Parent Experience with a Dual Diagnosis of Autism Spectrum Disorder and Hearing Impairment

Capstone Document

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Audiology in the Graduate School of The Ohio State University

By

Julie Stefanski, B.S.

Graduate Program in Speech and Hearing Science

The Ohio State University

2014

Capstone Committee:

Gail Whitelaw, Ph.D., Advisor

Christina Roup, Ph.D.

Paula Rabidoux, Ph.D.

Copyright by

Julie Ann Stefanski

2014

Abstract

The aim of the present study was to evaluate the experiences of parents raising children with a dual diagnosis of hearing impairment and autism spectrum disorder (ASD). Subjects were recruited through outreach to a network of professionals in related fields, as well as the Autism Research Institute's Network for Deaf/Hard of Hearing and Blind/Visually Impaired. Five qualifying parents consented to participation in the study and shared their experiences in a one-on-one interview. Results were analyzed using strategies from the thematic network analysis theory, a qualitative research model. Parents reflected on their experiences during the diagnostic processes, throughout interventions and therapy, and regarding their educational decisions. Results revealed unique experiences across families, as was anticipated; however, overlying themes included fluctuating emotional experiences with professionals during the diagnostic processes, eventual satisfaction with interventions received, and ongoing challenges regarding educational decisions. The results of this study support the goal of contributing to the limited body of research on the co-occurrence of hearing impairment and ASD, as well as raising awareness and insight for health care providers and educational professionals who provide services to individuals in this population.

Dedication

I dedicate this Capstone to my family and friends for their continued support in development of this document and beyond. A special dedication to my cousin Dean who has always taught my family that disability is never a limiting factor for a meaningful and beautiful life.

Acknowledgments

I thankfully acknowledge the never ending support of my advisor, Gail Whitelaw. Thank you to my committee members for participating in my capstone experience. I am grateful to The Ohio State University Speech and Hearing Science Department, as well as the Nisonger Center's LEND program, which have both inspired me to pursue this study.

Vita

June 2006……Westerly High School, Westerly, RI

May 2010……Bachelor of Science, Communication Sciences and Disorders, James Madison University, Harrisonburg, VA

September 2011-June 2013……Lend Trainee, Nisonger Center, Wexner Medical Center at The Ohio State University, Columbus, OH

May 2013-May 2014..……...Extern at Connecticut Children's Medical Center, Hartford, CT

Fields of Study

Major Field: Audiology

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction

According to the Centers for Disease Control and Prevention (CDC), the term developmental disability is defined as "a group of conditions due to impairment in physical, learning, language, or behavior areas" (CDC, 2013, p.1). Developmental disabilities can occur anytime in the first twenty-two years of an individual's life, and usually last throughout a person's lifetime. The focus of this study surrounded parents' experiences of raising children carrying the diagnoses of Autism Spectrum Disorder (ASD) and hearing impairment, which are both more broadly defined as developmental disabilities.

ASD has historically been used as an umbrella term encompassing the three following subtypes: Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). The Diagnostic and Statistical Manual of Mental Disorders has recently been revised from the DSM-IV to DSM-V. The upgraded manual includes revisions to the diagnostic criteria of ASD.

Individuals included in this study were diagnosed with ASD under the DSM-IV criteria. The DSM-IV separates the three classifications listed above based on specific diagnostic criteria (APA, 2000). The DSM-IV criterion for Autistic Disorder includes impairment in areas of communication, social interaction, and restricted repetitive behaviors, with the onset of symptoms occurring before age three. Asperger Disorder criterion includes impairment in social interaction and repetitive stereotyped patterns of behavior, without a significant delay in language development. A diagnosis of PDD-

NOS is made when a child presents with severe pervasive impairment in social interaction, along with impairment in verbal or nonverbal communication, but does not meet the diagnostic criteria for pervasive developmental disorder. Essentially, PDD-NOS is a diagnosis for atypical autism, and is made in cases when history is unavailable, impairment in one category is mild, or when onset of symptoms is later than three years of age (Witwer & Lecavalier, 2008). Although these subtypes have unique diagnostic criteria, they are routinely grouped into the umbrella category of ASD, as applied in this study.

As summarized in the American Academy of Pediatrics News (2013), the newly revised manual, the DSM-V, no longer observes the sub-characteristic diagnoses (Hyman, 2013). Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or PDD-NOS will be given the diagnosis of autism spectrum disorder. A new diagnosis, social communication disorder, may better serve individuals with deficits in social communication, but do not present with symptoms meeting criteria for autism spectrum disorder. The social communication disorder diagnosis is a new addition to the DSM manual, as well as another new addition featuring a severity level from 1-3 which is applied to a diagnosis of ASD based on level of need for support services.

In addition to a diagnosis of ASD, this study included parents of children carrying an additional diagnosis of hearing impairment. Hearing loss, or hearing impairment, is defined by a number of criteria. The Individuals with Disabilities Education Improvement Act of 2004 defines hearing impairment as "an impairment in hearing, whether permanent or fluctuating, that adversely affects a child's educational

performance" (2004, section 300.8). Hearing impairment is also defined as, "an impairment that happens when an individual's hearing is affected by a disease, disorder, or injury. Hearing loss can be present at birth or develop in childhood or adulthood." (AUCD, 2013, p.1). Although the terms "dual diagnosis", "co-occurring disabilities", or "co-morbid disorders" are all used to describe the presence of two diagnoses that co-occur in an individual, for the purpose of this study the concept of dual diagnosis refers to the presence of two specifically identified developmental disabilities, hearing impairment and ASD.

At the root of most developmental disabilities is the presence of behavioral impairment in communication, which is true for both ASD and hearing impairment, both when singularly occurring and in the realm of a dual diagnosis. Families of children with hearing loss, and a diagnosis of ASD, report complicated evaluation processes, citing frequent misdiagnosis as the result of one condition masking the other. A diagnosis of hearing impairment is estimated to occur in 1 out of every 53 children diagnosed with ASD, and a diagnosis of ASD is estimated to occur in 1 in 88 children (Szymanski, Brice, Lam, & Hotto, 2012; CDC, 2012). The CDC estimates the prevalence of hearing loss in all children to be between 1-1.5 per 1000 children; therefore, it is assumed that there is a higher incidence of hearing impairment in the population of children diagnosed with ASD (CDC, 2010; Donaldson, Heavner & Zwolan, 2004).

The purpose of this study was to evaluate several parents' perspectives on the diagnostic process, intervention course, and treatment of their children who have received dual diagnoses of hearing impairment and ASD. Results of detailed one-on-one interviews were analyzed to determine optimal courses of intervention, and best practice

of an interdisciplinary team involved in identification and treatment of this dual diagnosis. The primary and secondary research questions of the proposed study were:

1. Based on parent report, was there a typical intervention course for children with hearing loss and ASD for early identification, treatment, and educational settings?
2. What role does an interdisciplinary team play in making appropriate referrals, assessments, and recommendations?

The goal of this study was to contribute to the limited body of research focusing on the co-occurrence of ASD and hearing loss. A supplemental goal was to raise awareness for professionals providing services to children with hearing loss and ASD, and yield results that will contribute to best practice for assessment and interventions.

Chapter 2: Literature Review

A Dual Diagnosis of Hearing Impairment and ASD

Children with hearing loss may exhibit many behaviors similar to those characteristic behaviors thought to be associated with ASD. One specific example of a similar behavior associated with ASD and hearing loss is when a child with hearing loss does not respond or acknowledge a speaker when their name is called. This behavior may be a result of hearing loss, but also could be a typical behavioral pattern of a child with ASD. Likewise, if a child is playing alone with self-stimulating behaviors it may be because he or she cannot hear and prefers to play independently because of a communication barrier, or it may occur because of impaired social learning attributable to ASD (Szymanski & Brice, 2008). Self-stimulating behaviors are usually rigid, repetitive movements or vocal sounds, such as rocking back and forth, humming or grunting. The communication barriers that children with ASD and hearing loss experience may present as frustration and disruptive behaviors because of their inability to effectively communicate their needs with others.

Due to these overlapping behaviors, the diagnosis of ASD and hearing loss in children provides a unique challenge. However, it is essential to determine hearing ability in children suspected of having ASD. The Joint Commission on Infant Hearing (JCIH) established recommendations for early identification of hearing loss in children, with significant emphasis on newborn hearing screening programs (Green, Gaffney, Devince, & Gross, 2007). There are two commonly used screening tools, Otoacoustic

Emissions (OAE) testing and Auditory Brainstem Response (ABR) testing (McGrath, Vohr, & O'Neil, 2009). OAE testing is typically the screening tool utilized for initial screenings, and it measures the response of outer hair cells in the cochlea to an incoming stimulus. ABR testing is an electrophysiologic test which measures the brainstem's response to sound stimuli. ABR testing is typically used as a second screening measure following a refer result from OAEs, and has been recommended by the JCIH for use with infants in the neonatal intensive care units because of its sensitivity to cochlear, as well as neural hearing loss, for the higher risk population of infants (McGrath et al., 2009).

