t even know what it was ... It’s really been an eye-opening experience for all of us and it’s definitely been an adjustment to our family.”

Faith

As parents talked with me, some mentioned hope or faith as factors that affected their responses to their children’s special needs. Faith and God were mentioned several times by parents and seemed to provide a bulwark against grief. Buffy said, “I mean the way we look at it that’s the way God wanted her so..... that’s the way she’s gonna be no

matter what, and everything. She also asserted that “whatever happens happens...(you) have to keep the faith and have to keep hoping”. Later in the interview, Buffy shared that she felt guilty about Daphne’s condition because she drank before she knew she was pregnant. But she again quickly emphasized “that’s how God wanted her to be and she has all her chromosomes and blood cells and everything. They actually don’t know how and why she developed hydrocephalus....It’s just that something that happened.” Erica Lynn, wrestled with being angry and realized that anger is a form of grief. She described this confusing feeling, “I don’t know who I was angry at....I wasn’t angry at Junior for being that way, I wasn’t angry at God. There was no reason to be angry at him because there’s a plan for everything.” Erica Lynn explained dealing with these feelings:

You just want to get it over with. And once you get it over with, you can move onsomebody said “give it over to the Lord” and I said, “no, I want to be mad about it for a while”. Like if I don’t get mad about it ...it will take that much longer and I’ll have to deal with it again...no...., I’m not going to just give it over and give it up and think everything is ok. It’s not ok and I’m mad.

In opening up about her anger, refusing to internalize it into paralyzing hurt or grief, she instead let it motivate her. Parents who were motivated and proactive regained some control over unexpected circumstances. In fact, several parents, when asked what they would want others to know, directly advised other parents to take control, ask questions and make sure that their ideas and voices were heard.

External Support

Adding to the support provided by professionals and other parents, family members helped parents keep their jobs or daily activities running smoothly. Jez

mentioned that her father takes care of Andrew, filling the gap between her and her husband's different shifts since she works nights. "My husband works first shift and when I'm sleeping, my daddy has him". Lars said that his wife and the kids work on listening and language skills and physical therapy with Angus. "We've got three that are able to interact" with him. "It's a lot easier when it's the youngest".

Financial Support

Families whose children had Medicaid did not talk about financial burdens. Their therapies and equipment were not financial stressors for them. Lainey said "she has Medicaid, yes... And I thank God for it!"

The services of the Teachers for the Deaf are still at no cost to families who have private or no insurance in NC. The Sensory Support Program, which covers Teachers for Vision and Hearing, did begin to bill to Medicaid beginning in 2015. The EDHI program also funds the first set of hearing aids for newly diagnosed infants and toddlers in NC. Both programs help support families who have 0-2 year olds who have hearing loss.

Advice from Parents

Throughout the interviews, parents often reflected on what they would do differently or what they wished was available to them.

Advice to Professionals

Amara stressed the need to provide support and information. Hannah talked about the importance of those therapists who visit so frequently. "We can tell how invested they are in our child and how much they care and that just makes all the difference in our whole mind set." She also specifically spoke to case managers through the CDSA about needing information.

What I would say to case managers...I mean she's obviously more knowledgeable about that than I am and it would be great if they could bring that to our attention of just other things that could help us out because she's really my only resource. Otherwise, I'm just clueless about anything else about like CAP-C and programs like that.

Giselle, who had the most system-oriented perspective, said she wanted more inclusive therapeutic childcare centers and spoke at length about her view of North Carolina's fragmented early intervention system. She also advised case managers to send experienced providers to families: "Do not send a new grad to the house. We will kindly show them to the door".

One parent had the experience of working in early intervention in DC and NY, giving her an exceptional perspective. Giselle felt that Early Intervention Services in NC were fragmented in ways that impact the care children and families receive.

I worked in the early intervention program and so I knew what services were available and I knew the intensity of services that children got. One of the things that has frustrated me in North Carolina is that with early intervention for the deaf and hard of hearing now moving under the Infant Toddler Program, and the model that they follow, I don't always agree with how services are decided or how the intensity of services is decided. Just because I know what children in DC get. And I know what children in NY get. But on the flip-side I appreciate the fact that they have a system in place that catches children at birth. I appreciate that there is a system in place that financially does not limit or impact the child's ability to get

their first set of hearing aids. I think those are good. I think the service delivery piece...we did not always agree with.

Advice to Other Parents

Parents suggested to others where they might find reserves of strength and persistence. Jez said, "It doesn't really seem that bad now, but when you think back and think about certain things that happened, you think 'oh my God, how did I get through that?'" She specifically tells parent to have "patience, patience. Every child moves at their own pace." She also advises parents to stand up for what they want and know: "don't be afraid to state what you feel would be a better way to come at a problem." Buffy too, recommended persistence. "Just have faith. Don't give up. Just stick with it and don't give up." Erica Lynn said something similar, "Never give up. What you are willing to put in is what will truly shine from your child. We don't wake up one morning as a genius. Frustration may be today, but progress is tomorrow." Lainey recognized that raising a child with special needs is work but felt that parents could work with their team and "put the child's needs first."

What parents said to other parents was often encouraging, hopeful or focused on ways to manage life with a child who has special needs. Jez, laughing, advised parents to "take life with a grain of salt." She said, "life is just too short to make mountains out of mole hills. But, it is extremely hard sometimes. Especially when it's dealing with your own child. But it will all work out". Lars told parents to "be proactive. Really. You know, make phone calls, talk to people, wonder" why things haven't happened. Jeannie stressed how difficult it can be to keep hearing aids in. Buffy also spoke to other parents:

Just have faith. Don't give up. Just stick with it and don't give up. I mean we

could have ...when we found out, everyone was wanting us to abort it and I mean everybody just was and we just ...we heard the heartbeat...she has a life...so we just stuck with it and... whatever happen happens..... keep the faith and keep hoping.

Lainey gave advice to other parents about the importance of participating in their child's appointments and therapies. "When it comes to a child'sappointments or anything like that, I think every parent should always be there so they can know exactly what is going on with their child.....I need to be the first to know what's going on with my child."

Erica Lynn said this to other parents.

You have to go through your feelings and just be done with it so you can move on to the next best thing. So, that's another recommendation. Just get it out. Get it out at the beginning. Don't try to forget. You can't forget. It's gonna be there. It never goes away..... my heart's going to be broke for him, forever, until there's a day that it just goes away on it's own.

In her written response to the same question, Erica Lynn specifically addressed this to parents. "Note to parents: Never give up. What you are willing to put in is what will truly shine from your child." Jez also talked to parents about standing up for what they know and asking about what they don't.

And parents; don't be afraid to state what you feel would be a better way to come at a problem....If you have questions, don't be afraid to ask them. And keep asking your questions until you get the right answer or the answer that suits you. Don't just take "no" for an answer.

Peyton stood out as a parent who spoke to everyone expressing the intense difficulty of having a child with multiple special needs. Her words resonate

Because you never really know about this thing, unless actually going through it. I never expected that I, or any child of mine would be in this particular position. I honestly never even gave a second thought to those...it gave me a...once this all happened to us, it gave me a totally different and new perspective on caregivers and those who take care of mentally challenged people, be it children or adults or...(deep breath). ...Like I said, there are no words. It's not easy and it makes you, well me anyway, a lot more humble. And when I see other people I can actually relate, whereas before, I couldn't. You know, you can always sympathize, but when you can empathize it just has a much more profound affect.

CHAPTER FIVE: DISCUSSION

The purpose of this study was to describe how parents experience barriers and facilitators to participation in early intervention specific to their child's hearing loss when their child has additional special needs. I sought to portray this experience through parents' reflections. As I immersed myself in the stories shared by parents, I looked to themes emerging from parents' voices that speak about their current situations and acknowledge that, although these findings do not generalize, they provide useful insight and might be helpful to parents, professionals, educators and policy makers.

Parents who shared their experiences were frank about their experiences with diagnosis and intervention for their children. Although I didn't stress that I am a teacher of the deaf, they knew and nevertheless were candid when they prioritized intervention needs for their children. This finding, in itself, provides critical information that can lead to an opportunity for professionals to more fully engage parents in intervention targeted to a child's communication needs.

Research Questions and Answers

These are the research questions for parents who have babies with hearing loss and additional special needs.

- What factors or characteristics caused them to delay or to avoid participation with early intervention specifically to address hearing loss for their children?
- What information or interactions caused them to engage with and continue with early intervention for their children's hearing loss?

These questions were answered multiple times across several categories of data. Data

ranged from the reported time between birth, screening, diagnosis of hearing loss and inception of early intervention services for hearing loss to the expressed feelings of the participants regarding screening, diagnosis, intervention and family needs. Data also included parent prioritization of interventions for their children's special needs and their perceptions of various professional services and interactions.

The themes that emerged are visually represented in Figure 2, which represents the percentage of parents who commented about each of them. Comments about Early Intervention Hearing Specialists include Teachers of the Deaf and the Parent Educator from BEGINNINGS. Comments about medical and other professionals include physicians, audiologists and other therapists in the fields of Occupational Therapy (OT) Physical Therapy (PT) and Speech and Language Pathology (SLP).

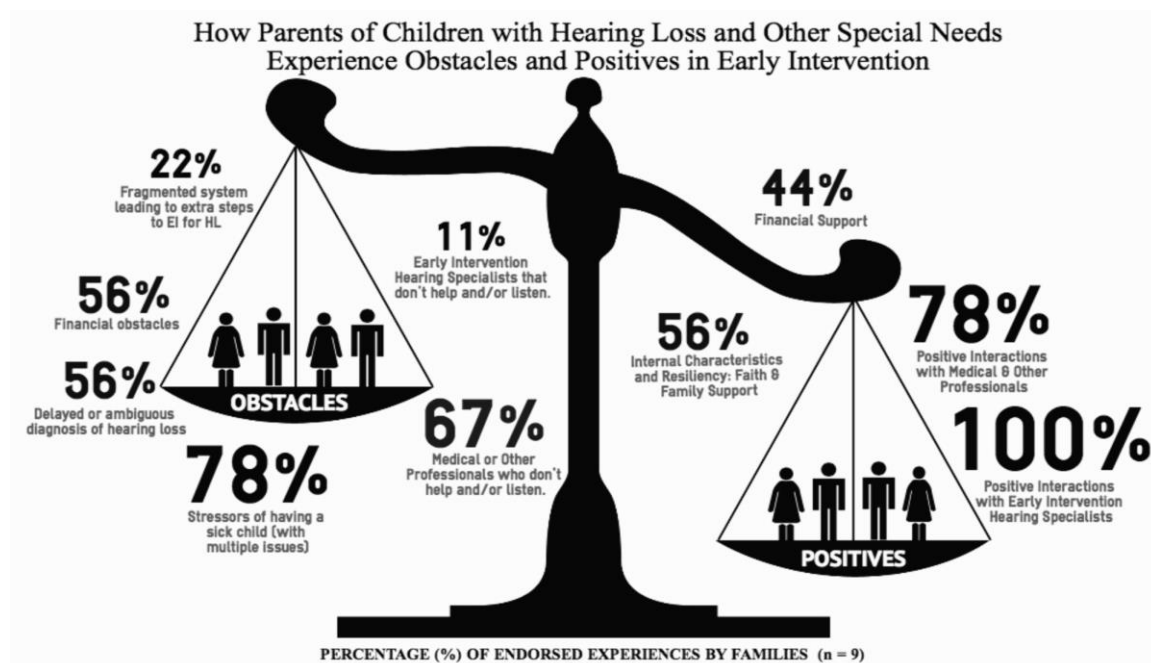


Figure 2. Parents' experiences with obstacles and positives in early intervention.

All of the parents represented in this study had chosen early intervention for their

child's hearing loss. When looking at the "scales", positive encounters with all professionals are greater than those in which professionals don't help or don't listen to parents, and that helped offset other family stressors. Encounters with professionals are clearly important factors in parent choice in early intervention.

- Parents' adjustments to the diagnosis of hearing loss are complicated by stressors associated with their child's additional special needs and co-occurring ambiguity or delay in the diagnosis of hearing loss. Families find strength in information, experience, faith and support.
- Professional practitioners who don't help or listen to parent needs can disenfranchise parents, whereas positive partnerships with professionals are treasured and kept parents engaged and hopeful.
- Costs are an obstacle to children receiving early intervention and a source of stress for parents. Financial support for hearing equipment and early intervention activities strengthens the family's ability to participate in their child's progress.
- The early intervention system is interconnected from the greater social policy to individual professionals' relationships with families. The child and family are in the central position and affected by the system around them (Bronfenbrenner, 1979). The ecology of the system can facilitate family-centered practice in EI or create barriers.

