Autism and Sight or Hearing Loss The Diagnostic Challenges of Dual Disorders

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Note: The Autism Network for Individuals with Hearing and Visual Impairments is a parent/professional subgroup of the Autism Society of America (ASA) for members and families of individuals with a sensory loss or impairment, in addition to an autism spectrum disorder. Target members are persons who are deaf, hard of hearing, blind or cortically or functionally visually impaired, or have progressive hearing loss or low vision in addition to autism. The Network recognizes that there are different ways for referring to people with these conditions. Descriptors such as "disabled" or "impaired" are not intended to offend or ignore anyone's preferred descriptor; rather, it is a way to identify our group.

FAMILIES OF PEOPLE IDENTIFIED WITH AUTISM AND A SIGHT AND/OR HEARING IMPAIRMENT MAY FEEL EVEN MORE ISOLATED THAN THOSE WITH ONE DIAGNOSIS OR THE OTHER. SERVICE PROVIDERS ARE SOMETIMES UNCERTAIN ABOUT WAYS TO COORDINATE AND SET PRIORITIES FOR THE PERSON'S MULTIPLE NEEDS. AND NAVIGATING THE OFTEN BUMPY ROAD OF DUAL DIAGNOSES, SEEMINGLY ENDLESS SCREENINGS, AND VARIOUS EDUCATIONAL OPTIONS CAN BE EVEN MORE OVERWHELMING.

In this article, we will explore the challenges of recognizing an autism diagnosis along with a sight and/or hearing impairment; characteristics of a person with autism and a sight and/or hearing impairment versus no autism diagnosis; which screenings are done and why; and where those with dual diagnoses fit in the education system.

If you think your child with autism may also be affected by sight or hearing loss, please contact us with any questions (see contact information on page 31).

Diagnostic Overshadowing

A child's dual diagnoses—autism and a vision and/or hearing disorder—are best addressed at the same time. A child's age when autism and a

vision and/or hearing disorder is diagnosed, and which disorder is diagnosed first, can be critical. However, families have reported a time lag of 18 months to 12 years between diagnoses, especially when a sensory loss is identified first. Though unfortunate, this happens for many reasons.

AUTISM. The first child with autism born into a family presents many demands on the family's way of life, and other impairments such as sight or hearing loss can go unnoticed. Sometimes, hearing and visual problems are missed because of diagnostic overshadowing, that is, behaviors resulting from hearing and visual problems may be considered part of the symptoms of autism, such as lack of attention, speech problems, lack of eye contact or shading of the eyes, and clumsiness. It also can be missed because we tend to speak more loudly, directly or closely to children who appear to not be paying attention without recognizing the basic need (to see and hear), in addition to the autism behavior.

Hearing and vision screening have been mandated in schools; newborn hearing is temporarily mandated. But sometimes a lack of cooperation or varying responses on the child's part during testing, and evaluators conducting tests who are not knowledgeable about autism or behavioral techniques, can lead to delays in more specific testing for hearing and visual problems. In addition, different boards of education across the country have set testing guidelines from annually to every three years without considering that some children come from families with a genetic history of hearing or sight disorders that include additional slow or progressive loss of input. These are usually not evident until adolescence or young adulthood, and may be missed when less testing occurs for the person with autism.

SIGHT AND/OR HEARING DISORDER. A child born with a sight and hearing dysfunction, both congenital disorders that can be progressive over time, requires increasing compensatory supports or accommodations. Additionally, sight/hearing dysfunction can be the result of a trauma related to an injury of which parents or care givers are unaware, or even can be secondary to taking some medications. If a child is first recognized as having hearing or visual loss before having an autism diagnosis, some of their autism-related behaviors may be mistaken by parents and professionals as a consequence of that loss.

More often, a child is born into a family without an immediate member with a sight/hearing disability, so parents and care givers are buried in learning about communication, safety and adapting daily living skills for their child. Autism may emerge later than the physical handicap, and occurs to differing degrees of severity, making it difficult to distinguish the signs—despite vision or hearing disorders and autism being very different challenges.