Currently, Universal Newborn Hearing Screening (UNHS) standards vary across states, however all states and districts have Early Hearing Detection and Intervention (EHDI) programs. At this time, at least 43 states, the District of Columbia, and Puerto Rico, have mandated hearing screening benchmarks set at screening at least 95% of infants within their first month of life (US Department of Health and Human Services, 2013). These programs have been reported to be effective. Sininger et al. (2009) concluded that children who received newborn hearing screenings at birth were diagnosed and receiving intervention services significantly earlier than those who did not receive a newborn hearing screening. In fact, newborn hearing screenings resulted in an earlier diagnosis of hearing loss by 24.6 months; children were fit with amplification 23.5 months earlier, and enrolled in early intervention services 20. 2 months earlier than those who did not receive hearing screenings shortly after birth (Sininger et al., 2009). While these statistics are encouraging, it is estimated that up to half of infants who fail their initial newborn hearing screening are still lost to follow-up (US Department of Health and Human Services, 2013).

Since the initiation of UNHS, the early identification for hearing loss has greatly improved, therefore individuals with hearing loss and ASD typically receive a diagnosis of hearing impairment first, if the hearing loss is present at birth. The diagnosis of ASD generally occurs later than a diagnosis of congenital hearing impairment, and age of diagnosis is inversely related to the number of behavioral symptoms of ASD present. Maenner et al. (2013) determined that average age of diagnosis is around 3.8 years old when there are twelve of the behavioral symptoms of the DSM-IV criteria present, and when seven or fewer symptoms are present the average age of diagnosis is around age 8.2 years old. One study indicated that children with ASD were found to receive an ASD diagnosis one year later on average if they had a co-occurring severe to profound hearing loss than their hearing peers (Mandell, Novak, & Zubritsky, 2005). However, individuals with unidentified hearing loss, or late onset hearing loss, may potentially begin intervention for hearing loss at the same time or later than for the initial diagnosis of ASD (Szymanski & Brice, 2008).

It is well established that individuals with hearing impairment are at heightened risk for the presence of co-morbid disabilities. Approximately 50% of hearing loss identified in children is attributed to a genetic cause, and about 30% of the genetic causes are linked to syndromes (CDC, 2013). Additionally, almost 23% of hearing loss in babies is associated with maternal infection during pregnancy, head trauma, or complications after birth (CDC, 2013). The diagnosis of additional disabilities is often linked to neurological risk factors that have been associated with both hearing impairment and behaviors associated with ASD (Szymanski, 2012). Some of these neurological factors include: rubella, cytomegalovirus, herpes, prematurity,

toxoplasmosis, CHARGE syndrome, meningitis and measles (McCay & Rhodes, 2009; Szymanski, 2012).

The Gallaudet Research Institute (GRI) publishes an annual survey that serves as a database of information specifically related to family characteristics, demographics, educational services, and the treatment and management of children receiving educational services under the classification of hearing impairment. The most recent publication is from the 2009-2010 annual survey of deaf and hard of hearing children and youth (GRI, 2011). Based on the survey results, the GRI estimated 40% of children that received special education services for hearing impairment also concurrently received services for a co-morbid disability.

Although the GRI's annual report serves as a respected database for tracking school aged children receiving services in an educational setting, there are some possible limitations in their database tracking system (Guardino, 2008). In all educational settings, the information gathered for each student is usually completed by a teacher or school representative without parental contribution, and further, several rural, mainstream, or charter schools do not receive the survey (Guardino, 2008). It has been estimated that the survey material reaches about two-thirds of identified deaf and hard of hearing children in the United States, and often individuals with multiple disabilities are overlooked. Since there is limited information about intervention and educational strategies for children with hearing impairment and co-occurring disabilities, close monitoring and tracking is important for educators and professionals to determine the best course for each child (Roper et al., 2003). Specifically with reference to additional services for ASD, the GRI (2011) survey reflected a gender split of 3:1 with a higher

percentage of boys receiving services for both hearing impairment and ASD than girls (Szymanski, 2012). This data is not surprising considering there are almost five times as many boys diagnosed with ASD compared to girls (CDC, 2012). Although there has been a documented gender difference in the prevalence of the diagnosis of ASD, gender differences are not well documented in the presence of congenital hearing loss, and likely are insignificant.

Research has suggested a stronger correlation between severe to profound hearing loss and the co-occurrence of ASD when compared to a weaker correlation between degrees of hearing impairment and a diagnosis of ASD (GRI, 2011; Rosenhall, Nordin, Sandstrom, Ahlsen, & Gillberg, 1999). As noted several years ago, there has been speculation that the challenges with behavioral testing that occur with this population may lead to overestimation of hearing loss, or the difficulty in identifying mild hearing loss (Rosenhall et al., 1999). Although this strong relationship has been reported, there did not appear to be a correlation between the severity of behavioral presentation of ASD and the severity of hearing loss (Jure, Rapin, & Tuchman, 1991). Similarly, hearing loss in itself does not inherently lead to behavior problems, but children with hearing loss and communication delays are more likely to have behavioral difficulties than children with normal hearing acuity (Stevenson, McCann, Watkin, Worsfold, & Kennedy, 2010).

As mentioned previously, the behavioral similarities of hearing loss and ASD can contribute to challenging assessment processes. A study of thirteen children with a dual diagnosis of ASD and hearing impairment revealed that the most common initial diagnosis was hearing impairment (Roper, Arnold, & Moneiro, 2003). The subjects' parents all expressed concerns regarding overall development or hearing abilities between

6 months to 5 years of their child's life, and rationalized a later diagnosis of ASD because of the masking effect hearing loss had on their child's behaviors. A masking effect occurs when the symptoms of ASD are endorsed as symptoms attributed to hearing loss. When this masking effect occurs, the symptoms of an additional disability, in this case ASD, fail to be recognized and an appropriate diagnosis is delayed.

Recent literature centered on individuals with this dual diagnosis consists primarily of small population studies. Roper et al. (2003) performed a retrospective review of three groups of children comparing results of the Autism Behavior Checklist (ABC) and the Interaction Assessment (IA), as well as a novel 12 item questionnaire for parents' reflections of early development. The subject groups consisted of two groups of children previously diagnosed with ASD, one of which included children who were additionally diagnosed with hearing impairment. The third group consisted of children identified with hearing impairment and learning disabilities. Results of the study revealed consistent delay in diagnosis of ASD because of communication difficulties, even when behaviors associated with ASD were present during early development stages. This study demonstrated the ability to discern behaviors of ASD in children with hearing impairment, because behaviors associated with ASD were not identified in the group with a dual diagnosis of hearing impairment and learning disabilities. Roper et al. (2003) emphasized the potential for developing a systematic review summarizing typical communication methods used by individuals dually diagnosed with ASD and hearing impairment; additionally they stressed the importance of differential diagnoses for implementing ideal education placements and intervention strategies.

Myck-Wayne, Robinson, and Henson (2011) performed a qualitative review of four young children with a dual diagnosis of hearing loss and ASD. The authors were motivated by the lack of current literature regarding diagnostic processes and treatment, and chose four families to document their experiences. Although each family had a unique story, all reported being "shuffled" between audiologists and ASD specialists, such as psychologists and behavioral pediatricians (Myck-Wayne et al., 2011, p. 388). While all families involved in the study were eventually satisfied with the fact that the dual diagnoses were identified, each reported insufficient communication between service providers. The authors declared a need for evidence about how service providers can best support the needs of families, and how service coordination and communication among service providers should be achieved.

Parents raising children with ASD were asked about their experiences in a study by Woodgate, Ateah, & Secco (2008). This study revealed parents' feelings towards advocating for their child. They described the need to act sooner rather than later when it came to pushing for evaluations, treatments or interventions. Parents also described their need to be more direct with professionals and educators in asking for supports and interventions needed for their child. Another study (Myers, Mackintosh, & Goin-Kochel, 2009) described parent's frustration with their children's behaviors in an educational setting and finding a setting that offers the supports needed for their children. Parents reported the stress and challenges of affording supplemental therapies and interventions that are not covered by insurance. In a similar way, parents of children with hearing impairment are forced to navigate challenges. Parents indicated some aspects of their experiences that could be improved including, "access to services and resources,

coordination within clinics and between various clinic providers and agencies" (Fitzpatrick et al., 2008, p.45). Parents also acknowledged that they eventually were able to traverse the system and be satisfied in services for their children, though they believed there were some flaws (Fitzpatrick et al., 2008).

Interdisciplinary Approach and the Professional's Role

Evidence supports the benefits of early intervention for both hearing loss and ASD. Families of children newly identified with hearing loss benefit from effective early intervention programs that focus on access to resources and developing methods to facilitate communication development. Yoshinaga-Itano (2003) concluded that children with hearing impairment that began receiving early intervention services by six months old performed better on measures of language and social-emotional development compared to children who were identified with hearing loss at a later age. This conclusion held consistent even when controlling for a range of variables including gender, ethnicity, socioeconomic status, communication modality, degree of hearing loss, or the presence of other disabilities (Yoshinago-Itano, 2003; Sass-Lehrer, 2011). In addition to the benefits of an effective program on the child's development, parents typically adjusted more quickly to their child's hearing loss than those who do not receive appropriate family services (Pipp-Seigel, Sedey, & Yoshinaga-Itano, 2002). Participants in the study received birth to three intervention services focusing on parent education about hearing loss, aural rehabilitation, and state assistance. They also received support in promoting auditory, speech, and language skills.

In a similar manner, research supports early intervention services for children with ASD (Dawson et al., 2009; Rogers & Vismera, 2008). One study concluded that children with ASD who are enrolled in intensive behavioral programs with an evidence base show improvement in cognitive and adaptive behavior measures, as well as language abilities and social interactions (Dawson et al., 2007). An important component of early intervention services for children with ASD is the implementation of strategies for parents and family members as well as early intervention providers.

