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when autism and deafness coexist in children

WHAT WE KNOW NOW

By Christen Szymanski and Patrick J. Brice

In February 2007, the Centers for Disease Control and Prevention (2007a) released new statistics on the prevalence of autism in 8-year-olds. Using data from a multistate national sample, the CDC concluded that approximately 1 in 150 children in the United States had been diagnosed with an autism spectrum disorder, a significant increase over the previous estimate of 1 in 166, released six years earlier (Centers for Disease Control and Prevention, 2007b). Either figure represents an astounding change from earlier estimates. As the CDC (2007b, para. 3) reports, “For decades, the best estimate for the prevalence of autism was 4 to 5 per 10,000 children.”

While many explanations have been offered for the increased rate of autism, the true cause remains unknown. Nonetheless, in the United States, *diagnoses of autism are increasing faster than any other diagnosis of developmental disability in children.* But this statement, like others pertaining to the characteristics of autism and the relevant intervention services, does not tell the whole story for *all* children diagnosed with autism. Every day, our knowledge grows about autism in those children who are hearing; researchers and educators develop new strategies, new programs, and new diagnostic instruments to serve these children. But research and intervention, as well as fund-raising and media attention, typically exclude those who have additional disabilities or do not speak English. Thus, the question becomes, “What do we really know about those children who are deaf *and* have autism?”

Though No Two Children With Autism Are Alike, Common Characteristics Exist

Both children and adults with autism generally display a particular set of common characteristics. The most commonly recognized include interactive difficulties (an absence or insufficiency of smiling, laughing, and eye contact), limited communication



Right: Autism affects normal socialization, exhibited in these photos.

Photos by John Consoli



abilities, insistence on routines and sameness (surprises and other changes are difficult), repetitious play, difficulty with make-believe play, challenges in interacting with peers, and behaviors that disrupt daily living. A diagnosis of autistic disorder is made when a child has impairments in his or her social interactions, communication abilities and style, and behavior. Each child who is affected by autism is unique—in no two children with autism are the severity and intensity of the impairments they encounter alike.

Does Autism Look Like Deafness? The Importance of Diagnosing a Hearing Loss

Before characteristics of autism and deafness can be described, it is necessary to understand the importance of knowing if your child has a hearing loss. This knowledge is essential because of the possibility that a hearing loss is masking autism. For example, several of the

characteristics of autism may look like hearing loss and vice versa. If a child cannot hear, he or she will not respond when called by name—often a key item on checklists of autism, but also a characteristic of deafness. And if a child cannot hear, social interactions with peers may be difficult—due to an inability to hear conversations, not because he or she has autism. Likewise, does the child engage in self-stimulating behaviors because he or she cannot hear and thus plays independently?

Knowing if your child has a hearing loss is not always simple. And the fact that hearing loss often is not diagnosed until a child is 2 or 3 years old—the same time that autism is often diagnosed in children—does not make this conundrum any easier. Children who do not have access to communication or who do not express themselves—as is sometimes the case with children who have an undiagnosed hearing loss or deafness—may grow up linguistically,

communicatively, emotionally, and socially isolated. This outcome is essentially the same as the core dimension of autism, a situation that contributes to the complexities of diagnosis for these children.

How Many Deaf Children Have Autism?

The rising estimate of the number of children with autism does not include children who are deaf. To begin to estimate the number of children who have both hearing loss and autism, one can look at the *Annual Survey of Deaf and Hard of Hearing Children and Youth*, which is conducted by the Gallaudet Research Institute.

In the survey for 2006-2007, researchers reported

that there were 37,352 deaf and hard of hearing children in special education programs in the United States, including both residential programs and public programs. Of that 37,352, in-depth information was available for 35,706. Using the data from this national summary report, one can conclude that 469 deaf and hard of hearing children in the United States also had a diagnosis of autism. In other words, 1 deaf child in 76 was receiving services for both a hearing loss and autism, about twice what is currently believed to be the national prevalence rate, 1 in 150. It is important to remember that the *Annual Survey of Deaf and Hard of Hearing Children and Youth* does not account for every deaf child in the United States. Thus, these data may underrepresent the population of children with a hearing loss and autism.