DEAFNESS AND AUTISM

Autism behaviors can be mistaken for behavior resulting from sight or hearing loss. Below are common characteristics of deafness alone versus deafness in addition to autism, and how to distinguish between them.

DEAFNESS/RELATEDNESS

- Child uses his/her eyes to watch people
- Likes hugs
- May be slower at developing "theory of mind" (taking another's point of view)
- Is sometimes socially isolated because others don't know communication system

COMMUNICATION

- Child tries to communicate with gestures or pointing in addition to or before learning sign language
- May have difficulty with language when using different grammatical systems, but can spontaneously use various formats
- Asks questions

BEHAVIORAL DIFFERENCES

- Child may have preferences or be persistent at a task, but accepts changes and multisensory input

DEAFNESS AND AUTISM/RELATEDNESS

- Child may not make or sustain eye contact
- May pull away from hugs and seem aloof
- May have deficits in "theory of mind" (taking another's point of view)

COMMUNICATION

- Child may take person's hand to an object to indicate need, or become agitated
- May not communicate feelings through facial expression, signs or devices
- May "echo" in sign language

BEHAVIORAL DIFFERENCES

- Child may insist on sameness or refuse to change
- May avoid or prefer certain lights, smells, and tastes and textures
- Becoming upset can sometimes lead to head-hitting

continued on next page

BLINDNESS AND AUTISM

Below are common characteristics of blindness alone versus blindness in addition to autism, and how to distinguish them.

BLINDNESS/RELATEDNESS

- Child may have more difficulty in bonding and reaching for a parent because of birth-related special care
- Person/object permanence may take more time to develop

COMMUNICATION

- Child may have some difficulty with pronominal reversal ("I and you")
- Needs and uses feedback to comprehend social situations and adapt to change

BEHAVIORAL DIFFERENCES

- Child may have poor posture or motor habits due to lack of visual model, but can be redirected
- Uses feedback from other sensory sources

BLINDNESS AND AUTISM/RELATEDNESS

 Child appears more stressed with contact and may be aloof, preferring to be alone and not explore other person's physical characteristics

COMMUNICATION

- Child may have extended difficulty with pronominal reversal, "I and you"
- May not understand or process language functionally
- May sound pseudo-mature, using adult expressions

BEHAVIORAL DIFFERENCES

- Child may engage in odd postures and repetitive hand movements, especially when stressed
- May withdraw from multisensory feedback or be hyper or hyposensitive to sounds and touch

Screenings for People with Autism

The following tests are provided by medical specialists, including developmental optometrists, speech and language clinicians, and developmental therapists and psychologists. They require different levels of cooperation on the part of the people with autism; not all are necessary, but everyone can be evaluated.

HEARING

- Aural Health Review: Checks ear anatomy, presence of chronic fluid; blood tests such as lead levels; metabolic functioning tests
- **Tympanogram:** Acoustic reflex measure of middle ear health; determines possible hearing loss
- Otoacoustic Emissions Testing (OAE or EOAE): Brief passive assessment; one to two minutes per ear; provides range of sounds within speech frequencies
- Auditory Brainstem Response (ABR): Recording from scalp electrodes; person may be sedated; limited measures provided
- Behavioral Audiometry: Evaluates specific frequency response and can be ear-specific if person wears headphones; requires a consistent alert response or movement, such as a block placed in a box to confirm
- Standard Audiometry: Requires verbal and/or raised hand to sound while wearing headphones; can include word discrimination tasks

VISION

- Eye Health Review: Appearance, inflammation/infection; testing related to syndromes; registration of light and reflexes
- Acuity Tests: Measures how clearly or sharply things are seen and need for corrective glasses (legally blind defined as vision not correctable at measured 20/200 Snellen); can include reflex testing with optokinetic drum, passive refraction or preferential looking techniques, symbol recognition
- Eye Teaming or Binocularity: Behavioral and test measures for depth perception, using both eyes together or eye deviance
- Eye Movement Control: Measures tracking and head movement; reading movements for fixation
- Visual Efficiency Scale: Measures low vision, including perceptual factors of discrimination, closure, light-dark intensity, spatial perspective
- Evoked Response Potential: Requires placement of electrodes and behavioral cooperation to look at screen, but no language