Individuals with disabilities are routinely served by professionals, family members and friends who form a supporting team. In many cases, a team is formed shortly after diagnosis, and extends throughout childhood and adolescence. Some members of this team may include teachers of the deaf or hard of hearing, early intervention specialists, audiologists, speech-language pathologists, parent educators, and sign language specialists (Sass-Lehrer, 2011). Individuals with hearing impairment and a co-occurring disability often have team members who change over time, based on the individual's specific needs at that time (Mascia & Masucia, 2003). Teams may represent several different aspects of a child's life, including a medically focused team as well as an educational team. The best practice for assessment and intervention is considered a transdisciplinary approach for early intervention of ASD and hearing impairment (Rabidoux, 2005). A transdisciplinary approach to a team service model includes many disciplines working together in a coordinated manner, with one primary professional as the supporting contact to a family (Kilgo et al., 2003). In a transdisciplinary model the roles of service providers are better defined by the needs of the child rather than strict discipline specific roles (Bruder, 2010). In an early intervention team modeling a

transdisciplinary approach there is greater focus on the provision of, "more efficient and comprehensive assessment and intervention services" (Bruder, 2010, p.344). Consideration of a medical home model of care may be appropriate with the presence of a dual diagnosis of hearing impairment and ASD. The concept of medical home emphasizes a physician's role in coordination of care and specialty services as the "team leader", while monitoring appropriate follow-up and resources for families (Mehl, 2007).

Families of children with a dual diagnosis of hearing loss and ASD often report any or all of the following: delayed speech and language development, inconsistent or absent responses to speech sounds or environmental sounds, or impaired social skills (Szymanski & Brice, 2008). Based on family concern about communication development, the initial evaluation that most children with hearing loss and ASD receive may be an audiological evaluation performed by an audiologist, or an otolaryngological evaluation completed by an otolaryngologist. Additionally, speech-language pathologists and behavioral interventionists can provide insight regarding strategies for obtaining behavioral results in children who are difficult to test. Audiologists are involved in the ongoing monitoring of responsiveness to interventions, and if concerning behaviors persist, a recommendation for a behavioral evaluation is warranted (Myck-Wayne et al., 2011). Audiologists have access to many validation measures, that are specific to different age groups, to be completed by family members, the children themselves, and teachers. These questionnaires are helpful in determining the benefit from rehabilitation, as well as suggesting situations and areas that are in need of improvement (Gabbard & Schryer, 2008).

Since audiological assessments are commonly performed on children with suspected developmental delays, it is important to consider possible modifications of audiological assessment and management techniques that may be required for children with multiple disabilities. In comparison to children who are typically developing, it may be necessary to modify behavioral techniques or to utilize electrophysiologic assessment tools, and other objective measures to determine the type and degree of hearing loss, such as OAEs and ABR testing (Roush, Holcomb, Roush, & Escolar, 2004). In 2007, Tas et al. sought to use electrophysiologic testing to determine the hearing acuity of children diagnosed with ASD. Results from two different electrophysiologic assessment measures revealed an increased prevalence of hearing loss in this population in comparison to typically developing peers. Tas et al. (2007) concluded that it is necessary for children diagnosed with ASD to have a comprehensive audiological evaluation, beyond behavioral measures, to help predict the responsiveness of interventions for ASD.

Obtaining a comprehensive audiological profile, including ear specific and frequency specific information, may be an ongoing process with any child and may be more likely to be an ongoing process for individuals with multiple disabilities, taking months or years to complete (Roush et al., 2004). It is recommended that individuals with multiple disabilities be fit with amplification as soon as possible following a diagnosis of hearing impairment, even if a full audiometric profile is unknown at the time. The American Academy of Audiology pediatric amplification guidelines recommend that at a minimum, reliable air and bone conduction thresholds at one low frequency, such as 500 Hz, and at one higher frequency, such as 2000 Hz, are needed for an appropriate hearing aid fitting (AAA, 2013). Additionally, evaluating benefit is

important for each and every hearing aid fitting. Hearing aid verification is important for pediatric fittings because it measures the hearing aid response at different input levels (AAA, 2013). These measures can be done with a probe microphone in the ear canal, or can be accomplished with simulation using a coupler in a test box while evaluating how appropriately the hearing aids are meeting targets based on a prescriptive formula (Gabbard & Schryer, 2008). Professional judgment determines which verification options are most appropriate with each specific child depending on their level of cooperation (AAA, 2013). A systematic approach to hearing aid fittings, with frequent follow-up, is important for individuals with concurrent disabilities and hearing impairment. Consideration of cochlear implantation is appropriate for candidates with severe to profound hearing impairment and concurrent disabilities, but in some cases behaviors thought to be associated with autism persist following audiological intervention (Edwards, 2007). Counseling families about realistic expectations is critical, and that the benefits of cochlear implantation may have varying effects on diagnosis of ASD and verbal language (Donaldson, Heavner, & Zwolan, 2004).

Awareness of characteristics of ASD for audiologists has been a recent focus, based on both the prevalence of ASD in the general population and the co-morbidity described in the literature. Egelhoff, Whitelaw, and Rabidoux (2005) described characteristic behaviors that audiologists should be aware of that may be the key to the identification of a dual diagnosis or support a differential diagnosis. It is essential for audiologists working with the pediatric population to have an understanding of developmental behaviors, to be able to distinguish typical behaviors from atypical behaviors that may be associated with ASD (Egelhoff et al., 2005). Audiologists and

otolaryngologists may play a key role in making a referral for an interdisciplinary developmental evaluation, as well as facilitating connections with early intervention services for a child. Additionally, audiologists and otolaryngologists have a significant role in the treatment and education plans for their patients when a hearing loss is detected along with suspicion of ASD.

Audiologists must be prepared to evaluate for behaviors associated with ASD among their pediatric patients (Ho, Keller, Berg, Cargan, & Haddad, 1999). A study using the Baby and Infant Screen for Children with Autism Traits determined a significant difference between total scores of children with ASD and children with only hearing loss when assessing symptoms associated with ASD. The study further analyzed the scores across three categories: socialization/non-verbal communication, repetitive behavior/restricted interests, and communication. Results in each category demonstrated a correlation between higher scores (reflecting greater risk) for individuals with ASD on the screening tool than children with hearing loss only (Worley, Matson, & Kozlowski, 2011). Questionnaires targeting social skills, communication skills, play skills, and repetitive behaviors are tools professionals can use to frame concerns and make appropriate referrals (Ho et al, 1999).

Further complicating the diagnostic process is the difficulty that may be associated in obtaining a valid assessment of individuals with hearing impairment for ASD. It is speculated that delays in diagnosis of ASD for children with hearing loss may be due to the inability to use standardized assessment tools for ASD due to the fact that they are not normed on a population of children with hearing loss or the difficulties inherent in administering tests when a hearing loss is present. For example, the Autism

Diagnostic Observation Schedule (ADOS), a commonly used tool in the diagnosis of autism, is not recommended in the diagnostic process of children who are deaf (Szymanski & Brice, 2008). The ADOS has not been normed on the hearing impaired population, and has not been accommodated for use with individuals who are nonverbal, which includes individuals who use sign language. Delays in the diagnosis of both hearing impairment and ASD diagnosis are attributed to the challenges of testing behaviorally. Potential misdiagnosis or diagnostic overshadowing prevents prompt intervention and treatment (Szymanski, 2012). As stated earlier, the evidence of early intervention and services, as well as access to appropriate amplification have significant positive impacts on social, emotional, communication, and behavioral milestones.

Treatment and Educational Impact

Literature focusing on optimal treatment and education of individuals with a dual diagnosis of ASD and hearing impairment is limited, but slowly emerging (Roush, Holcomb, Roush, & Escolar, 2004; Guardino, 2008; Szymanski et al., 2012). According to the Individuals with Disabilities Education Act (IDEA), all children with disabilities, including those with a diagnosis of ASD or hearing impairment, are entitled to a free and appropriate education in the least restrictive environment (Vernon & Rhodes, 2009). When children are diagnosed with ASD and hearing impairment, they are included in the population of children who are entitled to an educational setting addressing all behavioral needs for facilitating communication. Current research estimates that 1 in 76 school-aged children with hearing impairment received services for ASD and hearing impairment in the 2007-2008 school year nationwide (Szymanski & Brice, 2008).

Audiologists play an integral part of an interdisciplinary intervention team while addressing hearing habilitation and assistive devices needed in educational settings. There is currently little evidence focusing on hearing aid fittings or cochlear implant outcomes for children with hearing loss and ASD (Szymanski & Brice, 2008). Collaboration with other professionals including speech-language pathologists, behavioral interventionists, and educators is necessary to ensure appropriate and satisfactory aural rehabilitation at home and in school.