Question 1: What are the Barriers to Early Intervention?

Parents identified several barriers to engaging in early intervention for their child's hearing loss. Many have been previously documented in the literature and are referenced.

Delays in screening and diagnosis. Parents describe several instances in which their child's hearing screening was delayed, repeated or the child's ultimate diagnosis was ambiguous. Young and Tattersall (2005) found that communication from hearing screeners and audiologists impacts parents' understanding of the necessary steps to diagnosis and intervention and that these messages need to be carefully tailored to each family to assure understanding. Giselle said, "At first we didn't think we even needed to follow up on her newborn hearing screening referral. We thought it was just fluid in her ears." Another said, "In the hospital she did fail the newborn hearing screening and they was saying don't get worried um it may be cause her ears she was really small". Not getting a diagnosis quickly was intensified by a statewide dearth of pediatric audiology practices, a repeated theme in the literature (ASHA, 2008; Shulman et. al., 2010). Many parents reported that the best pediatric audiologists were a distance away and travel to these providers created financial expenses such as gas and lodging, as well as the logistical costs such as family-care and work. Hannah, Giselle and Erica Lynn reported the frustration of visiting more local audiologists before finding a pediatric practice skilled in diagnosis and treatment. Jez said, "For the hearing thing, you call and leave a message and no one ever calls you back...that's where you have to go.... No one else around here does children's hearing aids. I'm kind of in a rural area." Erica Lynn felt she still didn't have clear answers from the audiologist, "They were so confused...even the second appointment, the third appointment, the fourth appointment....even now we are still waiting."

Emotional overload and exhaustion. When a newborn is diagnosed with a special need, it can be a confusing and/or frightening time for new parents. The confusion

and fear may be increased when a newborn has multiple health issues and is in the Neonatal Intensive Care Unit. The exhaustion experienced for these parents during the first weeks with a typical neonate was compounded by medical needs, worries about their infants' health and survival, and lots of information being "dumped" on parents "all at once." It was clear from talking to these parents that the severity of their child's physical and multiple illnesses – and sometimes worry over their child's survival – resulted in high levels of stress that most of us will never truly understand. With this level of stress, day-to-day coping was compromised. The confusion and exhaustion parents feel during this time is evident as they speak of their response to the diagnosis of hearing loss and when they try to remember exactly how they chose early intervention specific to hearing loss. Parents reported that they didn't understand the early intervention system. Most parents were not prepared for a newborn with special needs and had no previous education about birth problems and ongoing special needs. These parents were exhausted and emotionally overloaded the first few months after their child's birth. Many parents remembered little about choosing services and providers for their child, "the first 6 months is just kind of a blur. I can't really remember...". This was intensified by their children's significant health and developmental challenges and the need to prioritize those needs. Although parents described feeling sad, ongoing exhaustion is common. Green (2007) characterizes this eloquently in *We're tired, not sad*. Green's interviews of mothers suggest that parents perceive benefits in caring for a child who has special needs and that socio-structural constraints create an "Objective Burden" for parents. This burden includes societal judgment about disability and the cost of care.

Adverse interactions with professionals. Aside from one parent's story about her priorities not being acknowledged by the Teacher of the Deaf, other recollections about adverse interactions with professionals involved practitioners from other fields. However, the fabric of early care is a whole cloth and when parents experience negative interactions with any professional in relation to their child, it can influence their willingness to engage with other interventionists. Parents reported incidents in which professionals exhibited insensitivity about their child's special needs, ignored the parent's expressed knowledge and expertise and failed to provide requested or needed information. These incidents sometimes caused parents to stop seeing certain providers and may have created a reluctance to engage with early interventionists in general.

Insensitivity. Parents reported insensitive words or careless actions by insistent professionals. Actions that particularly upset parents were those that resulted in their children screaming, choking or vomiting. Parents also felt the sting of hurtful attitudes expressed by professionals when the child was in utero, suspected of having a special need. Jeannie said she felt the doctors were judging their child as a "messed up person". Buffy said, "everyone was wanting us to abort it". The topic of negative interactions with professionals and the community regarding attitudes towards disability emerged from parent stories. Lars said that acquaintances looked at them as if to say, "I'm surprised you had him if you already knew."

In her autoethnographic work, Zibricky (2014) writes, "as mother-hood and disability intersect, I found that judgment became intense, relentless, and just plain harsh" (p. 45). There is a body of literature that directly speaks to this issue. A 2011 study by Côté-Arsenault and Denney-Koelsch found that parents who had lethal fetal diagnosis

early in pregnancy reported reactions by professionals that were emotional, inconsistent and insensitive when these parents chose to continue the pregnancy. A 2008 study (Rodger, Keen, Braithwaite, & Cook) reported parent dissatisfaction with early intervention stemmed, in part, from disrespectful and unsupportive encounters with professionals. There is ample mention in the literature suggesting that professionals in various fields, including hearing screeners, nurses, physicians, audiologists, deaf educators and speech and language pathologists, need better preparation in family-centered early intervention in order to better support and partner with parents (Houston, Bradham, Muñoz, & Guignard, 2011; Muñoz, Nelson, Blaiser, Price, & Twohig, 2015; Robbins, 2009; Rodger et. al., 2008; Tomasello, Manning, & Dulmus, 2010.)

Inability to provide information. Parents talked about needing information but sometimes not knowing what they needed to know. Parents were dismayed when they asked directly for specific information and still did not receive it; “Don’t just say, *wait till you know!*” The condition of not knowing or needing help seemed to put parents in a state of disequilibrium, anxiety or despair. When they couldn’t get answers from professionals, some parents tried to get it themselves; Amara said, “I was terrified cause I went on-line myself and was googling everything”. Erica Lynn repeated, “I can’t handle the unknown. I like to know things.” It may be that information, even when it is painful, can help a parent get through the day and help them mobilize their resources to take the next step, “if I’m not prepared for tomorrow... I’m not gonna make it through my day.” Information is necessary and empowering.

Not listening. Parents mentioned not being listened to, often with traumatic results for the child and a keen emotional response by the parent. As parents described events

that at times involved intense adverse physical reactions by their child, they appeared to have suffered right along with their child. When their protective instincts were engaged, they intervened and sometimes chose never to work with that provider again, “I would try to give her input, and she would not... listen”! Ultimately “the ones that he didn’t work really good with, I took away”. The manner in which a professional engages with a child and family is most important in maintaining the parent’s continued willingness to see that provider.

Costs. Parents talked about the direct costs of services for their children and indirect costs of the logistics to receiving and providing care. One mother tallied up the expense of getting to audiology appointments, “...add up deductibles, gas, food sometimes a place to stay... that alone is a lot of money. That’s not counting other bills in the mail you receive for services”. Three mothers stated that they had to stop work or couldn’t work in order to care for a child and to coordinate and participate in the child’s specialized therapies. Those who lived in rural areas and had to travel to specialists mentioned this expense more often than those in urban areas. Erica Lynn said she stopped going to a distant children’s hospital for motor evaluation due to barriers to travel. “Well I was out here ...and couldn’t make it to the appointment. I never made another appointment.”

Parents whose children had Medicaid, rarely brought it up, although one, when asked if her daughter had Medicaid said, “yes, thank god!” The parents whose children did not have Medicaid, frequently talked about the financial burden of care, of trying to work and manage the complex care of their child or of being unable to work. They reported insurance company denials for treatments and equipment, lack of providers

willing to visit and ongoing worries about finances. Having experienced provision of services with Medicaid and then without, one mother, with a bitter laugh, said, “I can really tell a big difference. It’s like no one wants to come out!”

Question 2: What are the Positive Factors in Seeking Early Intervention?

Supportive interactions with professionals. Family relationships with professionals was an important theme as I began the study and proved to be a rich topic as parents expressed themselves and shared their experiences. Research findings indicate that the relationships between parents and professionals have a profound impact on the family trajectory and can either hamper or facilitate positive outcomes for parents and their children (Fine & Nissenbaum, 2000). These interactions can “empower” parents as they take control over their life events after a child is diagnosed with a disability (Dunst & Trivette, 1996; Dempsey, Foreman, Sharma, Kehanna, & Aurora, 2001). Parents viewed as helpful those instances where parents and professionals worked as a team or in partnership. Parents demonstrated engagement when they used terms like “my team”.

Facilitated entry into EI. Smooth entry into the Infant Toddler Program and a clear diagnosis of hearing loss by pediatric specialists helped parents accept early intervention for their child’s hearing loss. Although parents reported that they didn’t understand the early intervention system or know about services for children who are deaf or hard of hearing, in most cases, these parents received a quick linkage to early intervention for hearing loss. Many did not remember how they began to get services from the Teacher of the Deaf, but were happy with the service. When parents spoke of those first months after diagnosis as “a blur”, it was clear that they appreciated it when “they came and explained everything about the services and things that were put in

place”. Buffy said, “they had it set up for us...through doctors and connections”. When early intervention worked as an integrated and coordinated care system, families were satisfied (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008).

Response to needs. Parents appreciated it when their child’s team was responsive to family schedules, stated needs and to questions. They also liked getting information they didn’t know they needed. When an experienced professional could identify needs and share information and community resources, parents note how helpful that is. One parent specifically mentioned that the teacher of the deaf “is the one that gives us a lot of extra information”.

Caring attitude. Parents quickly ascertained who genuinely liked them, respected their opinions and cared for their child. Parents often mentioned the need for patience. When directly asked “What do you want people to know from your experience with Andrew?”, his mother said “Patience. Patience. Every child moves at their own pace.” Parents were more focused on continuing with early intervention when given encouragement; “it makes all the difference in the world”, said Hannah. She indicated that she followed through more with therapy in daily activities when given encouragement by a person who cared.

Parents had good things to say about their intervention teams, but mention of the Teacher of the Deaf was often missing when parents described team meetings, indicating a system that might not facilitate collaboration. Positive comments were made about these teachers as individual visitors and included comments about professionalism, answering questions, educating parents, having good ideas and offering helpful links to community resources. Parents made some of their most positive comments about a parent

educator from BEGINNINGS for parents of children who are deaf or hard of hearing. She talked about her own son, who has hearing loss, giving parents a hopeful glimpse into the future; “this woman knowed exactly...and she was able to give me examples...that I was a able to look ahead and be ok with it”.

Parental resilience. Some parents had a previous experience with children who have special needs in their communities or through their professions. This is consistent with the literature that indicates experience with others who have special needs helps parents make decisions about their own children (France, Locock, Hunt, Ziebland, Field, & Wyke, 2012). Parents also mentioned faith and hope as strengthening factors and expressed their beliefs that their child “has a life” created by God.

External and financial supports. Parents briefly spoke of family and community supports but, as noted previously, parents frequently mentioned that Medicaid, which assured that the child received needed therapy, medical interventions and equipment. When I asked Lainey if her daughter Nikki had Medicaid, she exclaimed, “Yes, thank God!” Specific to hearing needs, North Carolina does have a mechanism in place for children to obtain amplification that doesn’t potentially burden a family when they don’t qualify for Medicaid. Two parents mentioned that the Early Hearing Detection and Intervention Program covered cost of initial hearing aids beyond what private insurance paid, although one parent talked about needing the help of her teacher in overcoming problems in dealing with her insurance company and accessing this fund. NC also provides a licensed Teacher of the Deaf to parents and their diagnosed infants and toddlers, without billing to private insurance for the cost of this intervention service.

Prioritizing needs. Parents talked about critically managing the scant time and energy they had with which to meet children's many needs. During the interviews, parents prioritized their children's needs for me speedily and even reported that it "was helpful". Prioritization was hierarchical. One framework that is familiar to many and is still used to explain motivation (Gorman, 2010) is Maslow's hierarchy of needs. Maslow posited needs can be classified in a hierarchy with lower level needs having to be fulfilled before higher level needs (Maslow, 1954). In Maslow's framework, physiological needs are primary. Although this framework is not fully applicable to the circumstances of these parents, when prioritizing needs and discussing rationale for each rating, parents looked to most basic survival first. Jez listed her priorities with clear rationale; "If you can't eat, I mean it doesn't matter if you can't hear. If you can walk and get around and work in your environment to get what you need, then, yeah, that comes before his hearing." Parents, dealing with major health issues, didn't think much about hearing loss when "other bad things could have gone wrong" or "we never thought we would actually bring him home from the hospital". This reasoning placed intervention for hearing/speaking/communicating lower on the list of priorities. Two parents did verbally recognize that the priorities for their child might change over time and indicated that prioritization "depends" on competing needs. When the Teacher of the Deaf suggested that Lars imagine his child in the future it helped him consider how his speech could sound at age 17 with intervention. Several parents spoke of concerns about their child's school-age years. Tuning-in to parent's priorities can create an opening to partner with parents in building their child's communication skills. It also highlights the need for

continuity of communication with parents about the impact of hearing loss from the very first hearing screening and along the pathways to early intervention.

