

Loud & Clear!

A Cochlear Implant Rehabilitation Newsletter

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Rehabilitation
Newsletter

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Advanced Bionics

Deafness with Autism

Changing HOW WE THINK

One in fifty-nine children with hearing loss also receives services for Autism Spectrum Disorder (ASD), according to the *Annual Survey of Deaf and Hard of Hearing Children and Youth* (Szymanski, et al., 2012). Professionals are faced with decisions on how to best support children with this dual diagnosis. Yet few have had training and there is little research to guide them in this decision-making progress.

This special series of *Loud & Clear* will bring together the current research to offer strategies for assessment and intervention. Key professionals from across disciplines will help us understand each piece of the puzzle to help us address the needs of

the whole child. Understanding the unique needs of these children will lead to a collaborative and shared vision for success.

We hope that each of you working with children who are deaf with ASD will find inspiration in collaboration. We hope to inspire you to work across disciplines and with the families of these children. It is only through our combined and informed efforts that we will be able to close the gap between identification of hearing loss and autism.

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Autism and Hearing Loss: What You Need to Know to Help Your Families

The prevalence of Autism Spectrum Disorder (ASD) has increased over the past 30 years, and recent data indicate that one in 68 children is likely to be identified as having some form of ASD (CDC, 2014). Males have a greater likelihood than females of developing ASD, with a ratio as high as five to one. Although its etiology is still unknown, ASD is recognized as a genetically based neurobiological condition (Bailey, Phillips & Rutter, 1996; Rutter, Bailey, Simonoff & Pickles, 1997). There are currently no cures or preventive measures for ASD; however, there are a number of empirically validated, ASD-specific interventions and educational programs available that have been shown to optimize long-term outcomes (National Research Council, 2001). Children who receive intervention by two to three years of age generally have more positive outcomes, specifically in terms of language development and school



placement (Fenske, Zalenski, Krantz, & McClannahan, 1985; Rogers, 1996). Therefore, early detection and diagnosis are critical.

Parents often report identifying symptoms consistent with ASD by the time their child is 18 months old (Chakrabarti & Fombonne, 2005; Ozand et al., 2003; Spitzer & Siegel, 1990; Volkmar, Stier, & Cohen, 1985), and many suspect developmental difficulties within the first year of the child's life (Coonrod & Stone, 2004; Orn itz et al., 1977; Zwaigenbaum et al., 2005). However, children may not be given a clinical diagnosis of autism until after they reach age three (Baio, 2012). Diagnoses for ethnic minority groups and children with co-morbid diagnoses, such as hearing loss, occur much later (Jure et al., 1991; Mandel et al., 2002).

Diagnostic Overshadowing

A child with ASD places emotional and financial demands on families, and other impairments such as hearing loss may go unnoticed (Mcyk-Wayne et al., 2011). Sometimes, after initially coping with the diagnosis of ASD, it can be difficult to confront the possibility of a secondary diagnosis. Many parents also report a lack of guidance and support from professionals during the diagnostic process and often are left to take a trial-and-error approach when facing assessment and intervention decisions (Myck-Wayne et al., 2011).

Hearing loss also may be missed because of diagnostic overshadowing. That is, behaviors resulting from hearing loss may be considered part of the symptoms of autism, such as lack of attention, speech impairments, lack of eye contact, and clumsiness. Additionally, children with ASD often present with behavioral challenges that can interfere with audiological testing. This often results in inconclusive results or test procedures spanning multiple sessions, thereby delaying a possible diagnosis. Moreover, while symptoms of ASD can be measured reliably by 18 months of age (Charman et al., 1997; Lord, 1995; Stone et al., 1999), currently it is unclear how gold-standard assessment procedures may be applied to children with hearing loss.

Prevalence of ASD & Hearing Loss

Comorbidity rates of hearing loss in children with ASD are high and increasing (Szymanski et al., 2012). Currently it is estimated that one to six percent of children who are deaf also have an ASD diagnosis. Further, there are a disproportionate number of children with profound hearing loss who have a co-existing

diagnosis of ASD (35.4%). Studies conducted by Gallaudet Research Institute report a gradual increase in a dual diagnosis of hearing loss and ASD among deaf and hard of hearing children. The 2009-2010 Annual Survey of Deaf and Hard of Hearing Children and Youth indicated that one in 59 children with hearing loss also receives services for ASD. This is considerably higher than reported in national estimates for hearing children (Baio, 2012).