There are many educational settings that serve individuals with ASD and hearing impairment. An analysis of the recent GRI report revealed that children with a dual diagnosis of hearing impairment and ASD are less likely to be integrated with hearing peers during the school week and are more likely educated in programs for the deaf (Szymanski, 2012). At this time, the National Deaf Academy in Florida is one of the only facilities offering residential and educational services for youth who are deaf, have ASD, or carry both diagnoses (Vernon & Rhodes, 2009). This facility encourages the use of Applied Behavior Analysis (ABA), in strategies for behavioral intervention. ABA is a structured method of behavioral intervention and training that breaks down learning into discrete steps and reinforces positive behaviors while developing useful skills (Spreckley & Boyd, 2009). The National Deaf Academy also promotes sign language, voicing, Picture Exchange Communication Systems (PECS), and assistive technology support for acquisition of communication skills (National Deaf Academy, 2013). Using a combination of communication strategies enhances the acquisition of language and communication (Bradley, Krakowski, & Thiessen, 2008). Many professionals believe residential deaf schools are the most appropriate facilities for students with a co-

occurring diagnosis of ASD. Typical education settings have little to no experience working with children who are deaf with a dual diagnosis of ASD, and are unprepared for the supplementary challenges in an educational approach. A well established program for this unique population should have several approaches to accommodate the various symptoms and behaviors (Szymanski, et al, 2012).

An edition of the *Odyssey*, a publication of the Laurent Clerc National Deaf Education Center at Gallaudet University (2008), featured a collection of articles on the co-occurrence of ASD and deafness. The series focused on anecdotal experiences of families with children with this dual diagnosis, educational strategies for deaf education special needs classrooms, and tips for parents and advocates of children with ASD and deafness. One of the articles highlighted the extended time it takes educators and service providers to understand the individual needs of children with ASD and hearing impairment (Bradley, et al., 2008). Since this can often be a challenging process, individuals with a dual diagnosis need a strong advocate from early intervention services through postsecondary transition planning.

Literature surrounding this dual diagnosis is limited, and therefore serves as a motivating factor for further exploring this population. The inspiration behind this study was the importance of exploring experiences from a parent perspective. Parents of children with ASD and hearing loss have reported frustration throughout the process of determining diagnoses, stated that they struggled with medical decision making for their children, and were sometimes unsatisfied with the services their children were receiving (Myck-Wayne et al., 2011). This study was designed around parents reporting their experiences, which were then evaluated through a qualitative analysis process.

Professionals who work closely with parents of children in this unique population can apply insights from the conclusions drawn to enhance their practice, as well as spread knowledge to other families in similar circumstances.

Qualitative research and addressing dual diagnosis

As noted, currently there is limited research that has been performed with the population of individuals with hearing impairment and ASD, and more is needed. The nature of this study lent itself favorably towards a qualitative interview style because of the small population of potential candidates and the lack of established research thus far. The objectives of this study were to study an under represented group and gain insight from parents' perspectives as they reflected on their past and present experiences.

Qualitative research method may optimally capture participants' perspectives of their experiences raising children with both hearing impairment and ASD. There are several ways that qualitative studies are unique, and these characteristics are well summarized in a publication by Merriam (2002). The first characteristic is the researcher's focus on inferring the meaning behind how people understand their world and their experiences. Another common feature of qualitative research is the researcher's primary role in data collection and analysis. Merriam noted the importance of qualitative researchers in acknowledging their innate biases and shortcomings while serving as the primary avenue for data collection and analysis. Lastly, qualitative research is inductive, and researchers collect data and analyze findings to determine overlying concepts. The raw data is arranged to create themes that are induced through reasoning and interpretation. There are several ways to collect data in qualitative studies, however the three most popular are interview, observation, and document review. Family Health

International (2005) described the interview method in their qualitative research guideline; “In-depth interviews are optimal for collecting data on individuals’ personal histories, perspectives, and experiences, particularly when sensitive topics are being explored”(p.30). Furthermore, interviews are appropriate for “eliciting individual experiences, opinions, feelings, and addressing sensitive topics” (Family Health International, 2005, p. 30).

In qualitative research, once data collection is complete, analysis is the last step in a structured study. Throughout literature, qualitative research has been criticized because there is no standardized methodology and there are limited tools designed for this type of analysis (Attride-Stirling, 2001). The structured approach chosen for analysis of the data in this study is rooted in the thematic network analysis theory published by Attride-Stirling (2001). “Thematic analyses seek to unearth the themes salient in a text at different levels, and thematic networks aim to facilitate the structuring and depiction of these themes” (Attride-Stirling, 2001, p.387). Attride-Stirling (2001) credits the foundations of thematic network analysis to several existing theories. Thematic network analysis is formatted through a web-like organization that provides a step by step way to transition from text to concepts (Figure 1). The thematic hierarchy includes the lowest order basic themes, followed by organizing themes, and then ultimately global themes. This method lends itself effectively to the type of information targeted in this study. The participants in this study all reported on unique experiences with their children, and the thematic network design provided structure for deriving themes across families.

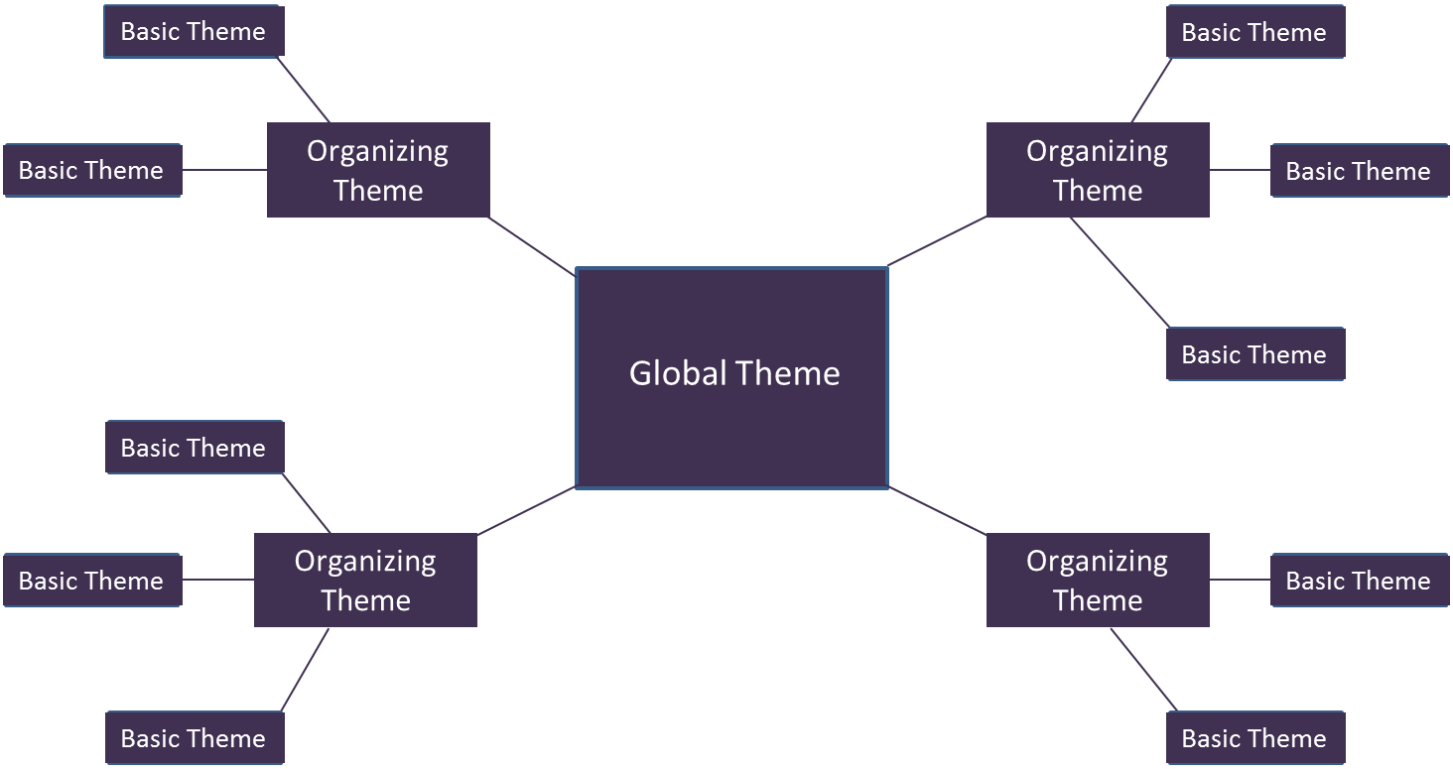

Figure 1: Thematic Network Analysis Diagram

Chapter Three: Methods

Parents of children with a dual diagnosis of hearing impairment and ASD were recruited to participate in the present study. Eligible participants consented to participation in a one-on-one style interview to share and reflect on their parental experiences raising a child with hearing loss and ASD.

Participant Recruitment

This study was approved by the Behavioral and Social Sciences Institutional Review Board at The Ohio State University. Eligible participants for this study included parents/guardians of children who were diagnosed with hearing impairment and ASD. The recruitment process began with an organized distribution of recruitment letters (Appendix A) to professionals in the local community with potential resources to assist in participant recruitment. In addition to local service providers, a recruitment letter was forwarded to the Autism Research Institute's Network for Deaf/Hard of Hearing and Blind/Visually Impaired. Professionals were also given a separate recruitment letter for parents/guardians (Appendix B) to distribute to qualifying participants. All interested parents/guardians were instructed to contact the study investigators for further information about how to become involved in the study. A consent form was then sent to interested participants explaining the study requirements and participant's rights.

Based on these recruitment efforts, seven families expressed interest in participating in the study; however, one-on-one interviews were scheduled for five

parents who consented to participation. Two of the participants who initially showed interest did not return consent forms and could not be reached after several attempts. Participants in this study were parents of children enrolled in educational settings including preschool programs, elementary schools and middle schools. The number of families is appropriate for this study due to the low incidence population of individuals with a dual diagnosis of hearing impairment and ASD. Individuals did not receive monetary compensation or any inherent benefits for their participation in this study.