When the focus of professionals seemed to parents not to mesh with their most strongly identified needs and what they knew about their child, the result was dissonance. Parents did not form partnerships readily with providers who failed to attend to their needs, ideas and concerns, even when those needs were removed from or conflicted with those professionals' areas of expertise. In fact, one parent said angrily, "the difficulty was meshing priorities...so we finally got to the point where, we will do what we can do, and that's it!" Parent identification of their child's needs by most acute to least acute demonstrated how professional Teachers of the Deaf, most often with exceptional training and skills, could risk alienation from the parent and the team by having an agenda that didn't match the parents' hierarchy of identified needs. This could occur even when teachers were acting most professionally, using evidence-based skills and developmentally appropriate practices.

Strengths and Limitations of the Study

The study targeted a problematic gap in existing research, which has traditionally focused on children who have hearing loss without specific focus on those who have additional special needs. The study of the experience of choosing early intervention for hearing loss within a constellation of other needs has been largely neglected. The use of a qualitative research design captured glimpses of participants' lived experiences, each at a different station along the trajectory of working within the early intervention system. This design supported description of parents' rich personal stories through their own voices.

Although the number of participants was small, parents who were Black and White

were almost equally represented, as were those who live in rural or urban/suburban areas and those whose children were and were not eligible for Medicaid insurance. Participants were broadly distributed by looking at children's degrees of hearing loss (from mild to profound), ages and varieties of additional special needs. Participants were drawn from a geographically heterogeneous area in the western third of NC. Although the Infant Toddler Program has uniform guidelines for processes and procedures across NC, the actual day-to-day functioning of each of the 16 Children's Developmental Services Agencies (CDSAs) and the information and links they provide to professionals may vary due to unique resources, constraints and professional training. Participants were enrolled through only three of the 16 statewide CDSAs and therefore their experiences in early intervention may not fully capture what other parents experiences might have been with other early intervention program personnel across the state of NC. Only one respondent was male. Luterman (2004) has suggested that mothers and fathers experience a child who has special needs differently. He proposed that it is common for parents of children who have special needs to feel guilt. The mother's guilt is often focused on what might have caused the child's special needs whereas the father's guilt may be related to a perceived failure to protect the entire family, part of his acculturated role.

Overall, results of qualitative studies lack generalizability. Such is the case with this study. However, qualitative research allows the possibility to go beyond the narrow interpretations of data and extrapolate other applications of the findings (Patton, 2002). Such understandings can serve as guides for improving practice, programs and policy-making. Qualitative study generates additional questions and perspectives. Participants join in generating questions from their lived experiences and from the act of sharing

them. In turn, their stories encourage readers to look at experiences in ways that generate fresh perceptions influencing practice and future research.

Recommendations for Future Research

Because the field of early hearing screening, diagnosis and intervention remains in a state of rapid change and growth, continued study of the real impact on children and families is essential. There is a need for additional research in the following areas with a focus on parents, early intervention systems, state and national policy. One parent specifically drew attention to the fact that early intervention for children who are deaf and hard of hearing is under one umbrella, the Department of Public Instruction, while the Infant Toddler Program is within Department of Health and Human Services and suggested this could create lack of cohesive and expanded support. Research does highlight how structural elements such as lack of access to services and lack of continuity and coordination of care leads to parent dissatisfaction (King, Cathers, King, & Rosenbaum (2001). Early intervention system issues may also impact provider proficiency, job satisfaction and retention. Comparison of child and family outcomes and parent satisfaction in states that have different service delivery systems and alignment with educational institutions could identify systems that foster integrated, seamless, innovative and family-centered practices.

Family Focused Research

A qualitative exploration of the experience of parents whose children were lost to follow-up after referral from newborn hearing screening or diagnosis of hearing loss would provide essential information beyond this study, which included only those not lost to follow-up. The group of parents, which does not choose to engage in intervention,

is best equipped to illuminate those issues, which lead to their lack of participation in EI. Comparisons of parents' experiences of early intervention when their child has and does not have additional special needs could illustrate differences leading to tailored support by professionals. The perspective of fathers of children who have hearing loss needs to be more fully explored and included in studies. Specific focus on how parents hear messages from the first responders (newborn hearing screeners, re-screeners, medical home etc.) could help these first responders carefully design and communicate messages that parents understand and can use to take action.

Public Policy and the System of Service

This study was designed to describe the perspective of parents, yet their experiences, with their family as a microsystem, are part of a larger ecological system of service (Bronfenbrenner, 1979). Parents in this study talked about the Infant Toddler Program (ITP), the Teachers of the Deaf from the Sensory Support Program and other therapists from various disciplines. They spoke of the Early Hearing Detection and Intervention Program, which collects information about and monitors children who have hearing loss as well as designating funds for a first set of hearing aids. Parents also spoke of others who are essential parts of the community that may be the first responders for these infants: physicians, ranging from general practitioners to specialists, nurses who screen babies, are in the NICU or in a pediatrician's office, audiologists, and other members of the health community who help guide families to appropriate supports for their children. They are all part of the fabric of care, a fabric that needs to be seamlessly interwoven and strong enough to promote the well-being and optimal development of families and children. My recommendations for study and change, though not

comprehensive, do touch on elements of the microsystem and the macrosystem (Bronfenbrenner, 1979):

A study enlisting the viewpoint of early intervention Teachers of the Deaf across the state could help pinpoint system barriers and supports to their ability to work with parents of children who have hearing loss and additional special needs.

Those interviewed for this study whose children did not have Medicaid expressed significant anxiety about paying for therapy and equipment. A comparison of the impact of Medicaid versus private insurance on provision interventions and outcomes for children who are deaf and hard of hearing and have additional special needs could inform decision-makers on the benefits and drawbacks of such medical insurance. Comparisons across states would be informative as to strengths and costs of healthcare in relation to state policies. In examining the quantitative data about North Carolina's newborn hearing screening program for this study, it came to my attention that the last compiled information showed that between 2012 and 2013 enrollment in the Infant Toddler Program by those children who have a diagnosed hearing loss was reduced by 8%. Continuing to track enrollment in the ITP for children with diagnosed hearing loss could inform the Early Hearing Detection and Intervention system of changes that affect enrollment and particular components in need of adjustment to best promote easy access to intervention for diagnosed infants who are D/HH.

Implications for Practice

What Parents Want Other Parents and Professionals to Know

Parents specifically asked professionals for encouragement, to honor their choices, to give and share information (even when they don't know what to ask for), to

listen to them, to value their child, to work as a team and to go above and beyond for their child. They asked for patience and wanted professionals to know, “There are good days and bad days for everybody”. Parents, when speaking directly to other parents told them, “Have faith and keep hoping”. “Make phone calls, talk to people”. “Ask questions”. “Keep asking your questions until you get the right answer or the one that suits you”. “Don’t take no for an answer”. “Don’t be afraid to state what you feel would be a better way to come at a problem”. One mother wanted other parents to know “It is extremely hard at times”. Another said, “Take life with a grain of salt”. Finally, a mother said, “Never give up”.

Suggestions for Changes in the System of Care

Recommendations for system changes include:

- Training and /or materials for hearing screeners and community health providers so when they deliver the message about a child needing diagnostic audiology, parents are more likely to understand the meaning of the message and not delay.
- Information for all parents about childhood hearing loss embedded in the initial screening process.
- Strengthening early pediatric audiology services across the state to alleviate the delay in diagnosis and care.
- Professional Training: Education of providers in family-centered practice (Dunst, Trivette & Deal, 1988). University-level curricular design reflecting Interprofessional Education (IPE) across disciplines of health and education (Pardue, 2013).

- Increased visibility for the program serving infants and toddlers who have hearing loss (brochures, enhanced web presence, other materials for professionals and parents) to improve awareness of the availability of these intervention services at no cost to parents.
- Allocation of funds to support free early intervention for children who are deaf or hard of hearing and audiology services and equipment through the Early Hearing Detection and Intervention Program. Independent program evaluations to determine most effective and seamless alignment of service delivery system to meet JHIC (2013) guidelines for screening, diagnosis and intervention.
- Alignment of funding, state policy and system organization to support seamless early intervention with a family-centered approach.
- Development of accessible, culturally aligned materials (eg. parent-to-parent “conversation” videos) to help parents gain experiential knowledge about hearing loss and additional special needs.

Recommendations for practitioners include:

- Foster and participate in Family-Centered Practices and Inter-Professional Education to promote family engagement and team collaboration. Overall provision of treatment and interactions should be characterized by family-centered practices.
- Encourage parents to share their prioritization of intervention needs for their child in order to open responsive conversations with the educator about ways to connect communication skill development with family priorities.

- Use prioritization tools to revisit parent's changing priorities and renew conversations to develop strategies to embed early communication skills into the intervention priorities identified by parents.

Helping parents imagine the future, particularly in regard to communication needs, could lay the foundation for awareness of this more invisible intervention need and help parents prioritize communication intervention. Tailored resources (curriculum and instruction) can support parents who have children diagnosed with permanent congenital hearing loss with additional special needs. Support in the form of videos using parent-to-parent storytelling could provide parents with a glimpse into the future, something several parents mentioned as helpful and hopeful. This experiential knowledge of special needs could help parents imagine their child's future and make more informed decisions about intervention (France, et al., 2012).

Lessons I Learned

Participants in this study changed my thinking regarding prioritizing children's need. Although my evidence-based knowledge about the importance of early intervention for hearing loss remains firmly in place, an enhanced understanding of parent priorities gives me a new awareness of the potential clash when a child's invisible hearing loss fades in comparison to needs such as feeding and motor skills. Urgency of survival is paramount. However, this doesn't mean that teachers of the deaf should absent themselves from the team. On the contrary, open and ongoing discourse about hearing, communication and child development that are attuned to parents' current situations, that is family-centered and collaborative is essential.

Conclusion

This study reinforced previous literature concerning barriers and supports to early intervention, among them, confusing messages from hearing screeners, ambiguous diagnoses compounded by lack of pediatric audiologists, cost to families and the invisibility of hearing loss. The most revealing aspects of these interviews involved the impact of negative and positive encounters with professionals highlighting the importance of family-centered early intervention. Encounters with professionals can tip the scales for parents, encouraging them to participate in early intervention. Medicaid eligibility was shown to have an impact on parent's feelings of being able to meet their child's therapy needs. This group of parents rated their child's need for hearing/speaking/communication rather low in their hierarchy of needs even after critical health crises were resolved. Parent prioritization has implications for early management of hearing loss and communication skills. Without free, early, consistent and easily understood parent education about the impact of hearing loss, parents may put off focus on communication skills until the time of optimum brain receptivity for language development has already passed.

REFERENCES

- Allen, T.E. (1994). Who are the deaf and hard of hearing students leaving high school and entering post secondary education? Paper submitted to Pelavin Research Institute. Gallaudet University, Washington, DC. Retrieved from <http://www.gallaudet.edu/~cadsweb/whodeaf.html>.
- Allen, T. E., Letteri, A., Choi, S. H., & Dang, D. (2014). Early visual language exposure and emergent literacy in preschool deaf children: findings from a national longitudinal study. *American Annals Of The Deaf*, 159(4), 346-358.
- Allen, T.E., Rawlings, B., & Schildroth, A. (1989). *Deaf students and the school to work transition*. Baltimore, MD: Paul H. Brookes.
- American Speech-Language-Hearing Association. (2008). *Loss to Follow-Up in Early Hearing Detection and Intervention* [Technical Report].
doi:10.1044/policy.TR2008-00302
- American Speech-Language-Hearing Association (2013). *State Insurance Mandates for Hearing Aids* Retrieved 11/28/13 from http://www.asha.org/advocacy/state/issues/ha_reimbursement/
- Arnold, C. L., Davis, T. C., Humiston, S. G., Bocchini, Joseph A. Jr, Bass, Pat F.,3rd, Bocchini, A., Kennen, E. M., White, K., & Forsman, I. (2006). Infant hearing screening: Stakeholder recommendations for parent-centered communication. *Pediatrics*, 117(5), S341-S354. doi: 10.1542/peds.2005-2633N
- BEGINNINGS for Parents of Children who are Deaf or Hard of Hearing.
Communication Options. Downloaded 11/2/13 from https://ncbegin.org/index.php?option=com_content&view=article&id=99&Itemid

=232#

- Bertram, B. (2004). Cochlear Implantation for Children with Hearing Loss and Multiple Disabilities: An Evaluation from an Educator's Perspective. *Volta Review*, 104(4), 349-359.
- Berrettini, S., Forli, F., Genovese, E., Santarelli, R., Arslan, E., Chilosi, A., & Cipriani, P. (2008). Cochlear implantation in deaf children with associated disabilities: Challenges and outcomes. *International Journal of Audiology*, 47(4), 199-208. doi:10.1080/14992020701870197
- Bowe, F. (1991). *Approaching equality: Education of the deaf*. Silver Spring, MD: T.J. Publishers.
- Breen, L. J. (2009). Early childhood service delivery for families living with childhood disability: Disabling families through problematic implicit ideology. *Australasian Journal Of Early Childhood*, 34(4), 14-21.
- Brewer Jr., E. J., McPherson, M., Magrab, P. R., & Hutchins, V. L. (1989). Family-centered, community-based, coordinated care for children with special health care needs. *Pediatrics*, 83(6), 1055.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge: Harvard University Press.
- Carney, A. E., & Moeller, M. P. (1998). Treatment efficacy: Hearing loss in children. *Journal of Speech, Language & Hearing Research*, 41(1), S61.
- Catts, H. W. (1993). The relationship between speech-language impairments and reading disabilities. *Journal of Speech and Hearing Research*, 36, 948-958.