The increased prevalence of ASD in children with hearing loss is particularly alarming as the co-occurrence of hearing loss and ASD may lead to delayed or missed diagnosis (Jure et al., 1991; Roper et al., 2003). Families have reported a time lag of 18 months to 15 years between diagnoses, especially when a hearing loss is identified first.

One possibility for this time lag is the emotional state of the parents. Results of a recent case study indicated that, while families began to see delays in motor development and unexplained behavioral issues, they were reluctant to attribute the delays and behavior to ASD. The families shared that, after initially coping with the diagnosis of hearing loss, it was difficult to confront the possibility of a secondary diagnosis (Myck-Wayne et al., 2011). It is also difficult to diagnose ASD in children who have hearing loss because communication impairments are inherent in both disabilities (Easterbrooks & Handley, 2005). Referral to

Table 1. Social-Emotional Milestones

0-3 Months	3-6 Months	6-9 Months	9-12 Months
<ul style="list-style-type: none"> • Learns to be comforted and soothed by adults • Enjoys social stimulation and smiles at people • Enjoys touch 	<ul style="list-style-type: none"> • Responds to name • Smiles • Laughs • Plays peek-a-boo 	<ul style="list-style-type: none"> • Express emotions (happiness, sadness, fear) • Distinguishes between familiar and unfamiliar people • Shows frustration • Responds to spoken words 	<ul style="list-style-type: none"> • Imitates simple actions • Feeds him/herself small bites of food • Expresses anxiety when separated from parent

1-2 Years	2-3 Years	3-4 Years	4-5 Years
<ul style="list-style-type: none"> • Recognizes him/herself in mirror • Initiates play activities • Imitates adult actions • Starts trying to help • Expresses negative emotions • Acts pleased when he/she accomplishes something 	<ul style="list-style-type: none"> • Demonstrates personal preferences • Starts to say, "no" to adults • Enjoys watching and playing with other children • Uses objects symbolically • Begins to dress and undress him/herself 	<ul style="list-style-type: none"> • Follows directions • Shares toys with other children • Makes up games and asks other children to join in • Begins engaging in pretend play 	<ul style="list-style-type: none"> • Develops friendships with other children • Compares him/herself to other children and adults • Becomes more aware of other people's feelings (theory of mind) • Enjoys imaginative play with other children

a specialized and experienced clinician can help to distinguish the unique communication differences that may point to a dual diagnosis. Yet a third possibility may be the difficulty associated with testing individuals suspected of a dual diagnosis. Children with ASD often present with behavioral difficulties (e.g., problems with cooperation, attention deficits, and cognitive impairments) that can negatively impact hearing testing (Rosenhall et al., 1999). Further, ASD screening and diagnostic procedures have yet to be established for children with hearing loss.

Identifying Symptoms of ASD

A child's age when autism and/or a hearing loss are diagnosed, and the order in which the disorders are diagnosed, can be critical in terms of access to appropriate intervention services and long-term outcomes. The best way to identify a child who is at risk for developing symptoms of ASD is to monitor his or her developmental milestones. If a child is not meeting the developmental milestones, particularly the social-emotional milestones presented in [Table 1](#), consider referring the family for a comprehensive developmental evaluation.

Children with ASD have difficulty in three major areas: 1) social interaction, 2) communication, and 3) restricted and repetitive behaviors (see [Figure 1](#)). Importantly, although some symptoms between hearing loss and autism overlap,