Interview

The parent questionnaire (Appendix C) was categorized into four subheadings: 1. child's medical history, 2. the diagnostic processes, 3. interventions, and 4. educational settings and decisions. The four subheadings were selected as a way to organize the questionnaire in a logical flow and obtain information from birth to the present. This also allowed for consistency and organization during analysis of the themes across families. The questions were developed with the intent to gather basic information about the child regarding aspects of medical history and age of each diagnosis, while also incorporating several qualitative questions targeting parents' experiences. Starting with basic questions is a strategy explained by Jacob and Ferguson (2012), to build rapport before delving into more difficult or complex questions. Specific questions were developed to gauge parental satisfaction throughout the processes, allow participants to further explain or describe concerns and experiences, as well as reflect on decisions they made throughout their child's life. Prior to the interview, parents were asked to answer questions as openly and honestly as they felt appropriate. The interviews were conducted by one investigator; however the mode of delivery varied based on subject choice. Three participants chose

to complete their interviews over the telephone, one via Skype, and one was completed in person. The participants were able to choose between the three options for interview style. A one-on-one style interview was chosen over a written survey to better capture parents' experiences, and allow for additional commenting and input. All participants verbally consented to recording prior to the interview, and each full interview was recorded in real time. The recordings for the Skype and in-person interview were made using the Apple Voice Memo app, and the telephone interviews were recorded using a SONY IC recording device. Once the interviews were completed, they were transcribed from the audio recordings, and the original audio files were deleted.

Analysis

Five participants completed the interview process and answered all of the questions to the best of their ability. The analysis was completed by the investigator who performed the interviews, and was conducted at two different intervals to ensure consistency in the conclusions and strengthen intra-rater validity. The first step in analyzing the data was to manually code the transcriptions while reading line by line looking for meaningful segments of information. Inductive codes were used in the analysis, meaning the codes were created during examination of each question based on the participants' responses. Once the coding was completed for each subheading, the data was further analyzed following the thematic network analysis steps described previously. Analysis was completed for each of the four subheadings, and resulted in the development of basic themes, organizing themes, and global themes across participants' responses.

Chapter 4: Results and Discussion

Based on the organization of the interview, the analysis was completed for each subset individually: 1. medical history, 2. diagnostic process, 3. intervention, and 4. educational settings and decisions. Results have been summarized into four tables and further explanation and discussion immediately follow each table.

Medical history: The basic, organizing, and global themes derived in this subheading are summarized in Table 1. In this section, parents answered questions regarding their children's birth history and early development.

Basic Themes	Organizing Themes	Global Themes
All children were born at 36 weeks to full term gestation.	Relatively unremarkable pregnancies and birth history may be noted in children carrying these diagnoses. Signs of developmental disabilities are not always present shortly after birth, and may take time to appear.	Parents reported that they know their children best, and have been instrumental in reporting concerning behaviors and potential delayed skills. A passing score on a newborn hearing screening does not rule out the potential for late onset hearing loss in the future.
NICU stay was uncommon; 1 out of 5 children required time in the NICU (only four hours).		
4 out of 5 children passed their universal newborn hearing screening.	Cases in which universal newborn hearing screening results were a pass may be because of a late onset hearing loss or false negative screening results.	
4 out of 5 children had a significant history of ear infections; 3 out of 4 children were treated with myringotomy and tympanostomy tube placement in early years.		
Parents were the first to voice concerns about their children's global development and hearing.	Parental concern is a red flag for diagnoses of hearing impairment and ASD. Providers must look for early signs of hearing loss and ASD and endorse parental concerns by following through with referrals for appropriate diagnostic testing and screening measures.	
Pediatricians were not always concerned with their reports of potential developmental delays.		
Parents observed signs early on suggesting developmental delay: speech and language delay, repetitive and unusual behaviors (ie: lack of eye contact, excessive energy), and lack of social reciprocity.		

Table 1: Medical History Themes

As indicated in Table 1, parents reported relatively unremarkable birth histories for their children. It was uncommon among participants to report that their children spent time in the neonatal intensive care unit (NICU) after birth (only one out of five). As represented in this study population, developmental disabilities may be present in children with typical birth histories. The universal newborn hearing screening results did

not signify early signs of hearing loss in all of the children. More parents reported that their children passed their newborn hearing screening (four out of five) than received refer results. Additionally, four out of five children experienced a significant history of ear infections, and three of those children required myringotomy and tympanostomy tube placement as treatment.

When participants were asked who initially was responsible for voicing concerns about their children's development, the majority of participants indicated that they were the first ones (four out of five). Although parents reported discussing developmental concerns with their children's pediatrician, they did not always feel like their concerns were heard. Two participants even indicated that their children's health care providers made them feel "crazy" when they brought up concerns. On the other hand, some parents reported that their children's pediatricians acknowledged their observations, thus proving that parental experience is not universal.

As one parent reflected about their experience, they indicated that their pediatrician deferred making referrals for further diagnostic testing until their child's subsequent well-child appointments, instead of taking their concerns seriously from the start. The most common developmental disabilities that parents reported were speech and language delay, repetitive or abnormal behaviors, and lack of social interactions. While several parents acknowledged that they identified these signs as unusual early on, they sought professionals who would validate their concerns.

Discussion

As indicated by the results, screening measures did not identify risk for hearing loss in several of the children. Regardless of whether some of the later diagnosed hearing

losses were present at birth or were later onset, it is important to educate parents about the results of screening measures and the possibility that hearing loss may appear in children who initially pass screenings. The population in this study had a strong history of chronic otitis media, and likely underwent hearing evaluations during the diagnostic and treatment processes. Perhaps the frequency of hearing evaluations in individuals with chronic ear infections contributed to the identification of hearing loss in those that were unidentified through universal newborn hearing screening. Additionally, the presence of a strong history of ear infections and tympanostomy tube placement contributes to the possibility of a conductive component of hearing loss.

A trend across participants revealed that parents perceive themselves as knowing their children best, and felt that they could confidently describe their concerns to others. Nonetheless, their concerns were not always alarming to their children's pediatricians. According to the American Academy of Pediatrics (2006), the following recommendations are specified in their policy statement for identifying developmental disabilities in infants and children:

> Developmental surveillance should be incorporated at every well-child preventive care visit. Any concerns raised during surveillance should be addressed promptly with standardized developmental screening tests. In addition, screening tests should be administered regularly at the 9-, 18-, and 24- or 30-month visits (p. 417-418).

These recommendations are important for early identification of potential risks for developmental disabilities. Although pediatricians may choose to develop a protocol for this implementation, they remain as guidelines. Furthermore, as seen in this study population, the presence of one disability does not rule out the diagnosis of another developmental disability.

Overall, the themes developed in this section of the study may help educate health care professionals working with young children to look for early signs of developmental disabilities, use appropriate screening tools to identify risk factors, and identify when there is need for further diagnostic testing. Furthermore, parents wished their pediatricians had acknowledged their concerns promptly. This principle may raise awareness for health care providers to be cautious when dismissing reports of concerning behaviors, delayed speech and language skills, or unusual social interactions.

Diagnostic Process: The basic, organizing, and global themes derived in this subheading are summarized in Table 2. In this section, parents reported on their children's age of diagnosis for hearing impairment and ASD, as well as their experiences with professionals throughout the diagnostic processes.

Basic Themes	Organizing Themes	Global Themes
Age of diagnosis of ASD was 2-9 years old.	There was a trend for an earlier age of diagnosis for hearing loss compared to the diagnosis of ASD. Comorbidity of other disorders further complicates the diagnostic process.	Many professionals and team members were needed for making both hearing loss and ASD diagnoses. Parents reported frustration, but eventually were satisfied with the diagnoses even though they did not always feel supported.
Age of diagnosis for hearing loss was birth-4 years old.		
Comorbidity of ADHD was common in children with a dual diagnosis of ASD and hearing impairment (3 out of 5 children).		
A large number of professional disciplines were involved in the diagnostic processes including: psychiatrists, psychologists, early interventionists, speech-language pathologists, audiologists, and developmental behavioral pediatricians.	The diagnostic processes were complicated and required several professionals' evaluations in order to make appropriate dual diagnoses.	
Parents felt frustrated throughout the diagnostic processes and did not always feel supported. Parents used words like "crazy" to describe how they were made to feel.	Parents were ultimately satisfied with diagnoses but were not always made to feel supported throughout the processes.	
Parents were typically unsatisfied with at least one of the diagnostic processes.		
There was a range of severity of hearing loss, and more commonly presented with a severe to profound sensorineural hearing loss (3 out of 5 children). One child had a mild hearing loss, and one had a moderate to severe (mixed hearing loss).	Parents reported that hearing loss was typically their children's first diagnosis.	
Hearing loss was typically diagnosed before ASD, as reported in 4 out of 5 children.		
ABR was the most common diagnostic tool to identify hearing loss (4 out of 5 children)		

Table 2: Diagnostic Process Themes

As described in Table 2, there was a reported discrepancy between the age ranges of diagnosis for hearing impairment compared to ASD. There was a wider age range for

diagnosis of ASD (2-9 years of age) compared to hearing impairment (birth-4 years of age). The majority of individuals received a diagnosis of hearing impairment through ABR testing, and parents indicated dissatisfaction with repeated unsuccessful attempts at behavioral evaluations prior to the decision to perform an ABR test. One parent described the process of a hearing loss diagnosis as time consuming, and would have preferred skipping repeated behavioral audiometry attempts and gone right to ABR testing, even if it required sedation.

