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The missing piece: An online resource for deaf educators working with children with a dual diagnosis of deafness and autism spectrum disorder

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**THE MISSING PIECE: AN ONLINE RESOURCE FOR DEAF
EDUCATORS WORKING WITH CHILDREN WITH A DUAL DIAGNOSIS
OF DEAFNESS AND AUTISM SPECTRUM DISORDER**

by

Haley Shae Brown

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submitted in partial fulfillment of the
requirements for the degree of:**

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**Approved by:
Greta Bohnenkamp, M.S., Independent Study Advisor**

Abstract: This paper will examine the need for a comprehensive online resource that contains easily accessible information about autism spectrum disorder (ASD). This includes: general facts about ASD, how the characteristics of ASD may compare to those exhibited by a child who is deaf or hard of hearing, and potential methods of instruction for children with both diagnoses.

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Introduction

Deaf educators must be more than simply teachers of the deaf as the population of children who are deaf and hard of hearing is becoming increasingly diverse. Nearly 40% of children with an identified, permanent hearing loss have an additional disability (Fitzpatrick, Lambert, Whittingham, & Leblanc, 2014; Meizen-Derr et al. 2013; Schieve et al., 2014). This includes autism spectrum disorder (ASD), which creates a dual diagnosis that has been increasing (Szymanski, Brice, Lam, & Hotto, 2012). “Approximately 4% of children who are deaf or hard of hearing have co-occurring autism spectrum disorder” (Meizen-Derr, 2013, p.112). Szymanski et al., (2012) reported that one in fifty-nine eight year old children with hearing loss also received services for ASD. Approximately 65% of teachers of the deaf have reported having some experience with a child with a dual diagnosis of a hearing loss and ASD (Borders, Bock, and Szymanski, 2014).

However, general research on the dual diagnosis is severely lacking, which leads to a deficit in early identification and quality intervention for children with this dual-diagnosis (Meizen-Derr et al., 2013). In addition, based on an online search of the curricula of training programs for deaf educators, it appeared that only one Council on Education of the Deaf (CED) accredited teacher preparation program listed a specific course in ASD. This lack of specialized professionals and resources related to the dual diagnosis can lead to delayed, or even missed, diagnoses (Roper, Arnold, & Monteiro, 2003).

It is imperative that teachers of the deaf have an easily-accessible resource that can provide research-based information about this population as well as possible methods of instruction. This project is intended to be the link for teachers of the deaf working with children with a dual diagnosis of hearing loss and ASD. This project includes a literature review of

current information about ASD as well as how it presents in children who are deaf and hard of hearing. The instructional methods for children with ASD and children with a dual diagnosis have also been examined and compiled into an online resource that will be available to professionals working with this population.

Defining Characteristics and Prevalence Rate

According to the *Diagnostic and Statistical Manual of Mental Disorders (DSM- 5)* (2013), the diagnostic criterion for autism spectrum disorder consists of “Persistent deficits in social communication and social interaction across multiple contexts,” and “Restricted, repetitive patterns of behavior, interests, or activities” (American Psychiatric Association, 2013). The *DSM-5* also notes that an individual must meet both criteria in order to have a diagnosis of ASD. If the individual exhibits impairment in social communication, without restricted or repetitive behaviors, this could be the manifestation of a communication disorder, not ASD.

Research suggests that the prevalence of ASD is increasing (King & Bearman, 2009; Matson & Kozlowski, 2010). Centers for Disease Control and Intervention currently state that 1 in 68 children have been identified with ASD (Baio, 2012). However, this number is controversial and often debated among professionals in the field (King & Bearman, 2009; Matson & Kozlowski, 2010). Prevalence rates have been reported to range from 9.6-40.8% over the past ten years (King & Bearman, 2009; Matson & Kozlowski, 2010).

Diagnostic Challenges

Current evidence suggests that there is a neurobiological component, or “gene-environment,” related to the cause of ASD; though the cause is unknown (Bailey, Phillips, &