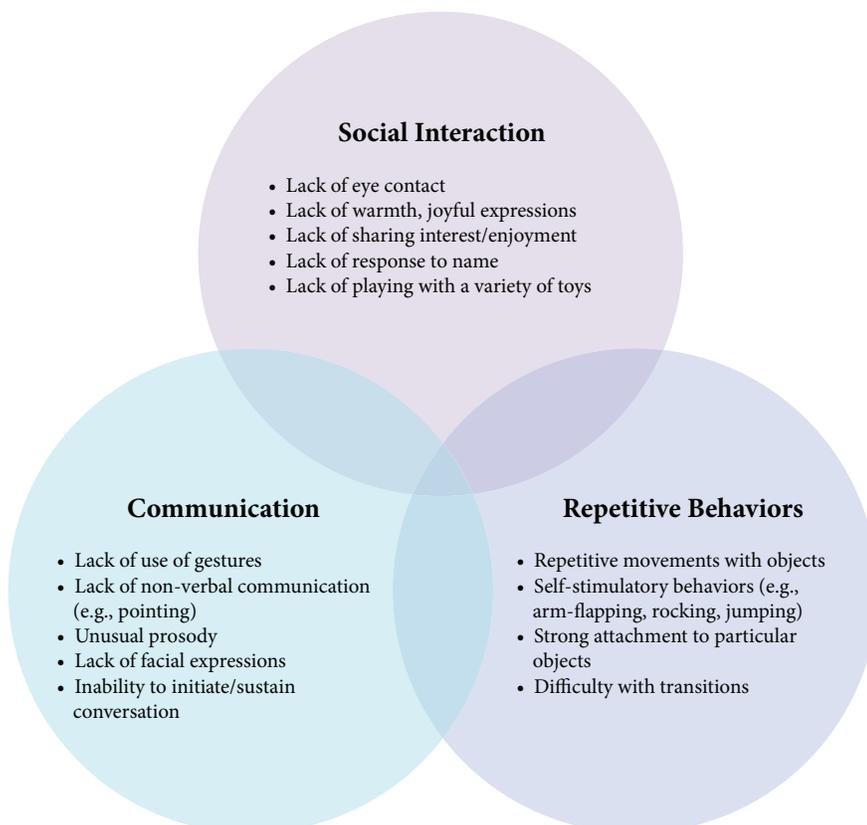


Figure 1. Autism Spectrum Disorder

several features can assist you with differentiating the two. For example, children with hearing loss have frequent language delays but typically use appropriate eye contact and non-verbal communication to express their needs (e.g., pointing, showing, or unintelligible speech). Further, children with hearing loss typically enjoy touch and being around other children, while a child with ASD may pull away from hugs and appear disconnected from others. Children with ASD also have difficulty with transitions, may engage in self-injurious behaviors (e.g., head-banging), and may be under- or oversensitive to sounds, touch, taste, pain, etc. The Autism Speaks™ website (www.autismspeaks.org) has a video glossary, including side-by-side comparisons of children with and without ASD, which may assist you with identifying children on the spectrum.

If you are concerned about a child's development, you should refer to a developmental pediatrician or clinical psychologist for further evaluation. According to the American Academy of Pediatrics, all children between the ages of 18 and 24 months should be screened for autism. Always remember to ask your families, if the pediatrician or any other healthcare professional has reported any concerns about the child's development. This will help you determine whether other professionals also are concerned and seeing atypical behavior. If you are still unsure whether or not to refer a family for evaluation, you may utilize one of the screening tools listed below to help identify children who are at risk.

- Modified Checklist for Autism in Toddlers (M-CHAT)
- Autism Spectrum Screening Questionnaire (ASSQ)
- Childhood Autism Rating Scale – Second Edition (CARS-2)
- Social Communication Questionnaire (SCQ)
- Parents Evaluation of Developmental Status (PEDS)
- Ages and Stages Questionnaire (ASQ-3)

For more information about screening tools and diagnostic measures for ASD, please refer to the Audiology Online webinar (Deafness with Autism: A Psychological Perspective, Part I)

<http://www.audiologyonline.com/ce/advanced-bionics/events/details/23772/deafness-with-autism-psychological-perspective>

Having the Talk with Families

As a hearing health provider, it is extremely important to discuss your concerns with the family as soon as they arise. An important reason for expressing your concerns frankly and early is to engage parents. Parental involvement is a powerful determinant of outcomes. Many providers describe this conversation as difficult and are unsure how to bring up their concerns. Remember that parents often have concerns before anyone else has noticed, and they also may

feel uncomfortable talking about their concerns. Your role is not to mention a diagnosis but simply to encourage parents to take the next step and have their child evaluated for any developmental disorders. Prior to having the conversation, you should plan what you want to say and role-play with colleagues. It is always recommended that you document all of your observations and concerns and that you think about your discussion in advance. During your conversation, you should use the following tips:

- Be sensitive and avoid using words such as “normal”
- Listen to the parents’ concerns
- Validate their thoughts and feelings (e.g., I know this might be hard for you to talk about...)
- Use a neutral tone of voice and be empathic with the family
- Start with discussing positive behaviors that you have observed in the child or any progress he/she has made
- Remain objective and pick a behavior that you observed to begin discussing your concerns
- Use any information obtained through developmental screeners

After you have had the conversation with the family, it is extremely important to maintain ongoing communication and follow up on any referrals you have given. Remember, your goal is to empower the family, provide support, and ensure that early detection and early intervention is received. In addition, it is often helpful to provide families with resources in their area prior to leaving the appointment (see Resources section). This is important, as parents are likely to begin doing research following the discussion, and you want to ensure that they are obtaining relevant, correct information.

Interventions

The Academy of Pediatrics recommends that treatment start when autism is suspected rather than when a formal diagnosis is made. Every child is different, and the treatment program should be tailored to the individual child. An interdisciplinary approach to treatment often is recommended. Interventions may include behavioral treatments, speech therapy, occupational therapy, music therapy, and medication.

It also is important to note that ASD commonly co-occurs with other developmental (e.g., learning disorder, intellectual disability), psychiatric (e.g., anxiety, depression), neurological (e.g., seizures, cerebral palsy), and genetic disorders (e.g., Down syndrome, Fragile X). Thus, other interventions may be needed to treat the co-existing disorders. It is estimated that 83% of children with ASD have one or more non-ASD developmental diagnoses, and 10% have one or more psychiatric diagnoses (Levy et al., 2010). Parental involvement is crucial to the success of any treatment program. Parents need to work side by side with providers to learn the strategies being taught during therapy so that they may implement them outside of the clinic and in the home or other settings.

Behavioral intervention is the most effective method of addressing the needs of children with ASD. Applied Behavior Analysis (ABA) is one type of behavioral intervention for children on the spectrum. ABA uses techniques and principles to bring about positive change in behavior. The goal of therapy is to reduce

inappropriate behavior while increasing communication and social behavior. For information about how to implement ABA techniques in your practice, please visit Autism Speaks™ or ABA Educational Resources, Ltd.

Several studies have reported that ABA techniques help improve communication, social relationships, play, and school performance. In addition, children who are enrolled in comprehensive, intensive early intervention programs that use ABA techniques exhibit better outcomes in these areas as well. Early intervention programs should target a range of skills, including communication, self-care, and social skills. According to Autism Speaks™, “intensive” refers to programs that total 25-40 hours per week for one to three years. To learn about other behavioral interventions, such as behavioral play interventions (e.g., Floortime, Relationship Development Intervention), refer to Audiology Online Webinar (Deafness with Autism: A Psychological Perspective, Part II).

<http://www.audiologyonline.com/ce/advanced-bionics/events/details/23773/deafness-with-autism-psychological-perspective>

Summary

The dual diagnosis of hearing loss and ASD has been documented for the past 20 years; however, research and clinical guidelines on young children with this dual diagnosis are sparse. Given the increased rate and the delay in the dual diagnosis, hearing health professionals should routinely begin to screen children at risk for ASD and refer for comprehensive developmental evaluations when appropriate. Several well-established instruments to screen for autism are available, although not yet validated for children with hearing loss. Earlier identification of the dual diagnosis will allow for proper intervention to begin, which ultimately leads to better overall outcomes.

Resources

Autism Society of America (www.autism-society.org)

Center for Autism and Related Disorders (www.centerforautism.com)

Autism Speaks (www.autismspeaks.org)

Center for Disease Control (www.cdc.gov/ncbddd/actearly/index.html)

Cochlear Implant Online

(<http://cochlearimplantonline.com/site/autism-hearing-loss>)

ABA Educational Resources (<http://www.abaresources.com/>)

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