The children presented with a variety of types and degrees of hearing loss. Three out of five children had a severe to profound sensorineural hearing loss, one child had a mild hearing loss that was unknown whether it was conductive or sensorineural in nature, and the last child had a moderate to severe mixed hearing loss. Some parents reported that their children were evaluated by several audiology practices before a definitive diagnosis was made.

In this study, four out of five parents reported that their children received a hearing impairment diagnosis prior to an ASD diagnosis. Additionally, this study supports the likelihood of co-occurring disabilities, and three participants reported that their children were additionally diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), psychiatric disorders or emotional disorders.

As described by parents in this study, many professionals were involved in making both diagnoses for their children. Parents reported frustration with some professionals, and did not always feel supported. One parent described the journey to their child's ASD diagnosis as deceitful. This family was unaware that their pediatrician

was considering an ASD diagnosis until they arrived at an Autism specific clinic for a behavioral evaluation. Another family reported that their child did not receive an ASD diagnosis until they saw several professionals, which created an obstacle for their child to begin receiving necessary services. Consistently, parents reported that the diagnostic processes were challenging, but they were eventually satisfied with the diagnoses because they were able to move forward with treatment and intervention phases and their children could receive the necessary services and interventions.

Discussion

The results of the present study support the conclusion that delayed speech and language development is a leading reason for a referral for audiological testing and ASD evaluations. Furthermore, audiology testing is typically recommended prior to ASD evaluations to rule out hearing loss as a contributing factor to delayed speech and language development. In general, the earlier age for diagnosis of hearing impairment compared to ASD is likely due to universal newborn hearing screenings, as well as the use of electrophysiologic diagnostic tools in young children. Most of the children from this study passed their newborn hearing screenings and subsequent hearing loss diagnoses were made at a later age. It is also reasonable that parents reported a later age of diagnosis for ASD than hearing loss, because a diagnosis of ASD relies on observed behavioral symptoms, and research has suggested that a reliable and stable diagnosis can be made at two years of age or older (Kleinman et al., 2008). Some parents reported that their children were seen by several audiology practices before a firm hearing impairment diagnosis was made. This may have been due to testing and equipment limitations, lack of pediatric expertise, or parental decision to seek a second opinion.

An interesting finding in this study was the presence of additional disabilities reported beyond ASD and hearing impairment. In a recent study from the Children's Hospital of Philadelphia, co-occurring non ASD developmental disabilities were observed in 83% of eight year olds carrying an ASD diagnosis (Levy et al., 2010). The additional disabilities reported in this study were ADHD, emotional disabilities, and psychiatric disorders. Parents reported that co-occurring disabilities have an impact on their children's behaviors, educational settings, and ultimately makes their children's experiences unique. Based on the evidence of co-occurring disabilities, professionals working with young children who receive a diagnosis of ASD may strongly consider recommending further diagnostic evaluations; especially when behaviors associated with ASD may mask these additional disabilities.

Overall, parents voiced their appreciation for professionals who were upfront and honest about their concerns, while remaining sensitive during conversations. Parents indicated dissatisfaction with professionals who edged around the difficult conversations, because it ultimately did not help their children receive appropriate evaluations and stalled the diagnostic processes.

Intervention: The basic, organizing, and global themes derived in this subheading are summarized in Table 3. In this section, parents reported on services their children have received, as well as the professionals that provided these services. Also, parents reported on their satisfaction with current or past interventions.

Basic Themes	Organizing Themes	Global Themes
Participant's children commonly were served through early intervention services. These services (including auditory verbal therapy, physical therapy, occupational therapy, speech/language therapy, family counseling) were delivered by a variety of professionals.	Parents believed early intervention services were beneficial, and were provided by a lot of professionals working with the children and families.	Children with a dual diagnosis of hearing impairment and ASD typically received a variety of services provided by a supporting team of professionals. Parents reported on the importance of intervention services and therapies for their children; however, they believed therapies can be financially overwhelming and challenging as they are a large time commitment.
Several children attended hearing impaired preschool programs where they received intervention services embedded into the program.	Children attended hearing impaired programs early on, and also received evidence based interventions for behavioral intervention like ABA.	
Special needs preschool programs were also common avenues for early intervention delivery.		
ABA therapy was useful in some cases for targeting behavioral interventions.		
Parents reported that their children wear hearing aids (3 out of 5) or cochlear implants (1 out of 5), and use FM systems in school.		
Communication modalities varied across children, including non-verbal/gesturing/pointing (1 out of 5), primarily oral/verbal (3 out of 5), or sign language (1 out of 5).	Across participants, there were several communication modalities used. There did not appear to be one specific communication modality utilized by individuals with this dual diagnosis.	
Parents were frustrated with their insurance coverage for services, and needed to stop some therapies because of the financial burden.	Providing access for children to appropriate services can be a financial burden on families, as well as overwhelming and time consuming.	
Parents reported difficulty dealing with insurance companies regarding coverage for therapies. In cases where children were not making documented progress, the services were then discontinued.		

Table 3: Intervention Themes

As outlined in Table 3, all of the participants in this study reported the importance of early intervention on the development of their children's communication skills, motor skills, and for behavioral support. Based on their developmental delays, and regardless if diagnoses of ASD and hearing loss were established at the time, it was common for children to receive early intervention services in the home or in special education preschool settings. Some services that were reported by parents included auditory verbal therapy, physical therapy, occupational therapy, speech and language therapy, and family counseling. Since there were a variety of services involved in early intervention, a diverse group of professionals were involved in service delivery based on expertise in their respected areas.

Participants indicated some overwhelming aspects of interventions, whether it was the time commitment, financial commitment, or difficulties working with insurance companies about therapy coverage. Some parents reported that services have varied over the years. Parents also reported disconnect between service providers concerning their children's developmental goals, and modes of communication. Communication modalities varied across children in this study: three children were described as primarily oral/verbal, one was reported as using mostly sign language with use of gesturing/pointing, and one child was described as nonverbal while primarily using gesturing/pointing for communication. Two families indicated that they learned sign language early on to more effectively communicate with their children; this helped limit their children's frustration over not being able to communicate.

Specific interventions for hearing impairment were reported by parents, including the use of hearing aids, cochlear implants, or FM systems. Parents reported that three out

of five children currently wear hearing aids, one child uses a cochlear implant and hearing aid on the contralateral ear, and one child no longer wears hearing aids as recommended by their audiologist. Additionally, parents reported that their children currently use FM systems in the classroom, or have used them in the past.

Discussion

The distinctive profiles of children further explain the unique parental experiences. There seems to be many appropriate avenues for intervention, but all parents reported that intervention specialists were necessary in supporting their family. All of the service providers mentioned by parents play a role in the treatment and rehabilitation of one or both diagnoses. Professionals working with these children with a dual diagnosis must consider how each diagnosis interacts with their therapy delivery or treatment approach. Ultimately, professionals benefit from working together to share information about a child's development and skills while shaping their treatments.

Throughout the study population it is evident that communication modalities are inconsistent across individuals with ASD and hearing impairment. Parents generally reported that speech and language skills continue to be delayed, even after therapy and intervention. The commitment to therapy was reported as challenging by several parents, and there appeared to be several barriers for access to therapy, including financial and time commitments. Unfortunately, some parents believed that their children could continue to receive benefit from certain interventions but they were unable to keep up with services.

Educational settings and decisions: The basic, organizing, and global themes derived in this subheading are summarized in Table 4. In this section, parents reported on their

children's current and past educational settings, as well as their level of satisfaction with how these academic settings have addressed their children's needs.

Basic Themes	Organizing Themes	Global Themes
Parents whose children attended schools for the deaf believed that they were the most academically beneficial for their children.	Across families, the chosen academic programs vary. Amongst the school settings were: schools for the deaf, hearing impaired programs, and public schools. Parents felt that hearing impaired programs were the best fit for academic and learning needs, but behaviors suffered in those settings.	Parents felt hearing impaired programs served their children well with communication and academic focuses, but behavioral support was not as good as in public settings.
Parents believed public school settings better addressed their children's behavioral needs.		
Special needs preschool settings were common for children with early ASD diagnoses.		
One parent reported that public school settings have been beneficial; however their child's language skills suffered.		
Several families permanently moved for access to specific services and proximity to better school district programs.	Parents wanted the best for their children and moved their families, learned languages, and became involved in support groups. Deciding on the best school setting for their children was extremely difficult.	
Parents seemed generally more satisfied with hearing impaired schools than public school settings; future plans are blurry.		
Parents had mixed feelings about participation with support groups.		
Families were involved in some therapies as well as learning sign language if their child was nonverbal.		

Table 4: Educational Settings and Decisions Themes

As referenced in Table 4, the majority of parents reported that their children have been in educational settings specifically for the hearing impaired, including programs targeting ASD interventions, and in special education classrooms in public school

settings. Parents shared mixed feelings about satisfaction with their children's current educational settings. All parents reported that future decisions regarding their children's educational placements remain uncertain. One parent reported that they would like to see their child be able to attend a mainstream program because that would suggest their child was improving, and wouldn't need to be at an ASD specific school anymore. Another parent reported that their child, who is currently in middle school, has been to over four different schools and has been kicked out of several due to unmanageable behaviors.