- Centers for Disease Control and Prevention. (2015). Retrieved from www.cdc.gov/ncbddd/hearingloss/data.html
- Chapman, D. A., Stampfel, C. C., Bodurtha, J. N., Dodson, K. M., Pandya, A., Lynch, K. B., & Kirby, R. S. (2011). Impact of co-occurring birth defects on the timing of newborn hearing screening and diagnosis. *American Journal Of Audiology*, *20*(2), 132-139. doi:10.1044/1059-0889(2011/10-0049)
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 509–535). Thousand Oaks, CA: Sage.
- Chilosi, A. M., Comparini, A., Scusa, M. F., Berrettini, S., Forli, F., Battini, R., & Cioni, G. (2010). Neurodevelopmental disorders in children with severe to profound sensorineural hearing loss: A clinical study. *Developmental Medicine & Child Neurology*, *52*(9), 856-862.
- Côté-Arsenault, D., & Denney-Koelsch, E. (2011). 'My baby is a person': Parents' experiences with life-threatening fetal diagnosis. *Journal Of Palliative Medicine*, *14*(12), 1302-1308. doi:10.1089/jpm.2011.0165
- Creswell, J.W. (2008). *Educational Research: Planning, Conducting, and Evaluating Quantitative and Qualitative Research*. Upper Saddle River, NJ: Pearson.
- Culpepper, B. (2003). Identification of permanent childhood hearing loss through universal newborn hearing screening programs. In B. Bodner-Johnson & M. Sass-Lehrer (Eds.), *The young deaf or hard of hearing child* (pp. 99-126). Baltimore, MD: Brookes.
- Dalzell L, Orlando M, MacDonald M, Berg A, Bradley M, Cacace A.....

- Prieve B. (2000). The New York State universal newborn hearing screening demonstration project: ages of hearing loss identification, hearing aid fitting, and enrollment in early intervention. *Ear Hear* 21: 118-130.
- Danhauer, J. L., & Johnson, C. E. (2006). A case study of an emerging community-based early hearing detection and intervention program: Part I. parents' compliance. *American Journal of Audiology*, 15(1), 25-32. doi:10.1044/1059-0889(2006/004)
- Danhauer, J. L., Johnson, C. E., Finnegan, D., Hansen, K., Lamb, M., Lopez, I. P., Meuel, C., Pecile, A., Resnick, S., & Williams, V. (2006). A case study of an emerging community-based early hearing detection and intervention program: Part II. team building with otolaryngologists and pediatricians using a survey approach. *American Journal of Audiology*, 15(1), 33-45. doi:10.1044/1059-0889(2006/005)
- Dauman, R., Roussey, M., Belot, V., Denoyelle, F., Roman, S., Gavilan-Cellié, I., ... Garabedian, N. (2009). Screening to detect permanent childhood hearing impairment in neonates transferred from the newborn nursery. *International Journal Of Pediatric Otorhinolaryngology*, 73(3), 457-465. doi:10.1016/j.ijporl.2008.12.001
- Dempsey, I., Foreman, P., Sharma, N., Khanna, D., & Arora, P. (2001). Correlates of parental empowerment in families with a member with a disability in Australia and India. *Developmental Disabilities Bulletin*, 29(2), 113-131.
- DesGeorges, J. (2003). Family perceptions of early hearing, detection, and intervention systems: Listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(2), 89-93.
- DesJardin, J. L. (2005). Maternal perceptions of self-efficacy and involvement in the

- auditory development of young children with prelingual deafness. *Journal of Early Intervention*, 27(3), 193-209.
- DesJardin, J. L. (2006). Family empowerment: Supporting language development in young children who are deaf or hard of hearing. *Volta Review*, 106(3), 275-298.
- Dorman, M. F., Sharma, A., Gilley, P., Martin, K., & Roland, P. (2007). Central auditory development: Evidence from CAEP measurements in children fit with cochlear implants. *Journal of Communication Disorders*, 40(4), 284-294.
- Dunst, C. J., & Trivette, C. M. (1996). Empowerment, effective help giving practices and family-centered care. *Pediatric Nursing*, 22, 334-337, 343.
- Dunst, C.J., Boyd, K., Trivette, C. & Hamby, D. (2007). Meta-analysis of family-centered help giving practices research. *Mental Retardation and Developmental Disabilities*, 13, 370-378.
- Dunst, C. J., Trivette, C. M. & Deal, A.G. (1988). *Enabling and Empowering Families: Principles and Guidelines for Practice*. Cambridge, MA: Brookline Books.
- Early Childhood Technical Assistance Center (2013). *Family Centered Principles and Practices*. Downloaded from ectacenter.org/topics/families/famctrprin.asp
- Early Hearing Detection and Intervention Act of 2010 (HR. 1246, S. 3199).
- Enns, C. (2009). *VL2 Early Education Longitudinal Study Parent Questionnaire*. Washington, DC. Gallaudet University.
- Farrell, J. (2009). Developing a strong early hearing detections and intervention program. *ASHA Leader*, 14(4), 8-11.
- Fine, M. J., & Nissenbaum, M. S. (2000). The child with disabilities and the family: Implications for professionals. In M. J. Fine & R. L. Simpson (Eds.), *Collaboration*

with parents and families of children and youth with exceptionalities (pp. 3–26).

Austin, TX: PRO-ED

Fischer, C. T. (2009). Bracketing in qualitative research: Conceptual and practical matters. *Psychotherapy Research, 19*(4/5), 583-590.

doi:10.1080/10503300902798375

Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I. D., & Coyle, D. (2008).

Parents' Needs Following Identification of Childhood Hearing Loss. *American Journal Of Audiology, 17*(1), 38-49. doi:10.1044/1059-0889(2008/005)

Fitzpatrick, E., Graham, I. D., Durieux-Smith, A., Angus, D., & Coyle, D. (2007).

Parents' perspectives on the impact of the early diagnosis of childhood hearing loss. *International Journal Of Audiology, 46*(2), 97-106.

doi:10.1080/14992020600977770

Flexer, C. (2012). Auditory brain development - language and literacy development.

(n.d.). Retrieved from

<http://hearinghealthmatters.org/hearingandkids/2012/auditory-brain-development-the-key-to-developing-listening-language-and-literacy/>

Foley, G.M. (2006). The Loss-Grief Cycle: Coming to terms with the birth of a child with a disability. In G.M. Foley & J. D. Hochman (Eds.), *Mental health in early intervention: Achieving unity in principles and practice* (pp. 227-243). Baltimore: Paul Brookes.

Foley, G.M., & Hochman, J.D. (2006). *Mental Health in Early Intervention: Achieving Unity in Principles and Practice*. Baltimore, MD: Paul Brookes.

Folsom, R.C., Widen, J.E., Vohr, B.R., Cone-Wesson, B., Gorga, M.P., Sininger, Y.S, &

- Norton, S.J. (2000). Identification of neonatal hearing impairment: Recruitment and follow-up. *Ear and Hearing, 21*, 462-470.
- France, E. F., Locock, L., Hunt, K., Ziebland, S., Field, K., & Wyke, S. (2012). Imagined futures: how experiential knowledge of disability affects parents' decision making about fetal abnormality. *Health Expectations, 15*(2), 139-156. doi:10.1111/j.1369-7625.2011.00672.x
- Gallaudet Research Institute. (2008). *Regional and National Summary Report of Data from the 2007-2008 Annual Survey of Deaf and Hard of Hearing Children and Youth*. Washington, DC: Gallaudet University.
- Gavidia-Payne, S. & Stoneman, Z. (1997). Family predictors of maternal and paternal involvement in programs for young children with disabilities. *Child Development, 68*(4), 701-717.
- Geers, A. (2003). Predictors of reading skill development in children with early cochlear implantation. *Ear & Hearing (01960202), 24*(1), 59S-68s.
- Geers, A. & Hayes, H. (2011). Reading, writing, and phonological processing skills of adolescents with 10 or more years of cochlear implant experience. *Ear and Hearing, 32*, 49S-59S. doi:10.1097/AUD.0b013e3181fa41fa
- Geertz, C. (1988). *Works and lives: The anthropologist as author*. Stanford, CA: Stanford University Press.
- Glesne, C. (2011). *Becoming qualitative researchers; an introduction* (4th Ed.). Boston, MA: Pearson.
- Giannoni, P.P. & Kass, P.H. (2010). Risk factors associated with children lost to care in a state early childhood intervention program. *Research in Developmental*

Disabilities, 31, 914-923.

Giorgi, A. (2002). Validity in qualitative research. *Journal of Phenomenological Psychology*, 33(1), 1-18.

Gorman, D. (2010). Maslow's hierarchy and social and emotional wellbeing. *Aboriginal and Islander Health Worker Journal*, 33(5), 27-9.

Green, S. E. (2003). They are beautiful and they are ours; Swapping tales of mothering children with disabilities through interactive interviews. *Journal of Loss & Trauma*, 8(1), 1-13. doi:10.1080/15325020390168672

Green, S.E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science and Medicine*, 64, 150-163.

Grosse, S. D., & Ross, D. S. (2006). Cost Savings From Universal Newborn Hearing Screening. *Pediatrics*, 118(2), 844-845. doi:10.1542/peds.2006-1146

Guba, E.G., & Y.S. Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In Denzin and Lincoln (eds.), *Handbook of Qualitative Research*, Sage, Thousand Oaks.

Hein, S. F., & Austin, W. J. (2001). Empirical and hermeneutic approaches to phenomenological research in psychology: A comparison. *Psychological Methods*, 6(1), 3-17. doi:10.1037/1082-989X.6.1.

Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess, S. A., & Ladany, N. (2005). Consensual qualitative research: An update. *Journal Of Counseling Psychology*, 52(2), 196-205. doi:10.1037/0022-0167.52.2.196

Holte, L., Walker, E., Oleson, J., Spratford, M. Moeller, M.P., Roush, P., ... Tomblin, J.B. (2012). Factors influencing follow-up to newborn hearing screening for infants

who are hard of hearing. *American Journal of Audiology*, 21, 163-174.

Hoffman, J., Muñoz, K. F., Bradham, T. S., & Nelson, L. (2011). Loss to follow-up:

Issues and recommendations. *Volta Review*, 111(2), 165-180.

Houston, K., Bradham, T. S., Muñoz, K. F., & Guignard, G. (2011). Newborn Hearing

Screening: An Analysis of Current Practices. *Volta Review*, 111(2), 109-120.

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

Ingber, S., & Dromi, E. (2010). Actual versus desired family-centered practice in early

intervention for children with hearing loss. *Journal of Deaf Studies and Deaf Education*, 15(1), 59-71.

Johnson, J.L., Mauk, G.W., Takekawa, KM, Simon, PR, Sia, CCJ, Blackwell, PM.

(1993). Implementing a statewide system of services for infants and toddlers with hearing disabilities. *Seminars in Hearing*, 14, 105-119.

Joint Committee on Infant Hearing (1994). *Year 1994 Position Statement*. ASHA, 36, 38-41.

Joint Committee on Infant Hearing. (2000). *Year 2000 position statement. Principles and guidelines for early hearing detection and intervention programs*. *Pediatrics*, 106(4). Retrieved from <http://www.infanthearing.org/jcih>.

Joint Committee on Infant Hearing. (2007). Year 2007 position statement. Principles and guidelines for early hearing detection and intervention programs. *Pediatrics*, 102, 898-921.