Rutter, 1996; Rutter, Bailey, Simonoff, & Pickles, 1997; Schieve et al., 2014). Without a known cause, ASD can be difficult to diagnose because the criteria is behavioral, not biological (Newschaffer et al., 2007). It is further challenging to identify children at very young ages because the diagnostician or team looks for an absence of skills (e.g., eye contact, gestures, pointing, and pretend play) rather than the presence of characteristics (e.g., such as spinning parts of toys, lining up toys, or repeating phrases) (Meinzen-Derr et al., 2013, p. 112). Meinzen-Derr, et al., (2013) argue that the earlier a diagnosis of ASD can be reached, the more likely that child is to improve their abilities to communicate in social situations. “Early identification of children with ASD is critical in their medical management and treatment” (Meinzen-Derr, 2013, p. 112). Children with ASD who receive services by two or three years of age may also have a higher chance of succeeding academically (Fenske, Zalenski, Krantz, & McClannahan, 1985; Rogers, 1996). Although recognition of symptoms is being reported as early as 18 months of age, most children are not diagnosed with ASD until after age four (Baio, 2012). Wiggins et al., discussed that the most accurate clinical judgment is made by experienced clinicians using standardized diagnostic instruments (2014). Yet another challenge can be finding experienced clinicians who are qualified to make the diagnosis. The professionals that diagnose ASD are developmental pediatricians, pediatric neurologists, child psychologists, child psychiatrists, and speech-language pathologists (SLP) (Filipek, Accardo, Ashwal, 2000; Johnson & Myers, 2007; Lord, et al., 2006). According to the American Speech-Language-Hearing Association’s position statement (2006) on the diagnosis of ASD, the SLP that assists with the diagnosis typically works with a team of other qualified professionals to reach a formal diagnosis. Other professionals that make the diagnosis need formal training and experience as well (Filipek, Accardo, Ashwal, 2000; Johnson & Myers, 2007; Lord et al., 2006). A more accurate diagnosis

is reached when a clinician uses judgment in conjunction with a diagnostic instrument (e.g., the *Autism Diagnostic Interview Revised- ADI-R* and the *Autism Diagnostic Observation Schedule- ADOS*,) (Gotham, Risi, Pickles, & Lord, 2007; Lord et al., 2000).

Standardized Testing

Currently, no standardized test for ASD is normed for children who are deaf or hard of hearing (Wiggins et al., 2014; Wiley, Gustafson, & Rozniak, 2013). This can cause major difficulties for a professional or a team of professionals that is attempting to make a diagnosis. It is reported that parents of children with the dual diagnosis often feel frustration because the battery of tests used during the study, may not be truly appropriate for their child (Wiley et al., 2013).

Each child with this dual diagnosis will be different. There is a spectrum for the diagnosis of ASD and hearing loss is diagnosed with different types and degrees. (Meinzen-Derr, et al., 2013). This results in children with the dual diagnosis that all have different abilities and needs. Wiley et al. (2013) noted that a child with the dual diagnosis must be given instruction that considers both of their diagnoses. “Most students who are deaf or hard of hearing depend heavily on their visual skills for assistance in communication” (Chamerlain, Morford, & Mayberry, 2000). Chamerlain et al. (2000) go on to say, “Visual communication requires attending and eye contact. Typically people with ASD avoid both of these.” This behavior alone could cause many issues in language learning for children with the dual diagnosis. Wiley et al. (2013) also noted that the use of an interpreter could be a challenge during testing.

Dual Diagnosis

Meinzen-Derr, et al. (2013) found that children receive the diagnosis of the hearing loss on average, almost three years before they are diagnosed with ASD. They suggest that Universal Newborn Hearing Screenings result in early diagnosis of hearing loss; however, the symptoms of ASD may be overlooked or considered a characteristic of the hearing loss (Meinzen-Derr, et al., 2014; Young & Tattersall, 2007). Children with ASD and children who are deaf and hard of hearing have shared characteristics, including: language delay, pragmatic language difficulties, and delayed development of theory of mind. Research suggests that hearing loss can affect children's social skills (Hamre & Pianta, 2001). Yoshinaga-Itano (2015) evaluated children who are deaf and hard of hearing by using "The Pragmatics Checklist" that included pragmatic categories. These pragmatic categories include: Instrumental ('I want'), Regulatory ('Do as I tell you'), Interactional ('You and Me'), Personal ('Here I come'), Heuristic ('Tell me why'), Imaginative ('Let's pretend') and Informative ('I've got something to tell you') (Yoshinaga-Itano, 2015). Yoshinaga-Itano (2015) used this checklist to study 129 children who are deaf and hard of hearing to assess their pragmatic development. She found that "Although their language scores on standardized and normed tests indicated that the majority of the children had language skills at age level, the children had significant delays in their pragmatic development" (p. S54). Specifically, she found that for children that are typically hearing, all but two of the forty-five items on the checklist were mastered, (defined as 75% or more of the children mastered the skill with complex language). Comparatively, the group of children with a hearing loss had only mastered three of the forty-five items on the checklist at the same age as their typically hearing peers (Yoshinaga-Itano, 2015).

Another similarity that children who are deaf or hard of hearing share with children who have ASD is the delayed development of theory of mind. The term theory of mind was first introduced by Premack and Woodruff in 1978 (Peterson and Siegal, 2000). Baron-Cohen, Tager-Flusberg, and Cohen (1993) define it as “the ability to impute mental states like beliefs, intentions, memories, and desires to self and others as a way of making sense of and predicting behavior” (p. 3). Wellman (1993) expanded that idea and stated that “the assumption is that this understanding guides all social action and interaction” (p. 10). Peterson and Siegal (2000) concluded that deficits in early conversational interactions influence the development of theory of mind. They explained that deaf children from hearing families fail theory of mind tasks at older chronological and mental ages, indicating a similar performance to children with ASD that are the same mental age. Peterson and Siegal (2000) also discovered that some theories related to ASD and delays in theory of mind relate to a neurological deficit; however, there seems to be no neurological component hindering children that are deaf from developing the concept. Their study reviewed information about children that are deaf or children that have ASD, but none with the dual diagnosis. Therefore, based on available research, it is unclear how the dual diagnosis may complicate the development of theory of mind.