Children with diagnoses of hearing loss and ASD have been served in hearing impaired schools and classrooms, special education classrooms, and ASD specific schools. Parents reported that their children's "primary disability" usually influenced their decisions for placements. With that being said, parents reported that in some settings their children did not receive enough focus on needs related to one of their disabilities, and therefore speech and language skills or behaviors suffered.

Parents reported that hearing impaired schools are the most educationally beneficial settings for academic needs. They reported that hearing impaired schools emphasize visual learning, have teachers of the hearing impaired, and work on goals for developing desired communication modalities. Nonetheless, some parents also reported that their children are currently in public school settings, and believe that the special education settings appropriately address ASD related behaviors that are often disruptive in hearing impaired classrooms. One parent expressed satisfaction in their child's special education classrooms at a hearing impaired school. According to the parent, this setting seems to address both disabilities well.

Parents reported making sacrifices for their children, like learning new languages and meeting parents involved in supportive groups for resources. Parents seemed to have mixed feelings regarding support groups, some preferring not to discuss their personal challenges with other parents, while others were grateful for supporting resources. Several parents reported that their families have moved for better access to educational opportunities that would best serve their children.

Discussion

A common theme in this study was parental acknowledgement of their children's constantly evolving needs. Some parents in this study seemed more comfortable with their children's current educational placements than others. It was interesting that parents seemed to be unsure of where their children will attend school in the future, and this uncertainty was shared among participants. It appears that educational decisions, similarly to other decisions regarding interventions, change frequently. These results included some important aspects for parents to consider and weigh when making choices for their children, such as the academic focus of a placement, behavioral support in the setting, the possibility for individual support, and social integration. Some of the educational decisions reported in this study supported the conclusions found in Szymanski et al. (2012):

> Children with hearing loss and ASD were more likely, than their peers without ASD, to be educated in schools or programs specifically designed for the deaf, as well as educated with exposure to sign language. A placement in a school for the deaf may provide a naturalistic sign language environment, thus prompting language, behavioral and socialization improvements (p. 2035).

While this statement relates to some families in this study, it seems that families continue to have many choices for both educational placement and educational and communication theories.

Chapter 5: Conclusion

The present study addressed the primary and secondary research questions posed prior to the onset of the study. It was evident from the five participating family experiences that there were many intervention courses for children with hearing loss and ASD for early identification, treatment, and educational settings. Nonetheless, parents reported many similarities in family experiences with professionals throughout the diagnostic processes including early frustration and confusion with eventual satisfaction. Parents also reported the significance of professionals and interdisciplinary members in delivery of intervention services. It was clear that parents felt many professionals were needed to determine accurate diagnoses and effective interventions, and expressed that professionals supported their children best by working together and sharing knowledge.

This study also met the goal of contributing to the limited body of research focusing on the co-occurrence of ASD and hearing loss. Additionally, it is anticipated that the results will help to facilitate awareness for professionals providing services to children with hearing loss and ASD. For example, parents reported that they wished pediatricians had recognized the importance of developmental screenings and appropriate timing for referrals like audiology, developmental pediatrics, and psychology. Audiologists will likely benefit from knowing that parents were dissatisfied with the length of time it took to determine a hearing impairment diagnosis and implement treatment plans. Recommendations for educational settings varied across children in this study, but parents felt the best setting was one which targeted their children's greatest

areas of need. Overall, by learning from parents of children with a dual diagnosis, professionals will have a greater understanding of how both disabilities can co-occur and interact with each other.

Limitations of the study and future directions

There were some limitations in the current study that may be improved upon in future studies. Although the recruitment process included outreach to several professionals, as well as a national autism network, it is unclear how many parents received the recruitment information. It is possible that some parents who did not receive the recruitment information may have been interested in participating. Therefore, the results of this study may not be representative of all parents of children with a dual diagnosis. Another potential limitation in the current study is the innate bias of the sole investigator who analyzed the results. The nature of the analysis in this study did not lend itself to outside interpretation. In future studies, more descriptive questions may help expand upon parents' experiences and reveal more information about their perspectives, especially concerning the professionals who worked with their children. Some potential further questions for parents include:

- What could have improved and streamlined the diagnostic processes for your child?
- What could your child's health care providers have done to help you better understand the diagnoses?
- Did your child's health care providers provide support to you when needed?
- What advice would you give to parents in a similar situation that you wish you had known?
- What was the most influential therapy or intervention your child received?

Further exploration of this study on a larger scale may also lead to additional insight into parents' experiences. Ultimately, the key to understanding how to best serve individuals with a dual diagnosis of ASD and hearing impairment is to encourage research studies and raise awareness for health care providers and educational professionals.

.

References

American Academy of Audiology. (2013). American Academy of Audiology clinical practice guidelines: Pediatric amplification. Washington DC.

American Academy of Pediatrics, Council on Children With Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2006). Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. Pediatrics, 118(1):405-420.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th edition., text revisions). Washington DC: American Psychiatric Association.

Association of University Centers on Disabilities. (2013). Resources. http://www.aucd.org/resources/dictionary.cfm?letter=H.

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators. (2012). Prevalence of autism spectrum disorders-Autism and developmental disabilities monitoring network, 14 sites, United Sates, 2008. Surveillance Summaries, 61(SS03), 1-19.

Bradley, L.E., Krakowski, B., &Thiessen, A. (2008). With little research out there it's a matter of learning what works in teaching students with deafness and autism. *Odyssey, 9*(1), 18-20.

Bruder, M.B. (2010). Early childhood intervention: A promise to children and their parents for their future. *Exceptional Children, 76*(3), 339-355.

Centers for Disease Control and Prevention (2013). Developmental disabilities. http://www.cdc.gov/ncbddd/developmentaldisabilities/index.html

Centers for Disease Control and Prevention (2013). Hearing loss in children. http://www.cdc.gov/ncbddd/hearingloss/facts.html.

Centers for Disease Control and Prevention. (2012). Prevalence of autism spectrum disorder—Autism and developmental disability monitoring network, 14 sites. United States, 2008. In Surveillance summary (pp. 1-19). Morbidity and Mortality Weekly Report, 61.

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., … Varley, J. (2009). Randomized, control trial of an intervention for toddlers with autism: The early start Denver model. *Pediatrics*, 124, e17-e23. doi: 10.1542/peds.2009-0958.

Donaldson, A..I., Heavner, K.S., & Zwolen, T.A. (2004). Measuring progress in children with autism spectrum disorder who have cochlear implants. *Archives of Otolaryngology, Head and Neck Surgery, 130,* 666-671.

Edwards, L. (2007). Children with cochlear implants and complex needs: A review of outcome research and psychological practice. *Journal of Deaf Studies and Deaf Education, 12*(3), 258-268.

Egelhoff, K., Whitelaw, G., & Rabidoux, P. (2005). What audiologists need to know about autism spectrum disorders. *Seminars in Hearing, 26*(4), 202-209.

Family Health International. (2005). Qualitative research methods overview.. *Qualitative research methods: A data collector's field guide.* Research Triangle Park, North Carolina: Mack, N., Woodsong, C., MacQueen, K.M, Guest G., & Namey, E.

Fitpatrick, 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,* 38-49.

Gabbard, S.A., & Schryer, J. (2008). Considerations in early amplification: Selection, fitting, validation, counseling. *The Hearing Journal, 61*(11), 10-17.

Gallaudet Research Institute. (2011). Regional and national summary report of data from the 2009-2010 Annual Survey of Deaf and Hard of Hearing Children and Youth. Washington, DC: Gallaudet University.

Gallaudet University Laurent Clerc National Deaf Education Center. (2008). New Directions in Deaf Education. *Odyssey, 9*(1), 1-56.

Green, D.R., Gaffney, M., Devince, O., & Grosse, S. (2007). Determining the Effect of Newborn Hearing Screening Legislation: An Analysis of State Hearing Screening Rates. *Public Health Report, 122*(2), 198-205.

Guardino, C.A. (2008). Identification and placement for deaf students with multiple disabilities: Choosing the path less followed. *American Annals of the Deaf, 153*(1), 55-64.

Ho, P.T., Keller, J.L., Berg, A.L., Cargan, A.L., & Haddad, J. (1999). Pervasive developmental delay in children presenting as possible hearing loss. *The Laryngoscope, 109,* 129-135.

Hyman, S. (2013). New DSM-5 includes changes to autism criteria. *AAP News, June 4, 2013.*

Individuals with Disabilities Education Improvement Act of 2004. P. L. 108-446. 20 USC 1400.

Jacob, S.A., & Ferguson, S.P. (2012). Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *The Qualitative Report, 17*(6), 1-10.

Jure, R, Rapin, I., & Tuchman, R. (1991). Hearing impaired autistic children. *Developmental Medicine and Child Neurology, 33*(12), 1062-1072.

Kilgo, J.K., Aldridge, J., Denton, B. Vogtel, L., Vincent, J., Burke, C., & Unanue, R. (2003). Transdisciplinary teaming: A vital component of inclusive services. *Focus on Inclusive Education, 1*(1), 1-4.

Kleinman, J.M., Ventola, P.E., Pandey, J., Verbalis, A.D., Barton, M., Hodgson, S., Green, J., Dumont-Matheiu, T., Robins, D.L., Fein, D. (2008). Diagnostic stability in very young children with autism spectrum disorders. *Journal of Autism and Developmental Disabilities, 38*(4), 606-615.