Joint Committee on Infant Hearing (2013). Supplement to the JCIH 2007 position statement: Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Pediatrics*, 131(4):e1324-e1349

- Kavanagh, K.T., Smith, T.R., Golden, G.S., Tate, N.P. & Hinkle, W.G. (1991).
Multivariate analysis of family risk factors in prediction appointment attendance in
a pediatric otology and communication clinic. *Journal of Health and Social Policy*,
2, 85-102.
- King, G., Cathers, T., King, S., & Rosenbaum, P. (2001). Major Elements of Parents'
Satisfaction and Dissatisfaction With Pediatric Rehabilitation Services. *Children's
Health Care*, 30(2), 111-134.
- Kuhl, P. K. (2004). Early language acquisition: cracking the speech code. *Nature
Reviews. Neuroscience*, 5(11), 831-843.
- Kuhl, P. K. (2010). Brain Mechanisms in Early Language Acquisition. *Neuron*, 67(5),
713-727. doi:10.1016/j.neuron.2010.08.038
- Kuhl, P. K., Conboy, B. T., Padden, D., Nelson, T. & Pruitt, J. (2005). Early speech
perception and later language development: Implications for the "critical period."
Language Learning and Development, 1, 237-264.
- Kurtzer-White, E., & Luterman, D. (2003). Families and children with hearing loss: Grief
and coping. *Mental Retardation & Developmental Disabilities Research Reviews*,
9(4), 232-235. doi:10.1002/mrdd.10085
- Kvale, S., & Brinkmann, S. (2009). *InterViews: learning the craft of qualitative research
interviewing*. Los Angeles: Sage Publications, c2009.
- Larsen, R., Muñoz, K., DesGeorges, J., Nelson, L., & Kennedy, S. (2012). Early Hearing
Detection and Intervention: Parent Experiences With the Diagnostic Hearing
Assessment. *American Journal Of Audiology*, 21(1), 91-99. doi:10.1044/1059-
0889(2012/11-0016)

- Lincoln, Y.S., & Guba, E.G. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In Denzin and Lincoln (eds.), *Handbook of Qualitative Research*, (pp. 163-188). Thousand Oaks, CA: Sage.
- Lipkin, P.H., Davidson, D., Spivak, L., Straub, R., Rhines, J., Chang, C.T. (2002). Neurodevelopmental and medical outcomes of persistent pulmonary hypertension in term newborns treated with nitric oxide. *J Pediatr*; *140*:306-310.
- Liu, C., Farrell, J., MacNeil, J. R., Stone, S., & Barfield, W. (2008). Evaluating loss to follow-up in newborn hearing screening in Massachusetts. *Pediatrics*, *121*(2), e335-e343.
- Luterman, D. (2004). Counseling families of children with hearing loss and special needs. *Volta Review*, *10*(4) (monograph), 215-220.
- Mace, A., Wallace, K., Whan, M., & Stelmachowicz, P. (1991). Relevant factors in the identification of hearing loss. *Ear Hear*, *12*, 287.
- Madell, J., & Flexer, C. (2011). *Pediatric Audiology Casebook*. New York: Thieme Medical Publishers.
- Malone, D. G., Easterbrooks, S., & Gallagher, P. A. (2005). Service providers perceptions of universal newborn hearing screening and intervention training needs. *Teacher Education and Special Education*, *28*(1), 29-39.
- Marshall, C. & Rossman, G.B. (1999). *Designing qualitative research*. (3rd Ed). Thousand Oaks, CA: Sage.
- Maslow, A. (1954). *Motivation and personality*. New York, NY: Harper.
- Mason, C. A., Gaffney, M., Green, D. R., & Grosse, S. D. (2008). Measures of Follow-Up in Early Hearing Detection and Intervention Programs: A Need for

- Standardization. *American Journal Of Audiology*, 17(1), 60-67.
- Matthijs, L., Loots, G., Mouvet, K., Van Herreweghe, M., Hardonk, S., Van Hove, G., & ... Leigh, G. (2012). First Information Parents Receive after UNHS Detection of Their Baby's Hearing Loss. *Journal Of Deaf Studies And Deaf Education*, 17(4), 387-401.
- McManus, M.A., Hayden, M.S. & Fox, H.B. (2001). *Medicaid reimbursement of hearing services for children*. Maternal and Child Health Policy Research Center, Washington, D.C.
- Miles, M.B. & Huberman, A.M. (1984). *Qualitative data analysis: A sourcebook for new methods*. Thousand Oaks, CA: Sage.
- Moeller, M. P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics*, 106(3), E43-E43.
- Mohr, P., Feldman, J., Dunbar, J., McConkey-Robbins, A., Niparko, J., Rittenhouse, R., & Skinner, M. (2000). The societal costs of severe to profound hearing loss in the United States. *International Journal Of Technology Assessment In Health Care*, 16(4), 1120-1135.
- Morrow, S.L., & Smith, M.L. (2000) Qualitative research methods in counseling psychology. In S.D. Brown & R.W. Lent (Eds.), *Handbook of Counseling Psychology* (3rd ed.) (pp.199-230). NY: Wiley.
- Muñoz, K. F., Bradham, T. S., & Nelson, L. (2011). A Systematic Analysis of Audiological Services in EHDI. *Volta Review*, 111(2), 121-132.
- Muñoz, K., Nelson, L., Blaiser, K., Price, T., & Twohig, M. (2015). Improving Support for Parents of Children with Hearing Loss: Provider Training on Use of

Targeted Communication Strategies. *Journal Of The American Academy Of Audiology*, 26(2), 116-127. doi:10.3766/jaaa.26.2.2

National Association of the Deaf (n.d.). *Deaf children's bill of rights*. Retrieved from <http://www.nad.org/issues/education/k-12/bill-of-rights>

National Center for Special Education Accountability Monitoring (NCSEAM)

Development of the NCSEAM Parent/Family Surveys

<http://accountabilitydata.org/ParentFamily%20Involvement%20Measures/Description%20of%20Development%20of%20the%20Surveys%20for%20web%20August%2009.pdf>

Newborn and Infant Hearing Screening and Intervention Act of 1999, H.R. 1193, 106d Cong., 1st Sess. (1999).

North Carolina Early Hearing Detection and Intervention Program (2015) accessed through director of NC EHDI program, May 1, 2015.

North Carolina Gen. Stat. §58-3-285

North Carolina Infant Toddler Program. *Defining Eligibility* (downloaded 1/23/14 from <http://www.bearly.nc.gov>

Opirhory, G., & Peters, G. A. (1982). Counseling intervention strategies for families with the less than perfect newborn. *Personnel and Guidance Journal*, 60(8), 451-55.

Pardue, K. T. (2013). Not left to chance: Introducing an undergraduate interprofessional education curriculum. *Journal of Interprofessional Care*, 27(1), 98-100.

doi:10.3109/13561820.2012.721815

Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods*. (3rd ed.). Thousand Oaks, CA: Sage Publications.

- Petitto, L.A., & Marentette, P.F. (1991). Babbling in the manual mode: Evidence for the ontogeny of language. *Science*, *251* (50000), 1493-1496.
- Petitto, L.A., Katerelos, M., Levy, B.G., Gauna, K., Tetreault, K. & Ferraro, V. (2001). Bilingual signed and spoken language from birth: Implications for the mechanisms underlying early bilingual language acquisition. *Journal of Child Language*, *28*(2), 130-143.
- Pimperton, H., & Kennedy, C. R. (2012). The impact of early identification of permanent childhood hearing impairment on speech and language outcomes. *Archives Of Disease In Childhood*, *97*(7), 648-653. doi:10.1136/archdischild-2011-301501
- Pipp-Siegel, S., Blair, N.L., Deas, A.M., Pressman, L.J. & Yoshinaga-Itano, C. (2000). Touch and emotional availability in hearing and deaf or hard-of-hearing toddlers and their hearing mothers. In C. Yoshinaga-Itano & A. Sedey (Eds.), Language, speech, and social-emotional development of children who are deaf or hard of hearing: The early years [Monograph]. *The Volta Review*, *100*(5), 279-298.
- Pipp-Siegel, S., Sedey, A.L., VanLeeusen, A.M., Yoshinaga-Itano, C. (2003.) Mastery motivation and expressive language in young children with hearing loss. *J Deaf Stud Deaf Educ.* *8* (2), 133-145.
- Prince, C. B., Miyashiro, L., Weirather, Y., & Heu, P. (2003). Epidemiology of Early Hearing Loss Detection in Hawaii. *Pediatrics*, *111*(5), 1202..
- Richardson, L. (2000). New writing practices in qualitative research. *Sociology Of Sport Journal*, *17*(1), 5-20.
- Robbins, A. M. (2009). The SLP and Early Intervention with Infants and Toddlers with Hearing Loss. *ASHA Leader*, *14*(4), 16-19.

- Rodger, S., Keen, D., Braithwaite, M., & Cook, S. (2008). Mothers' Satisfaction with a Home Based Early Intervention Programme for Children with ASD. *Journal Of Applied Research In Intellectual Disabilities, 21*(2), 174-182. doi:10.1111/j.1468-3148.2007.00393.x
- Rolls, L., & Relf, M. (2006). Bracketing interviews: addressing methodological challenges in qualitative interviewing in bereavement and palliative care. *Mortality, 11*(3), 286-305. doi:10.1080/13576270600774893
- Romanoff, B. (2001). Research as therapy: The power of narrative to effect change. In R. Meoeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 245-257.) Washington, DC: American Psychological Association.
- Schildroth, A. N., Rawlings, B. W., & Allen, T. E. (1991). Deaf students in transition: education and employment issues for deaf adolescents. *Volta Review, 93*41-53.
- Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education and the social sciences. (4th ed)*. New York: Teachers College Press.
- Sharma, A., Dorman, M. F., & Kral, A. (2005). The influence of a sensitive period on central auditory development in children with unilateral and bilateral cochlear implants. *Hearing Research, 203*(1/2), 134-143. doi:10.1016/j.heares.2004.12.010
- Sharma, A., Nash, A. A., & Dorman, M. (2009). Cortical development, plasticity and re-organization in children with cochlear implants. *Journal of Communication Disorders, 42*(4), 272-279.
- Shoup, A. G., Owen, K. E., Jackson, G., & Laptook, A. (2005). The Parkland Memorial Hospital experience in ensuring compliance with universal newborn hearing screening followup. *Journal of Pediatrics, 146*, 66-72.

- Shulman, S., Besculides, M., Saltzman, A., Ireys, H., White, K. R., & Forsman, I. (2010). Evaluation of the universal newborn hearing screening and intervention program. *Pediatrics, 126*(S19-27). doi:10.1542/peds.2010-0354F
- Sturges, J.E. & Hanrahan, K.J. (2004). Comparing Telephone and Face-to-Face Qualitative Interviewing: a Research Note. *Qualitative Research, 4*(1), 107-118. doi:10.1177/1468794104041110
- Tomasello, N. M., Manning, A. R., & Dulmus, C. N. (2010). Family-Centered Early Intervention for Infants and Toddlers With Disabilities. *Journal Of Family Social Work, 13*(2), 163-172. doi:10.1080/10522150903503010
- The Early Childhood Technical Assistance Center (updated 2/2013). Family –Centered Principles and Practices. Downloaded from <http://ectacenter.org/topics/families/famctrprin.asp>.
- Trier-Bieniek, A. (2012). Framing the telephone interview as a participant-centred tool for qualitative research: A methodological discussion. *Qualitative Research, 12*(6), 630-644. doi:10.1177/1468794112439005
- Trivette, C. M., Dunst, C. J., & Hamby, D. W. (2010). Influences of family-systems intervention practices on parent-child interactions and child development. *Topics in Early Childhood Special Education, 30*(1), 3-19. DOI: 10.1177/0271121410364250
- Tufford, L., & Newman, P. (2012). Bracketing in Qualitative Research. *Qualitative Social Work, 11*(1), 80-96. doi:10.1177/1473325010368316
- Turnbull, A. P., Summers, J., Turnbull, R., Brotherson, M., Winton, P., Roberts, R., & ... Stroup-Rentier, V. (2007). Family supports and services in early intervention: A

bold vision. *Journal Of Early Intervention*, 29(3), 187-206.

Universal Newborn Hearing Screening Act (H.R. 1193 and S. 956)

U.S. Bureau of the Census (1997). School enrollment -- social and economic characteristics of students, October 1995 (Update). Washington, D. C.: U.S. Government Printing Office.(Current Population Reports, Publication NO. PPL55).

U.S. Department Of Health and Human Services, Center for Disease Control, *Summary of 2011 National CDC EHDI Data, Revised January 2012*. Retrieved from http://www.cdc.gov/ncbddd/hearingloss/2009-data/2009_ehdi_hsfs_summary_508_ok.pdf.