Can It Be That Autism “Does Not Exist Outside of Culture”?

In countries other than the United States,



prevalence rates of autism vary. In *Unstrange Minds: Remapping the World of Autism*, Roy Richard Grinker (2007) suggests that a disability such as autism “does not exist outside of culture” (p. 11), and that the examination, diagnosis, and understanding of autism must come from within a culture and not from an outsider’s perspective. With this notion, one could argue that it is possible that a child who is deaf and has autism may look very different from a hearing child with

autism. Unfortunately, only limited research is available to justify this position. In fact, the only available research indicates that deaf children with autism demonstrate the same symptomatology as similarly diagnosed hearing children (Roper, Arnold, & Monteiro, 2003). The countless variations among deaf and hearing children in educational achievement, informational exposure and access, and social interaction underscore the need for further research.

Nonetheless, it is clear that children who are deaf are also being diagnosed with autism, and at a far greater rate. We also know that there is an increased prevalence of hearing loss in children with autism. The increased prevalence of deafness in children who have autism, while startling, is not new. Therefore, one would expect that we should know much more about autism in children who have a hearing loss. Unfortunately, the very opposite is true—we know much, much less about children who are deaf and have autism.

Deaf Children Get Autism Diagnoses Later

On average, a child who is deaf will be diagnosed with autism later in life than a hearing child with autism. In one study, deaf children were diagnosed an average of 1 year later: deaf-autistic group, 4.1 years old; hearing-autistic group, 3.1 years old (Mandell, Novak, & Zubritsky, 2005). In another study, deaf children were found to be diagnosed with autism

know the signs: CHARACTERISTICS OF autism in deaf children

Autism and autism spectrum disorders pose difficulties in nearly every aspect of daily life. These disabilities disrupt a child’s social interactions and communication, and obstruct the normal development of behaviors and interests. Symptoms usually are noticed before a child’s third birthday.

Possible Autism Red Flags for Children Who Are Deaf

- Resists being held or cuddled.
- Doesn’t reply to his or her own name when tapped or when attention is shared.
- Has difficulty engaging in shared attention. Nonautistic children often will visually track objects in a room or look in the same direction that a caregiver does. Children who are deaf do this often. A child who is deaf and has autism may not.
- Has difficulty imitating facial expressions and actions of caregivers (smiling, sticking out the tongue, clapping).
- Makes limited use of eye contact even though it is needed for communication.
- Has difficulty understanding others’ needs and feelings. (If someone is hurt, does the child ask if the person is okay?)

- Has unusual reactions to the environment that cannot be attributed to hearing loss, for example, fear of flashing lights, avoidance of smells and certain textures, refusal of hearing aids because of sensory sensitivity.
- Lags behind peers in language development; signing skills develop slowly even in an inclusive signing environment.
- Has difficulty understanding sign language or verbal language unless it is simplified.
- Does not play in the same way as same-age peers. Play is rigid and unimaginative.
- Shows an intense interest in a particular activity or object.
- Has difficulty interacting with other deaf and hard of hearing students, even with language access.
- Resists changes in routines, even though changes are clearly communicated.

between their fifth and sixteenth birthdays, while hearing children were diagnosed between their fourth and eleventh birthdays (Roper et al., 2003).

The substantially later diagnosis of autism in children who are deaf is alarming. Researchers and educators speculate that the reason behind delayed diagnoses is the difficulty encountered in distinguishing characteristics of deafness from characteristics of autism, as well as limited resources for parents and educators guiding the identification of autism and deafness. Also, it is possible that deaf children are diagnosed later because there are relatively few psychological tests that have been made for or even include considerations for children who are deaf. In fact, there are no approved instruments for making a diagnosis of autism in a child who is deaf. The current “gold standard” for diagnosing autism, the Autism Diagnostic Observation Schedule, includes a specific statement that it may not be used with children who are deaf.