Levy, S.E., Giarelli, E., Lee, L.C., Schieve, L.A., Kirby, R.S., Cunnif, C., Nicholas, J., Reaven, J., Rice, C.E. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental and Behavioral Pediatrics, 31*(4), 267-275.

Maenner, M.J., Schieve, L.A., Rice, C.E., Cunnif, C., Giarelli, E., Kirby, R.S…Durkin, M.S. (2013). Frequency and pattern of documented diagnostic features and the age of autism identification. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(4), 401-413.

Mandell, D., Novak, M., & Zubritsky, C. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*(6), 1480-1486.

Mascia, J., & Mascia, N. (2003). Methods and strategies for audiological assessment of individauls who are deaf-blind with developmental disabilities. *Seminars in Hearing, 24*(3), 211-221.

McGrath, A., Vohr, B., & O'Neil, C. (2009). Newborn hearing assessment in 2010. *Medicine & Health/ Rhode Island, 93*(5), 142-144.

Mehl, A. (2007). A medical home for infants who are deaf or hard of hearing. *Volta Voices*, (March/April), 24-27.

Myck-Wayne, J., Robinson, S., & Henson, E. (2011). Serving and supporting young children with a dual diagnosis of hearing loss and autism: The stories of four families. *American Annals of the Deaf, 156*(4), 379-390.

Myers, B.J., Mackintosh, V.H., & Goin-Kochel, R.P. (2009). "My greatest joy and my greatest heartache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their familes' lives. *Research in Autism Spectrum Disorders, 3*(2009), 670-684.

National Deaf Academy. (2013). Autism Connections. NDA Behavioral Health System. http://nda.com/autism/.

Pipp-Siegel, S., Sedey, A. & Yoshinaga-Itano, C. (2002). Predictors of parental stress in mothers of young children with hearing loss. Journal of Deaf Studies and Deaf Education. 7 (1), 1-17.Rabidoux, P. (2005). Early identification of autism: Roles of the speech-language pathologist and audiologist on a transdisciplinary team. *Seminars in Hearing, 26*(4), 210-216.

Rogers, S.J., & Vismera, L.A. (2008). Evidence-based comprehensive treatments for early autism. Journal of Clinical Child Adolescent Psychology, 37(1), 8-38.

Roper, L., Arnold, P., & Monteiro, B. (2003). Co-occurrence of autism and deafness. *Autism, 7*(3), 245-253.

Rosenhall, U., Nordin, V., Sandstrom, M., Ahlsen, G., & Gillberg, C. (1999). Autism and hearing loss. *Journal of Autism and Developmental Disorders, 29*(5), 349-357.

Roush, J., Holcomb, M.A., Roush, P.A., & Escolar, M.L. (2004). When hearing loss occurs with multiple disabilities. *Seminars in Hearing, 25*(4), 333-345.

Sass-Lehrer, M. (2011). *Early beginnings for deaf and hard of hearing children: Guidelines for effective services*. Washington DC: Laurent Clerc National Deaf Education Center, Gallaudet University.

Spreckley, M, & Boyd, R. (2009). Efficacy of applied behavior intervention in preschool children with autism for improving cognitive, language, and adaptive behavior: A systematic review and meta-anlaysis. *Journal of Pediatrics,* March, 338-344.

Stevenson, J., McCann, D., Watkin, P, Worsfold, S., & Kennedy, C. (2010). The relationship between language development and behavior problems in children with hearing loss. *The Journal of Child Psychology and Psychiatry, 51*(1), 77-83.

Szymanski, C., & Brice, P.J. (2008, Spring-Summer). When autism and deafness coexist in children what we know now. *Odyssey*, 10-15.

Szymanski, C.A., Brice, P.J., Lam, K.H., & Hotto, S.A. (2012). Deaf children with autism spectrum disorders. *Journal of Autism and Developmental Disorders.* DOI: 10.1007/s10803-012-1452-9.

Tas, A., Yagiz, R., Tas, M., Esme, M., Uzun, C., & Karasalihoglu, A.R. (2007). Evaluation of hearing in children with autism by using TEOAE and ABR. *Autism, 11*(1), 73-79.

U.S. Department of Health and Human Services. (2013). NIH Fact Sheets: Newborn Hearing Screening. http://report.nih.gov/NIHfactsheets/ViewFactSheet.aspx?csid=104.

Vernon, M., & Rhodes, A. (2009). Deafness and autistic spectrum disorders. *American Annals of the Deaf, 154*(1), 5-14.

Witwer, A.N., & Lecavalier, L. (2008). Examining the validity of autism spectrum disorder subtypes. *Journal of Autism and Developmental Disorders,* 38, 1611-1624.

Woodgate, R.L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*(8), 1075-1083.

Worley, J.A., Matson, J.L., & Kozlowski, A.M. (2011). The effects of hearing impairment on symptoms of autism in toddlers. *Developmental Neurorehabilitation, 14*(3), 171-176.

Yoshinaga-Itano, C. (2003). From screening to early identification and intervention: Discovering predictors to successful outcomes for children with significant hearing loss. *Journal of Deaf Studies and Deaf Education, 8* (1), 11-30.

Appendix A

Dear Professional,

I am writing to request your help in recruiting participants for my research project as part of my graduate audiology (AuD) Capstone project at The Ohio State University. The purpose of my study is to evaluate the diagnostic process, intervention, and treatment of individuals with a dual diagnosis of autism spectrum disorder (ASD) and hearing loss. This research study aims to contribute to the limited body of research focusing on the co-occurrence of ASD and hearing loss.

It is my understanding that you may have connections to families who will be willing to participate and share information about their child for research purposes. If a parent/guardian agrees to participate, they will be asked to complete a one-on-one interview, in person or via telephone that includes questions regarding their child's medical and educational history.

The information parents/guardians provide is confidential. Their responses will also remain anonymous to ensure that they cannot be linked to the participant. There are no anticipated risks from participating in this study.

Attached is a recruiting letter for parents/guardians. Please forward this letter on to any appropriate potential parents/guardians.

Thank you for your time and consideration. It is my hope that information obtained from this survey will benefit professionals working with children with this dual diagnosis, as well as families of children with ASD and hearing impairment. Please feel free to contact my academic advisor, Dr. Gail M. Whitelaw, or myself if you should have questions or require additional information.

Julie Stefanski
Doctor of Audiology (AuD) 2014
stefanski.13@osu.edu

Gail M. Whitelaw, PhD
Academic Advisor
whitelaw.1@osu.ed

Department of Speech & Hearing Sciences
The Ohio State University
110 Pressey Hall
1070 Carmack Road
Columbus, Ohio 43210

Appendix B

Dear Parent/Guardian:

You are invited to participate in a research project that is part of my graduate audiology (AuD) Capstone project at The Ohio State University. The purpose of this study is to evaluate the diagnostic process, intervention, and treatment of individuals with a dual diagnosis of autism spectrum disorder (ASD) and hearing loss. This research study aims to contribute to the limited body of research focusing on the co-occurrence of ASD and hearing loss.

If you agree to participate, you will be asked to complete a one-on-one interview, in person or via telephone that includes questions regarding your child's medical and educational history. If you choose to participate, I will arrange the interview with you at a time that is convenient with you. You will be asked the questions and asked to respond as honestly and accurately as you can.

The information you provide is confidential. The answers you give will remain anonymous and your answers cannot be linked to you. There are no anticipated risks from participating in this study.

Thank you for your time and consideration. It is my hope that information obtained from this survey will benefit professionals working with children who have this dual diagnosis, and also benefit families of children living with this dual diagnosis. Please feel free to contact my academic advisor, Dr. Gail M. Whitelaw, or me if you should have questions or require additional information.

Julie Stefanski
Doctor of Audiology 2014
stefanski.13@osu.edu

Gail M. Whitelaw, PhD
Academic Advisor
whitelaw.1@osu.edu

Department of Speech & Hearing Sciences
The Ohio State University
110 Pressey Hall
1070 Carmack Road
Columbus, Ohio 43210

Appendix C
Qualitative Interview Questions

Medical History

1. Were there any complications during pregnancy or childbirth? Was your child delivered at full term?
2. If there were complications during child-birth, did your child spend time in the neonatal intensive care unit (NICU)?
3. Did your child receive a newborn hearing screening? If so, what were the results?
4. Does your child have any history of ear infections, or ear related surgeries?
5. Explain any medical concerns/issues within the first three years of your child's life.
6. Did you have concerns about your child's overall global development?
7. Who was the first person to suggest an audiological or behavioral evaluation?
8. Were there any signs to suggest any developmental disability or hearing loss?

Diagnosis

1. At what age was your child identified with an autism spectrum disorder?
2. At what age was your child identified with a hearing impairment?
3. Explain the type and degree of hearing loss.
4. Which diagnosis came first?
5. Who made each diagnosis?
6. Were you satisfied with the professionals throughout the diagnostic process?

Intervention

1. List any interventions/therapies your child has received.
2. What professionals/providers have you worked with?
3. Describe your child's speech and language development.
4. What kind of communication modality does your child use to communicate?
5. What kind of amplification, if any, does your child use?

Education

1. What kind of educational environments have you chosen for your child?
2. Have you been satisfied with these decisions?
3. What are your plans for future educational pathways?
4. Are you involved in any parent support groups?