Vincer, M.J., Allen, A.C., Joseph, K.S., Stinson, D.A., Scott, H., & Wood, E. (2006). Increasing prevalence of cerebral palsy among very preterm infants: A population-based study. *Pediatrics* 118:6 e1621-e1626.

Watkin P., McCann D., Law C., Mullee M., Petrou S., Stevenson J., Worsfold S., Yuen H.M., & Kennedy C. (2007). Language ability in children with permanent hearing impairment: The influence of early management and family participation. *PEDIATRICS*, 120(3), e694-e701. doi:10.1542/peds.2006-2116

Wainscott, S.D., (2010). *Decision-making in families engaged in early hearing detection and intervention programs; A qualitative study*. Doctoral Dissertation. Gallaudet University; Washington, DC.

White, K. R. (2006). Early intervention for children with permanent hearing loss: Finishing the EHDI revolution. *Volta Review*, 106(3), 237-258.

White, K. R., Forsman, I., Eichwald, J., & Muñoz, K. (2010). The evolution of early hearing detection and intervention programs in the United States. *Seminars In*

Perinatology, 34(2), 170-179. doi:10.1053/j.semperi.2009.12.009

- Wiley, S., Jahnke, M., Meinzen-Derr, J., & Choo, D. (2005). Perceived qualitative benefits of cochlear implants in children with multi-handicaps. *International Journal Of Pediatric Otorhinolaryngology*, 69(6), 791-798.
doi:10.1016/j.ijporl.2005.01.011
- Wilson, K., Nevins, M.E., Houston, K.T. (2010). Professional development for in-service practitioners serving children who are deaf and hard of hearing. *Volta Review*, 110(2), 231-247.
- Woolfe, T., Want, S. C., & Siegal, M. (2002). Signposts to Development: Theory of Mind in Deaf Children. *Child Development*, 73(3), 768.
- Yoshinaga-Itano, C. (2003). Early intervention after universal neonatal hearing screening: Impact on outcomes. *Mental Retardation & Developmental Disabilities Research Reviews*, 9(4), 252-266. doi:10.1002/mrdd.10088
- Yoshinaga-Itano, C. (2004). Levels of evidence: Universal newborn hearing screening (UNHS) and early hearing detection and intervention systems (EHDI). *Journal of Communication Disorders*, 37(5), 451-465.
- Yoshinaga-Itano, C. (2013). American Academy of Audiology. *Joint Committee for Infant Hearing Position Statement, 2013 Update: Interview with Christie Yoshinaga-Itano*.
<http://www.audiology.org/news/Pages/20130516.aspx#sthash.7rOS2ncU.dpuf>
- Yoshinaga-Itano, C., Coulter, D., & Thomson, V. (2001). Developmental outcomes of children with hearing loss born in Colorado hospitals with and without universal newborn hearing screening programs. *Seminars In Neonatology: SN*, 6(6), 521-

529.

- Yoshinaga-Itano, C., & Sedey, A. L. (1998). Language of Early- and Later-identified Children With Hearing Loss. *Pediatrics*, *102*(5), 1161.
- Yoshinaga-Itano, C., & Sedey, A. (1999). Early Speech Development in Children Who Are Deaf or Hard of Hearing: Interrelationships with Language and Hearing. *Volta Review*, *100*(5), 181-211.
- Yoshinaga-Itano, C., Sedey, A., Coulter, D., & Mehl, A. (1998). Language of early- and later-identified children with hearing loss. *Pediatrics*, *102*(5), 1161-1171.
- Young, A., & Tattersall, H. (2005). Parents' of deaf children evaluative accounts of the process and practice of universal newborn hearing screening. *Journal of Deaf Studies and Deaf Education*, *10*(2), 134-145.
- Young, A., & Tattersall, H. (2007). Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development. *Journal of Deaf Studies and Deaf Education*, *12*(2), 209-220.
- Zibricky, C. D. (2014). New knowledge about motherhood: An autoethnography on raising a disabled child. *Journal Of Family Studies*, *20*(1), 39-47.
doi:10.5172/jfs.2014.20.1.39

LIST OF APPENDICES

	Page
Appendix A – Informed Consent	179
Appendix B – Interview Protocol	181
Appendix C – Your Child’s Needs	182
Appendix D – IRB Approval	183
Appendix E – Eligibility Definition for the NC Infant Toddler Program.....	185
Appendix F: A Sample of Parent Interview	188

Appendix A: Informed Consent

Informed Consent

A Descriptive Study of Parent Involvement in Early Intervention for Children who are Deaf or Hard of Hearing and have Additional Special Needs

Dear Parents/Caregivers:

I'm inviting you to participate in a research project studying involvement in early intervention of families who have children with hearing loss plus other special needs with the NC Early Intervention Program for Children who are Deaf or Hard of Hearing. I'm inviting you to participate because your child is now or has recently been a student in this program.

This project also is part of my doctoral degree through Western Carolina University. Sharing your experience could help professionals provide more responsive services to families like yours. You are the ones who could best help make early intervention for hearing loss more beneficial for you and your child. In addition, you might learn something about yourself and feel gratified knowing that your participation could help professionals understand what works well for family support.

I currently teach with the NC Early Intervention Program for Children who are Deaf or Hard of Hearing (Sensory Support) in the Western part of the state. As both a professional and the mother of an adult who is profoundly deaf, I have a strong interest in understanding decision-making and support systems for children who are deaf or hard of hearing and their families. I'm asking you to consider participating in this project because your child is now or has recently been a student in this program.

Procedures

You will, with your consent, participate in an interview that will be audio recorded and require approximately one hour or two of your time. The questions are about your child's needs and services and are open-ended so you could share the most meaningful experiences with your child in relation to early intervention. I will use the recordings for transcription and analysis, but only I will listen to the recordings. I would like to interview you face-to-face, but if you prefer a phone interview or to use Skype or another format, you may choose.

Confidentiality

To protect your confidentiality I will choose other names (aliases) for you and your child, so that when I write my report and/or present the research, your names will not be used. If you mention a person's name during the interview, I will also change that person's name to an alias. Names of agencies will remain the same. All the audio recordings and other information I collect will be stored in a locked filing cabinet, accessible only by me. All audio recordings will be destroyed after one year after the completion of my study.

Compensation

I am offering a \$25 gift card (either Amazon or Wal-Mart) if you participate. You can pick which gift card you would like at the conclusion of the interview.

Possible Risks

It is possible that in the interview process you may experience mild distress in self-reflection or social discomfort during sharing. Should you experience distress and need support, you may contact me directly and I would be happy to speak with you. I also could provide you

with links to local, state and national support for parents who have children with hearing loss and/or special needs. In addition, you could ask me questions prior to signing and during and after participation. Please do not hesitate to contact me with questions or concerns at 828-432-6651, my direct personal number, or via email at wbwieber1@catamount.wcu.edu.

You can stop at any time!

Your participation in the study is completely voluntary. You may withdraw from the study at any time, without negative consequence to you, and any information you provide will be destroyed. Your continued participation in the Infant Toddler Program or NC Public Schools Part B Program (Exceptional Children's Pre-K) will not be affected in any way if you choose to participate, not to participate or to withdraw. If you become concerned about your treatment as a participant in this study, you may also contact Dr. Tom Ford, the chair of Western Carolina University's Instructional Review Board at:

Research Administration
Office of Research and Graduate Studies
Cordelia Camp Building, Room 110
Cullowhee, NC 28723
828-227-7212

With thanks, Wendy



By signing, you are granting Wendy Wieber permission to use words and information from your audiotaped (sound) interview for research and presentation purposes only. Your signature below also indicates that you are over the age of 18.

Participant's name (please print) _____ **Date:** _____

Participant's Signature: _____

Address: _____

Phone: _____ **email:** _____

Preferred way to contact you: **Phone:** _____ **email:** _____

Appendix B: Interview Protocol

Family Questions

1. Think of the time when you first learned that your child had hearing loss? What was that like?
2. Think of the time when you first chose to work with an early intervention teacher for deaf and hard of hearing children. What caused you to make this decision?
3. Think about a time when you had to make a choice about the services and/or about the interventionists and the amount of time you spend with them. How did you make that choice or those choices? (Probes: What was that like for you? How do you choose what activities with your child are most important to give your time to?)
4. Think about a time when the early intervention service for your child went especially well (or was especially helpful). What made that intervention so helpful? (Or- What was that like for you?)
5. Think about a time when the early intervention service for your child did not go well (or was not helpful). What made that intervention unhelpful or ineffective? (Or- What was that like for you?)
6. Do you have other concerns that you want to share? For example, is there anything else you would like other families, teachers, and professionals to know from your experience?

Appendix C: Your Child's Needs

YOUR CHILD'S NEEDS

Your child may have several needs that she or he receives medical attention for and may also receive therapy or home intervention. Please rate your child's needs from the most critically in need of intervention (really want/need help-gotta fix this!) to the least important (we've got this handled!):

Type of special need (for example: heart, hearing/communicating, vision, motor, feeding)
1
2
3
4

of children in your family: _____ # of other children with special needs?

Services your child receives in the home :(check if applies)

	Weekly	2x a month	Monthly	4 x yearly	Yearly
Physical Therapy					
Occupational Therapy					
Nursing					
Nutrition					
Teacher of the Deaf					
Vision Services					
Speech Therapy					
Other					

Appendix D: IRB Approval

Western Carolina University
 Institutional Review Board
 c/o Office of Research Administration
 110 Camp Building
 Cullowhee NC 28723
 irb@wcu.edu | 828-227-7212
 IRB number: 2015-0004



Date of review: July 8, 2014

Investigators: Wendy Wieber, John Habel, Bill Ogletree

Project Title: A Descriptive Study of Parent Involvement in Early Intervention for Children who are Deaf or Hard of Hearing and have Additional Special Needs

Your IRB protocol has been approved, effective with today's date, under the following category of expedited review, as authorized by 45 CFR 46.110 and 21 CFR 56.110:

- Clinical studies of drugs and medical devices (a) when an investigational new drug application (21 CFR Part 312) is not required or (b) medical devices for which (i) an investigational device exemption application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling
- Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture
- Prospective collection of biological specimens for research purposes by noninvasive means
- Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves
- Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis)
- Collection of data from voice, video, digital, or image recordings made for research purposes
- Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies
- Continuing review of research previously approved by the convened IRB

Your protocol is approved for one year and may be renewed annually. If you wish to make changes to your protocol, including recruitment procedures, sampling, consent, interventions, data collection methods, and investigators, please use the amendment request located on the IRB website (<http://www.wcu.edu/6801.asp>) to submit your request in advance.

This approval does not cover research conducted prior to the approval date. Please remember that you are responsible for reporting adverse events or unanticipated risks to the IRB immediately.

IRB representative:

A handwritten signature in black ink, appearing to be 'T. R. O.', written in a cursive style.

Appendix E: Eligibility Definition for the NC Infant Toddler Program

NEW ELIGIBILITY DEFINITION FOR THE NC INFANT TODDLER PROGRAM

The following eligibility definition for the NC Infant Toddler Program for children aged birth to three under Part C of the Individuals with Disabilities Education Act (IDEA) has been approved by both state (Commission for Health Services and Rules Review Commission) and federal (U.S. Department of Education Office of Special Education Programs) entities, with an implementation date of July 1, 2006.

The Early Intervention Program (NC Infant Toddler Program) in the Early Intervention Branch and its Children's Developmental Services Agencies appreciate the public comment associated with this change in the eligibility definition.

This change in eligibility definition means that eligibility for children referred on or after July 1, 2006 will be determined under the new definition. Children who were referred to the program before July 1, 2006 will have their eligibility determined by the “old” criteria. Children who were determined eligible and enrolled in the program under the “old” eligibility criteria will continue to have their eligibility determined by that criteria. They will not be subject to the “new” criteria.

(a) Children from birth to age three (3) are eligible for early intervention services under Part C of the Individuals with Disabilities Education Act (IDEA) if they have been determined by the Children's Developmental Services Agency to meet the criteria of one of the two following categories:

- (1) developmental delay; or
- (2) established conditions.

(b) Developmental Delay.

- (1) A child is considered to have developmental delay if the child's development is delayed in one or more of the following areas:
 - (A) Cognitive Development;
 - (B) Physical Development, including fine and gross motor function;
 - (C) Communication Development;
 - (D) Social-Emotional Development; or
 - (E) Adaptive Development.
- (2) The specific level of delay shall be:

- (A) documented by scores of 2.0 standard deviations below the mean of the composite score (total test score) on standardized tests in at least one of the above areas of development; or
- (B) documented by a 30 percent (30%) delay on instruments which determine scores in months in at least one of the above areas of development, or
- (C) documented by scores of 1.5 standard deviations below the mean of the composite score (total test score) on standardized tests in at least two of the above areas of development, or
- (D) documented by a 25 percent (25%) delay on instruments which determine scores in months in at least two of the above areas of development.