An Ironic Development: The Success of Sign Language with Children with Autism

The use of signing with children who are autistic has been gaining recognition and acceptance for more than 40 years, even during times when using any visual language with deaf children was prohibited. It seems ironic that the use of sign language has been successful with children who have autism, since the terrible difficulties with eye contact experienced by people with autism would appear to prevent or interfere with any visually oriented learning.

Some suggest that children with autism have language difficulties because they struggle with cross-modality—converting auditory information to vocal utterances (Bonvillian, Nelson, & Ryne, 1981). Others have suggested that children with autism have severe

auditory processing deficits (Ruttenberg & Gordon, 1967).

Therefore, vocal languages may not be usable for communication or even understood by the child

with autism. Instead, a visual communication system—for example, the Picture Exchange Communication System, or PECS (Frost & Bondy, 2002)—or sign language may be helpful, enabling the child to bypass any difficulties with spoken languages. Some researchers believe that communication with an autistic child is impossible without gestures and facial expressions such as those used in sign language (Chamberlain & Mayberry, 2000).

Sign language requires not only eye contact but a skilled language model. Sign language is often taught in public schools to hearing children with autism and other disabilities with success but in many cases on a limited basis because the language model is not fluent. While



Socialization Milestones

Birth–6 months: Babbles, coos, and laughs, even if deaf; looks at others and smiles.

6–12 months: Enjoys games that involve reciprocal interaction and expressions of enjoyment by the child such as “peek-a-boo” and “Where’s baby?”; should raise his or her arms to be picked up.

1–2 years: Is very curious about other people and surroundings; will point, show, and bring objects to others.

2–3 years: May cry or throw tantrums to get attention but is consoled when held. Can answer simple questions, asks others simple questions, and begins to understand language play (for example, rhymes). Begins pretend play with others.

Communication Milestones

Birth–6 months: Babbles, coos, and laughs, even if deaf.

6–12 months: Understands “no,” recognizes his or her own name, can wave “bye-bye.” Uses “mama” or “dada” signs and words.

1 year: Has well-developed gestures and eye contact; is able to request or refuse.

2–3 years: Can take turns in conversations and understands what sharing and helping are. Develops the ability to copy and internalize signs and words, and begins to develop two-word sentences (age 2 years) and ask questions (age 3 years). Vocabulary grows rapidly, from 200 or more words at age 2 to more than 900 at age 3.

3–4 years: Understands the perspectives of others and can empathize with them; can tell stories and understand plays on words.

Behavioral Milestones

Birth–6 months: Can smile and look at others in his or her visual field.

6–12 months: Can look for hidden objects, explore the environment, and repeat behaviors that get praise.

1–2 years: Can recognize himself or herself in a mirror, looks at pictures in books, and begins to explore. Shows affection—will offer hugs and kisses. Begins to parallel-play with others, not necessarily interacting but playing alongside them.

2–3 years: Begins to pretend and engage in make-believe play with other children and adults; wants to be independent and begins to understand others’ feelings.



research shows that hearing children with autism acquire sign language and can use it to communicate on a limited basis, one could theorize that with continuous access, a child who is deaf and has autism would have even more exposure and be able to learn even more. After all, most deaf and hard of hearing children rely on visual skills (Rosenhall, Nordin, Sandstrom, Ahlsen, & Gillberg, 1999). If visual skills are essential to the deaf child, and visual skills and visual languages are essential to the child with autism, then the communication needs of the child who is deaf and has autism would appear to be best served visually.

While not much recent research is available on the use of sign language with children who are deaf and have autism, early studies found that teaching sign language led to spontaneous use of communication in social situations and some social interactions, as well as unprompted responses (Fulwiler & Fouts, 1976). More recently, in 2007, in a predissertation study, the lead author of the present article (Szymanski) found that children with a sign language vocabulary of more than 50 words did significantly better than those with more limited vocabularies (less than 50 words) on questions relating to stereotypical autistic behavior, difficulties with communication, social concerns, and interpersonal relationships.

Between Deaf and Hearing, Do Socialization and Behavior Patterns Differ?