Audiologic Considerations

An accurate picture of the child’s ability to hear can be an essential part of the child’s medical management, especially if that child is using devices. Audiologic testing may be difficult with children with ASD. Often, the testing procedure is modified to suit the individual with this dual diagnosis due to various circumstances that can lead to inconclusive testing (Beers, McBoyle, Kakande, Dar Santos, Kozak, 2013). Beers et al. (2013) also explains that the children

with ASD may have many issues surrounding the sensory aspects of audiologic testing. This can create challenges in obtaining accurate behavioral measurements. “Tactile defensiveness and oversensitivity to stimuli may prevent the fitting and use of hearing aids” in children with this dual diagnosis (Easterbrooks and Handley, 2006). These challenges may look different for every child, thus it is difficult to recognize a specific strategies that would help the process become easier for the child and the audiologist.

Instructional Methods

Considering the various challenges and potential complications arising from the dual diagnosis, teachers of the deaf must find ways to use effective, evidence-based instruction with this population. Research suggests that parents are frustrated about the lack of instructional methods that can be used for a child with a hearing loss and ASD (Wiley et al., 2013). There is currently no consensus between experts about which method for instruction should be suggested for all children with ASD (Heflin & Simpson, 1998). However, there are many different methods that have been used to improve overall function of children with ASD (Hayward, Eikeseth, Gale, & Morgan, 2009). One method called Applied Behavior Analysis (ABA) has been shown to improve the intellectual, language, and adaptive functioning in children with ASD (Cohen, Amerine-Dickens, & Smith, 2006; Eikeseth, Smith, Jahr, & Eldeik, 2002, 2007; Howard, Sparkman, Cohen, Green, & Stainslaw, 2005; Lovaas, 1987; Lovaas & Smith, 1988, Sallows & Graupner, 2005). The treatment is centered on the model for Early Intensive Behavioral Intervention (Lovaas, 2003). There are several fundamental principles in ABA treatment including: systematic reinforcement, stimulus control, motivational operations, and generalization (Hayward et al., 2009). ABA should be delivered in the child’s natural

environment, with parent involvement, for an extensive amount of time (e.g., at least 40 hours a week over a two year period) and under the supervision of a trained professional using research-based applications (Hayward et al., 2009). “The Early Start Denver Model” (ESDM) is a comprehensive early behavioral intervention for infants to preschool-aged children with ASD that integrates applied behavior analysis (ABA) with developmental and relationship-based approaches” (Dawson et al., 2010). Dawson et al. (2010) found that over two years, the children that received services using the ESDM model had significant improvements in IQ, adaptive behavior, and expressive and receptive language.

Floortime or Developmental, Individual, Difference Relationship-Based (DIR) is considered to be different from the behavioral therapy approaches, focusing more on social-pragmatic development based on typically developing children (Pajareya & Nopmaneejumrulers, 2011). The model was created to improve the ability of children with autism to communicate spontaneously, in a meaningful way (Greenspan & Wieder, 1997). Finally, Levy and Hyman (2005) discuss that many medical interventions, including dietary restrictions and other combinations of methods have been argued to help improve overall functioning in children who have ASD.

There are many methods that have been well-established with children with ASD but there is limited research that provides insight about the use of an instructional method for a child that has a dual diagnosis of hearing loss and ASD. Easterbrooks and Hadley (2006) conducted a case study which suggested that ABA therapy was successful for a child who is deaf. This indicates that more research is needed in this area and until that happens, teachers of the deaf must use methods that are evidence-based and tailored to each individual child.

Discussion

This lack of research regarding instructional methods for children with a dual diagnosis can be problematic for a teacher of the deaf who is working with a student that also has ASD. The website that has been developed as part of this study is intended to provide information to these professionals that will give them insight into ASD and how instructional methods may be used for a child with a dual diagnosis. As noted by Easterbrooks and Hadley (2006) it is imperative that each child with the dual diagnosis be considered as an individual. Teachers working with this population must also recognize that these instructional methods may only be needed as a baseline for instruction development, and that each teacher may find that they have to alter the method to fit the needs of that student. As more research is conducted about this unique population, there will be more information readily available to these professionals. Professionals must continue to utilize resources in order to instruct these children with a dual diagnosis of hearing loss and ASD in order to engage them in active learning and social language. This population deserves an educational experience that is robust, engaging, and appropriate. It is the job of the professional to seek out opportunities to help these children succeed.

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