(c) Established Conditions. A child is considered to have an established condition if the child has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay. Specific conditions through which a child may be deemed eligible in the established conditions category are as follows:

- (1) Congenital Anomaly/Genetic Disorders/Inborn Errors of Metabolism. These are children diagnosed with one or more congenital abnormalities or genetic disorders with developmental implications. Some examples are Down Syndrome, Fragile X Syndrome, familial retardation syndromes, and fetal alcohol syndrome.
- (2) Congenital Infections. These are children diagnosed with congenital infections with developmental implications. Some examples are toxoplasmosis, rubella, cytomegalovirus, and HIV.
- (3) Autism. These are children diagnosed with autism or autism spectrum disorders.
- (4) Attachment disorder. These are children with a diagnosed attachment disorder.
- (5) Hearing Loss. These are children diagnosed with unilateral or bilateral permanent hearing loss.
- (6) Visual Impairment. These are children diagnosed with a visual impairment that is not correctable with treatment, surgery, glasses, or contact lenses.
- (7) Neurologic Disease/Central Nervous System Disorders. These are children diagnosed with a disease or disorder known to affect the nervous system with developmental implications, such as Cerebral Palsy, Spina Bifida, Epilepsy, and Microcephaly.
- (8) Neonatal Conditions and Associated Complications. These are children diagnosed with one or more of the following neonatal diseases or disorders known to have developmental implications:
 - (A) Gestational age less than 27 weeks or birth weight less than 1000 grams;
 - (B) Neonatal encephalopathy with neurological abnormality persisting at discharge from the neonatal intensive care unit;

- (C) Moderate to Severe Ventricular Enlargement at discharge from the neonatal intensive care unit or a ventriculoperitoneal shunt;
- (D) Neonatal seizures, stroke, meningitis, encephalitis, porencephaly, or holoprosencephaly;
- (E) Bronchopulmonary Dysplasia requiring supplemental oxygen at discharge from the neonatal intensive care unit;
- (F) Intrauterine Growth Retardation;
- (G) Necrotizing enterocolitis requiring surgery;
- (H) Abnormal neurological exam at discharge;
- (I) Intraventricular hemorrhage III or IV; or
- (J) Periventricular leukomalacia.

Appendix F: A Sample of Parent Interview

Interview:
Pseudonyms
Mother- Jez
Son- Andrew (2 years 7 mos)

(Reflections- this parent answered last question directly to parents)

First we cover the YOUR CHILD'S NEEDS form:

Andrew is 2-7 Diagnosed with Auditory Neuropathy
He was born at 26 weeks after mom's water broke at 24 weeks "he was just not done cooking".
He was on vent for 4 weeks. Chronic Lung
Has two older brothers -(10 & 4)
Mother said neither of the older brothers has any disability but later mentioned that the 10 year old has ADHD.

Mother rated:
#1 Feeding (Sensory issues - g-tube feeding at night - now takes bottle too)
#2 Motor skills
#3 Hearing/Communicating

Jez: Hold onI have to turn up the phone to see if I can hear you....Gotta find the volume button. All right, now say something.

Interviewer: OK, can you hear me better?

Jez: Yeah, I can hear you better. I'm sorry, I ain't got my ears in this morning. I can't hear good without my ears.

Interviewer: Oh, you have hearing loss?

Jez: Yes, I am completely deaf in my right ear and um I have hearing loss in my left ear, the level of speech, so if people are talking and there's a lot of background noise, I can't hear a word you're saying.

Interviewer: So do you need to go get your hearing aids?

Jez: No, because when I'm on the phone, they wiggle out.

Interviewer: Do you have a telecoil that works?

Jez: No, I'm good. And I got the kids planted in front of the DVD player because for some reason or other our Direct TV isn't working. I should be good. My husband's not here this morning he had something he had to go do some work or something like that...

Interviewer: You've got your hands full.

Jez: Just a little bit.

Interviewer: So how many children do you have?

Jez: I have three. They are all boys. I have a 10 year old, a 4-year old and Andrew; he's 2 and a half.

Interviewer: Is Andrew the only one who has special needs?

Jez: He's the only one.

Interviewer: So the first thing we are going to do is rate your child's needs. Andrew may have several needs that he receives medical attention for or therapy or home intervention. Whatever Andrew has going on, from your point of view, what needs the most attention?

You can start with what you think he most needs .

Jez: I think he has more than one. I mean his hearing of course. His hearing is a big issue, but he has audio neuropathy. His hearing comes and it goes. Some days he hears really well and some days he doesn't hear so well. So, and he hears, he picks up a lot of stuff. Even without his hearing aids on, he picks up a lot of stuff.

Interviewer: I've heard from parents that auditory neuropathy is very weird in that way.

Jez: It is! It is! And like on rainy days, he doesn't hear worth poo.

Interviewer: Laughter..that's interesting.

Jez: On rainy days you can sneak up on him, but on clear days, like today, it's hard to sneak up on him.

Interviewer: That is so interesting! So do you feel that's his most critical need, or does he have something else that you think is more critical?

Jez: Well, he has a texture issue.

Interviewer: Uh huh...

Jez: Um, he doesn't eat. He doesn't eat food by mouth. He's gotten to where he will take his bottle with cereal in it and he'll take like three 8 oz bottles a day now. Where he wasn't doing that before. So I guess that would be the most critical because if you don't eat you die.

Interviewer: Ah, yes. So feeding is the most critical. And what do you think would be next?

Jez: Um. I guess his, um....I don't know. I guess his hearing and his, well I guess his gross motor and his fine motor.

Interviewer: Uh huh.

Jez: And then his hearing.

Interviewer: Ok.

Jez: I mean, if you can't eat, I mean it doesn't matter if you can't hear. If you can walk and get around and work in your environment to get what you need, then....yeah.

That comes before his hearing.

(There is some sense here that she is ready to filter in order to please me, knowing my field is deaf education, but she decides to go ahead and tell me what she thinks anyway)

Interviewer: Right. That makes sense the way you explained it. So, feeding, then motor skills, then hearing.

Jez: And motor skills; that would involve his walking too.

Interviewer: Right. Yes, so I have gross and fine motor. And fine motor would help with his feeding too. ...if he would be willing....

Jez: Exactly... (laughing). Well he will do bits and pieces of things but not anything that will sustain anybody. It wouldn't even make a good snack. But he's doing a lot better than he was doing. You know, he wouldn't even...you know, (teacher's name) the deaf and hard of hearing lady that comes from North Carolina...last year at this time, she brought him a pumpkin and they gutted out the pumpkin and he wouldn't touch it.

Interviewer: Oh, the slimy seeds?

Jez: Yeah, he wouldn't touch the inside of it. This year, he's like whole head in the pumpkin!

Interviewer: Ohhhh. That's great.

Jez: Yeah, he has come a long way!

Interviewer: So who comes to visit him at home for services?

Jez: Just (the teacher for the deaf).

Interviewer: Just (TOD). So he doesn't get physical therapy or...?

Jez: Not any more, no. Cause my insurance changed and my insurance doesn't cover anything and I talked with his social worker (name) and it was going to cost me \$40 every time somebody came out and I told her I definitely need (TOD) and I told her to get the lady for occupational therapy that we had last time. She deals with textures also and she (social worker/case manager) said that she would get her set up when school started back up and I haven't heard anything yet.

Interviewer: OK, so (TOD) and she's the only person who is coming out and she comes every week?

Jez: Yes, she comes every Thursday. And I met the other lady who is going to be working with him when he is 2 ½. Yeah, I met her one time and I really like her and Andrew likes her too.

Interviewer: Oh good!

Jez: I'm not really sure when she'll start picking up. So he's 2 years and 7 months.

Interviewer: Is she from the school system?

Jez: Yes, I think so.

Interviewer: Well, I don't know if he would go into a classroom when he turns 3 or if she could come out to the house or go to childcare. Is he home with you during the day or..... but you work right??

Jez: Yes, he is. He is. And I do what I know to do. What I've seen the therapist do. I help him work his legs. I help him move his hands. I have little stuff that I've seen them use and like peg things that help him with his fine motor skills.

Interviewer: Wow!

Jez: I mean wooden puzzles.

Interviewer: But you work. I know you said you have a wacky work schedule. Was it nights?

Jez: Yes, I usually work night weekends; Friday, Saturday and Sunday nights. But since our census is up so high right now and we don't have that many nurses, I'm having to work like four and five days in a row.

Interviewer: Ok, that's what you said; that it had been a really hard week. So who takes care of Andrew when you're not there?

Jez: My daddy. My daddy and my husband.

Interviewer: That's great.

Jez: Yeah. My husband takes care of him when he's here. My husband works first shift. And when I'm sleeping, my daddy has him.

Interviewer: That's really wonderful. I think your husband answered the phone a couple of times when I called. He had a very nice voice.

Jez: Yeah, that's that country.

Interviewer: Yes, I like that country. So, now I'm going into the questions. There are six of them. I think (TOD) gave you all the materials to help you decide if you wanted to participate, but, if your household is as crazy as mine, you may have put them somewhere or not have them any more.

Jez: Yeah, I can't find them.

Interviewer: That's all right. But I can send you the materials again in case you want to see them and there is also information about how to get a hold of me or how to reach the college if you had concerns or questions. For example if you felt upset because of the interview or wanted support, I can help with that because you are giving your time and energy and good information.

Ok.

1. Think of the time when you first learned that your child had hearing loss? What was that like for you?

Jez: It really wasn't a big deal for me. (Laughing) Believe it or not, it really wasn't a big deal.

Interviewer: So you just took it in stride because you are familiar with hearing loss?

Jez: Well, we never thought we would actually bring him home from the hospital.

Interviewer: Ohhh

Jez: Yeah, because he was 2 lbs 3 oz. So we never thought we would bring him home from the hospital.

Interviewer: That must have been....

Jez: So his hearing loss wasn't that big of a deal for me.

Interviewer: So it was just survival that was the concern.

Jez: Right.

Interviewer: How long was he in the NICU?

Jez: 5 months. He spent a month in the progressive care; the step-up unit and then we got to bring him home.

Interviewer: How much did he weigh when you brought him home?

Jez: 8 lbs and something....

Interviewer: And was he on any machinery or monitors?

Jez: He had night feedings through his tube. Which he still has that. But that's about all, I mean we didn't have oxygen or anything like that. He come home not on oxygen.

Interviewer: That's great.

#2- Interviewer: So, when you first chose to work with an early intervention teacher for deaf and hard of hearing children. What caused you to make that decision? You may have been offered a lot of different options, so what caused you to choose a teacher of the deaf?

Jez: He needs to be able to communicate. That's paramount. You can't get anywhere in this world if you cannot communicate.

Interviewer: And how is his communication now?

Jez: It's very good ..(laughing). He is talking. I mean he is actually stringing sentences together. His consonants do not sound right, but if you listen to him you can kind of make out what he's saying whether or not he has his hearing aids in or not. Like, the example: I was getting ready to work two weekends ago. And Andrew sleeps in our

room. I was putting my hearing aids on to go to work and he said "Mama put her ears on?" (Laughter) And I said "yes, mama's got to put her ears on".

Interviewer: Wow! That's really good!

Jez: And he's signing more too. He'll sign "more" and "animals". He'll sign "no" and he'll sign "stop" and he'll sign "poop". He won't sign "help" yet. He'll sign "bird", he'll sign "chicken". He'll sign "duck" and we're working on "please". "Please" is hit and miss. He signs a bunch of stuff. I mean for him not to be able to....and I thought it would be a good idea too. I don't know if my hearing loss is going to continue. So I wanted a way to be able to communicate with him also.

Interviewer: Right. And do you know what caused your hearing loss?

Jez: No, they can't find out. They don't know. And through MRIs and blood work, they don't know what caused my hearing loss.

Interviewer: Hearing is such a quirky thing.....

Jez: It sure is...

Interviewer: So, it sounds like you were getting several services for Andrew.

Jez: Yeah, we were getting...when he was on Medicaid, there were so many people, so many people coming out here they were blowing the hinges off the door. I can definitely tell a difference between when he had Medicaid and when he didn't. I can definitely tell a big difference because it's like nobody wants to come out.

Interviewer: That's terrible.

Jez: Yes, I know. It shouldn't matter where your funding is coming from. It should be what your child needs.

Interviewer: I agree. (#3) So, the choices you made about people coming out originally, did you have to choose between who was coming out when Medicaid was paying?