There has not yet been a published study solely investigating whether socialization or behavior patterns of children who are deaf and have autism differ from those of children with autism who are hearing. The only available information comes from Britain, where researchers reported

that spontaneous social responses and reactions of children who are deaf and have autism appear to be the same as those of children who are hearing (Roper et al., 2003). However, in that study, the deaf sample used only a few signs or gestures. None of the

deaf sample used sign language; most communicated with pictures while all the hearing children used spoken language, a difficult comparison. The experience of the world by children who are deaf is different from the experience of children who are hearing. Therefore, it would make sense that differences in behaviors or socialization patterns would be found; yet at this time there is no definitive evidence of such. It also may be possible that socialization differences exist but are difficult to recognize for researchers and educators not familiar with deafness. For example, a child who is deaf and has autism may bang on the table or wave to a classmate to get his or her attention. But how is this being interpreted? As a method of social interaction (attention getting) typical of a deaf child? Or as a behavior oddity in a child with autism?

What Do Children Who Are Deaf and Have Autism Look Like?

The biggest question remains: What do children who are deaf and have autism look like? Right now we are still not sure, but promising research, both recent and in the works, is slowly beginning to provide some answers. In Szymanski's 2007 predissertation project, 19 parental reports of deaf children with autism were examined. Sixteen responding parents were deaf and 3 were hearing. All of the children included in the study had an existing diagnosis of autism. But, as has been suggested previously, the complexities of distinguishing deafness from autism may very well mean that some of the children included did not meet all of the diagnostic criteria for autism. However, all children did meet the criteria for services within the school

system. Items on the survey included those that typically appear on currently used measures of autism. All of the children scored high for interaction deficits with family members, peers, and others around them. But parents who were deaf reported that problems with communication skills and behavior skills interfered far less with their child's life than socialization problems. Parents who were hearing reported that behavioral problems and socialization were the most problematic areas. But the question becomes why are there differences? Parents who were deaf reported that their children did not have the same behavioral characteristics (repetitive behaviors, self-injurious behaviors, twirling, staring through people) that one would expect from a child with autism. Neither did these children have the same characteristics reported by hearing

The Facts

FACT 1: Deaf children are diagnosed more often with an autism spectrum disorder than what is currently considered the prevalence rate of 1 in 150 children (Gallaudet Research Institute, 2005).

FACT 2: Research has shown that hearing loss occurs more often in children who have autism than in children without autism (Rosenhall et al., 1999).

FACT 3: Visual methods of communication (e.g., sign language and PECS) appear to be easier for children with autism to understand and use than spoken language.

FACT 4: There are no known instruments for diagnosing autism in a child who is deaf.

FACT 5: Development is just beginning of an understanding of how children who are deaf and have autism are best served, what they look like, and which interventions are effective.

parents of their deaf children—especially in the areas of behavior and language. Knowing that these differences are out there makes it important for us to persist, finding out not only why but also how best to serve these children.

In the End, Just What Do We Know?

What we know about children who are deaf and have autism is limited (see Box on page 14). Some of the information may be controversial and other information still only ideas and hypotheses. We are not sure of the communication,

socialization, and behavioral implications of deafness for autism and vice versa. We are not sure how to test these children and even where to educate them—in deaf programs or

mainstreamed programs. We also are still not sure which professionals are best suited to work with these children.

Though we have far to go, some small steps have already been taken. Residential schools are hiring increasing numbers of qualified aides for children who need them, and public schools are inviting researchers to share information on interventions. Young scholars are taking up the challenge of understanding language development in children who are deaf and have autism in Texas, while educational interventions and practices for these children are being explored in Missouri and Utah. Other researchers are looking to the neurological sciences to explain why children with autism who sign do better than children who do not on specific psychological tests. Research into the developmental characteristics of children who are deaf and have autism is occurring in hopes of answering the essential question, What do children who

are deaf and have autism really look like? And there is that group of dedicated parents who have embarked on their own effort to understand their children by establishing Autreat, a gathering for families of children with both hearing loss and autism (see <http://www.deafautism.com/autreat.html>).

What we really do know without a doubt is that researchers, educators, and parents are more aware of the concerns related to autism in all children, and that in the future, children with both deafness and autism will be guaranteed to have a group of adults dedicated to making sure their needs are met.

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