Jez: No, they just sent everybody that he needed. And I gave everybody a chance. You know what I'm saying? He had physical therapy coming out....well, no he didn't have physical therapy coming out for some time. I kept telling them that he needed physical therapy, but they never would send anybody. Because I kept telling them that he's getting behind in his motor skills. I'm noticing he can't walk. His hamstrings are tight. He needs physical therapy out here. And it wasn't until (name) the Occupational Therapist, you know, I was talking with her about it and she would work some of that stuff too. And it's when she started saying it too that they said,

“oh, we need to get physical therapy out here”. It was a big mess. No, I had occupational, I had play therapy out, I had ...we went to a feeding specialist up in Forest City. And it's just. I would just gage how Andrew would interact with them. And like some of the people he really did not interact that much with. So, people he just did not like because they were so forceful. And when you try to push him to do something the more he withdraws from it. So I just kind of critiqued that and the ones that he didn't work really good with, I took away.

Interviewer: Right. Ok, so that is how you made your choices?

Jez: Right. Because it made negative consequences. Example: His speech therapist who was supposed to help with speech and feeding, she kept trying to force a cup on him. And I kept telling her, “don't pushdon't force him into a cup like that...don't hold it up to his mouth and make him try to drink out of it, it's not going to work.” Well, to this day, and that was almost a year ago, to this day, he won't put a cup anywhere near him.

Interviewer: Oh dear.

Jez: He won't have nothing to do with a cup. And that has to come back form her. Has to.

Interviewer: I see. (#4) Well, think about a time when an early intervention service for Andrew went really well. Like with one of those people you mentioned that he and you really clicked with. What made that so helpful? How did you feel about it?

Jez: It felt really good. And it was (name) with occupational therapy. She worked really well with Andrew. She was able to get Andrew to try different foods. And he wouldn't eat any kind of food at all. And she got him semi-over some of the textures. Not all of the textures, but some of them. I mean he still won't eat baby food. He vomits baby food because of the texture. But now he'll eathe'll try scrambled eggs, bacon, bits of cheese, grated block cheese, bread, pancakes. He'll eat toast, but not with jelly on it. He doesn't like the consistency of the jelly. But you see, jelly is a lot like baby food.

Interviewer: So what do you think she didwhat was it about the way she worked with Andrew that worked so well?

Jez: She's very patient and she took her cues from Andrew. She wasn't trying to...she would push him to a point, but she'd let Andrew lead. Do you see what I'm saying?

Interviewer: I do.

Jez: I mean it wasn't like she had a schedule and we had to get this, this, this and this done today (stressed today). She's goal oriented but she was mindful of what the

child needs and how far she could push him. And she would make kind of a game out of it and he really loved (name)...really loved (name).

Interviewer: And she's the one who doesn't come any more because of the Medicaid?

Jez: I haven't been able to get her to come back out here. They were supposed to get her to come back here when school started because she would have some openings left in her schedule when school started back, because you know she had stuff to work on. But I just haven't heard nothing back from (name of EISC) on it. I would really love to have her back out here again. I'd pay the \$40 or \$100 a week if I had to.

Interviewer: She sounds really really good and you described it very well.

Jez: And she does very well with Andrew. I mean she has very good rapport with him.

Interviewer: That is so important.

Jez: And you can get further. You can get to your goals easier too. It's not such an uphill battle.

Interviewer: Right. (#5) So think about the opposite; a time when a service for your child did not go well or you thought it was really not helpful. What was that like for you?

Jez: It was awful! Because Andrew would get scared about going. It was the Speech Therapist we went to in Forest City. I mean he didn't like her. He wouldn't do anything for her and he cried. He did not like going up there!

Interviewer: So how often did you do that?

Jez: I had to go once a week.

Interviewer: And you had to drive a baby.

Jez: And she wouldn't listen to you. I mean I would try to give her input, and she would not...it was just what she wanted to do and an it uh uh. When I finally got him so he would feed off the bottle, if she saw that he was taking his bottle really well, she wanted to take the nipple and dip it in applesauce and then stick it in his mouth. And I asked her...I said "I really wish you would not do that because I finally got him to like this and if you trick him and try to pull over something like that it's going to make it where I can't feed him with a bottle any more.

Interviewer: Right.

Jez: Well, sure enough, she poked it in his mouth and he projectile vomited everywhere. And it took me a day and half to where he would take a bottle from me again.

Interviewer: Ah. It's always good for therapists to listen to parents.

Jez: They need to. But I didn't know anything. She didn't need to use the nipple off the bottle he was drinking out of! But she did introduce him to a z-vibe and that has gotten him to where he will brush his teeth. Where he wouldn't take anything in his mouth at all. But (name of other therapist she likes so much) works with a z-vibe too, but (speech therapist) introduced him to the z-vibe which I think has made things easier. To work his muscles out in his cheeks and tongue.

Interviewer: (#6) My last question has to do with any other concerns that you want to share. What you would want professionals in the field to know, or other families to know? What do you want people to know from your experience with Andrew?

Jez: Patience. Patience. Every child moves at their own pace. And parents; don't be afraid to state what you feel would be a better way to come at a problem.

Interviewer: Uh huh.

Jez: If you have questions, don't be afraid to ask them. And keep asking your questions until you get the right answer or the answer that suits you. Don't just take no for an answer.

Interviewer: That is a good point.

Jez: And nobody knows your child better than you do. I mean you need to take our cues off your child as well.

Interviewer: I sure wish we could have met face-to-face. But I guess everyone is just super busy.

Jez: It's kinda wild around here.

Interviewer: I'm sure it is. So is there anything else you want the world to know?

Jez: Oh Lord! (Laughing). Um, I'm not really sure., but I really wish.... And this has got nothing to do with you or with me it's just the general population. I just really wish that people would not frown on people who have disabilities. Just because they're not a perfect person in society it doesn't make them any less of a person. It doesn't mean they have less to contribute. But that's not something we can change.

Interviewer: Have you felt that towards Andrew or yourself?

Jez: I have felt that from therapists, yes. And I have even felt that from the people at the hospital. We did not have a good experience in the progressive care in Charlotte, we did not. We had a great experience in the NICU. All the nurses in the NICU were wonderful and when we stepped down to progressive care, it was like night and day.

Interviewer: So what do you think that was?

Jez: I think they had more patients per nurse. But then there was a breakdown in communication. I'm sure the NICU told them how Andrew was, but I don't think progressive care took that into consideration. Andrew was a very needy patient. He had a lot of issues. He had a floppy airway. So when you would lay him on his back, his airway would go shut. So you had to keep him...well, you could put him on his back but someone had to be close by to watch his SATS (oxygen saturation (SO₂), commonly referred to as "sats"). If his oxygen dropped and you don't get any oxygen to the brain, you know what happens, you get brain damage. So, I don't know, but I'm a nurse.

Interviewer: So you know this stuff.

Jez: I do. I would constantly get the question, "so what do you do for a living?" And I would say, "it doesn't matter what I do for a living". It should not matter what I do. I would just get feelings that something wasn't right so I would hop in the car and go to Charlotte. And most of the time it was when he was in progressive care. And one time I went in and there was no one around and his alarms were going off and his sats were dropping and he was laying on his back. Well, I flipped him over. I phoned in, put my gown on and I flipped him over. And his sats automatically start climbing up. And then I have a nurse come flying at me, "what do you think you're doing?" "I'm flipping him over because he has a floppy airway and his sats were down in the low eighties and seventies, are you his primary nurse?" And she said "yes I am" and I said "well, can you tell me how long he's been in the seventies and eighties?" "Uh uh uh, I don't know." "Well that's a pertinent piece of information". She said "well, you have to have an order to turn him over like that. He can't be in a crib with oxygen and be on his stomach". And I said "well yes, mam, he can". And she said, "you have to have an order for that." And I said, "well you go check because he's been in the NICU for a very long time on oxygen on his belly. Andrew has a floppy airway." And I said, "Where's your supervisor at?" I mean cause she made me mad. She gave me a lot of flack. She gave me a lot of attitude. And I do not like that. Yeah, I ended up talking to her supervisor and we got it straightened out. And I told her, "if Andrew has got a nurse who has a certain pod, he does not need to be on the other side of the nursery. He needs a primary and a secondary. He doesn't work well when he doesn't know whose coming at him because he works better when he know the person."

Interviewer: It sounds like you learned to be assertive when it was necessary.

Jez: If it was their child, how would they feel? And if I hadn't a drove up there when I did, there's no telling how long his sats would have stayed that low. Your brain can't take not having oxygen. You can end up with really bad problems.

Interviewer: It sounds like you have really stood up for him.

Jez: We've been through the ___ with Andrew, that's for sure. It doesn't really seem that bad now, but when you think back and think about certain things that happened, you think "oh my God, how did I get through that?" And Andrew is not my only child. I have two other children. And I have to work-have to work- and my husband has to work. I didn't have the luxury of staying at the Ronald McDonald House. They kept offering it over and over and over. I appreciate them offering that option to me, but there was no way I could take them up on that option. Just because Andrew's down here, I've got a life going on. I still have other kids and they have other needs too.

Interviewer: I don't think Ronald McDonald house takes siblings..??

Jez: Well, they wouldn't want mine! Both boys. And my 10 year old has ADHD and my 4 year old is just a daredevil! This doesn't have anything to do with what we're talking about but....(Tells long story about how 4 year old dropped pants at school in cafeteria and "shook his private at everyone and then turned around and shook his Henie at everyone" and how she had to go into school and talk with teachers). It was a very funny story.....but highlighted her way of talking with her kids.

Then we went into discussion about the pseudonyms. She chose Jezebel for herself! I shortened it to Jez so it would not be so weighted. She chose Andrew for her son. She chose Amazon gift card because she doesn't like to take boys anywhere!

Interviewer: Anything else you would like me to put into this writing, so people who read it know more about your experience and your thoughts?

Jez: Take life with a grain of salt. Laughing.

Interviewer: It sounds like you have a really good sense of humor.

Jez: That's true. We just squall all the time non-stop. Life is just too short to make mountains out of mole hills. But, it is extremely hard some times. Especially when it's dealing with your own child. But it will all work out...compared to where he was this time last year or two years ago, he's doing extremely well. His language is really coming along, That stringing words together just started. He's 6-8 months delayed in other areas like walking.

Interviewer: Is he walking at all?

Jez: Oh, he can hold on to things and walk. He can't free-walk because his hamstrings are tight and he'll just fall down. He'll walk up steps and hold on the spindles. But when he walks he's like a Tennessee Walking Horse, you ever seen one of those?

Interviewer: Yes.

Jez: They step their feet really high up. That's like what Andrew does. And his right foot kind of turns in too, but we're working on it. We're trying to get some leg braces. We've been working on it for the last year. We're trying to get it through the (name of service coordinator). Our insurance said they wouldn't pay for anything and they took everything back. We're going through different agencies for kids to try to get something for his legs so they will straighten so he doesn't have to have surgery on them.

Interviewer: I see. So if they stay tight too long, he could need surgery? It seems that an area in which you have a need is to get insurance to cover some of his necessities? Does he qualify for SSI or Medicaid?

Jez: I'm trying to do the SSI again. He should technically be under SSI just because of his birth weight. It's just extremely hard to get appointments with SSI. And it's hard to get into (name of hospital in Charlotte). Since they changed their phone system over you can't get anyone to call you back from (hospital). For the hearing thing. You call and leave a message and no one ever calls you back. And that's where you have to go for children's hearing aids. No one else around here does children's hearing aids. I'm kind of in a rural area. It's either that or go to Asheville and I don't really want to drive to Asheville.

Interviewer: Well, I'm out here near Asheville and we lost our pediatric audiologist at (hospital name). It sounds like the system has been difficult to navigate.

Jez: It is. And if you don't have any help, it's really hard too. (Service coordinator name) was good at one point. I don't know what the deal is. Maybe I need to switch social workers.

Interviewer: Clarifies that (name) is with the CDSA and acts as service coordinator. I asked if she thought she could ask for another service coordinator.

Jez: I could. But I wonder if that would make hard feelings. You know what I mean?

Interviewer: Yes, I hear you.

Jez: And then you have that to navigate too.

Interviewer: It sounds like you get caught between advocating for your child and the people pushing back when you do the very thing that a good mother does.

Jez: Yes. Between a rock and a hard place. (Long pause. I got the feeling that she was wearing out.)

Interviewer: This has been a really good interview. Thank you so much!

Jez: Oh you're welcome. I appreciate your time and I appreciate your patience!

Interviewer: Well, I was persistent!

Jez: I didn't mean to make it so hard to get a hold of me.

Interviewer: Well I just figured you had a lot going on! I'm glad we finally connected. I hope things go well for you and your family. Thank you again for talking with me.