Educational Placement for People with Dual Diagnoses

Fortunately, many children can receive services through early intervention programs in their home, and then move on to early childhood programs with specialized equipment in place, including enhanced acoustics and amplification choices, low vision lighting and magnification, as well as access to multisensory activities and mobility training. Some people can be served by itinerant teachers working to support classroom staff, as well as providing individual instruction.

Inclusion on a full- or part-time basis is increasing. There are, however, specific needs that must be fulfilled for a student with autism and a sight or hearing disability. Instructors at school and in the home must remember that people experience variability in seeing or hearing levels, and their adaptation to wearing and using devices. This can be due to physical fatigue, as well as a function of less or compromised motor function, and not a behavioral choice.

Also, individuals with autism often have difficulty forming and carrying out motor movements, including speech and signing. They may have seizure disorders and require medication that must be balanced with alertness and reaction time demands. If social interaction skills are delayed or atypical, incidental and peer-based learning is sometimes limited. The child may be less able to cope in that environment depending on his/her developmental stage and age.

Historically, people with identified sensory limits and autism have moved back and forth between programs, attending, for example, a class for the deaf and then a class for those with autism spectrum disorders. Sometimes, this builds on strengths and needs in sequence; sometimes, depending on the severity of autism, the person is best served in a class that better integrates relatedness and communication skills throughout the day.

Options and Needs in the Community

Currently, the Network is an all voluntary group. We are committed to supporting families affected by autism and a sight or hearing impairment, and connecting them with other families and professionals. We do this via a computer-based national directory of individuals, parents, professionals and international members affected by autism and a sight or hearing impairment. We hope research into these issues will increase if a significant database is available to researchers. Names on the Network are only provided with permission.

If your needs are in line with our resources, please join the Network and come to our annual meeting at ASA's National Conference this year in Providence, R.I. Margaret P. Creedon, Ph.D., FAACP, is an attending staff at Michael Reese Hospital, Chicago, and a consultant to various groups for individuals on the autism spectrum, including the ASA and ASI Panel of Professional Advisors. She has chaired annual meetings of the Network at ASA National Conferences and serves as a professional contact.

Join the Autism Network

To send information and/or permission to have your name shared, or to request a Network form, please contact:

Dolores and Alan Bartel 7510 Ocean Front Ave. Virginia Beach, VA 23451 Fax: 757-428-0019

Resources

Deaf/Hearing Impaired

Living with Autism and Deafness
By Dolores Bartel
www.boystownhospital.org/Hearing/info/genetics/perspectives/
live_autism.asp

Autism and Deafness
A Psychologist's Perspective
By Margaret P. Creedon, Ph.D., FAACP
www.boystownhospital.org/Hearing/info/genetics/syndromes/
autism.asp

Autism and Deafness

www.raisingdeafkids.org/special/autism/

Arnold, Paul, Monteiro, Brendan, Roper, Louise. Co-Occurrence of Autism and Deafness, Diagnostic Considerations. Autism, 2003, pgs. 7, 245-253.

Blind/Visually Impaired

Gense, D. Jay and Marilyn. *Autism Spectrum Disorders and Visual Impairment*. AFB Press, 2005.

Pring, L. Autism and Blindness: Research and Reflections. Whurr Publishers, 2005.

Pawletko, Terese, et al. *Autism in the Visually Impaired Child* www.tsbvi.edu/Education/vmi/autism-vi.htm; www.tsbvi.edu/Education/vmi/index.htm;

www.focusfamilies.org/focus/newsletter/Focal_point_Fall.pdf

Pawletko, Terese. Social skills-IEP Goals for Students with Visual Impairments and Asperger's Syndrome www.tsbvi.edu/Education/vmi/aspergers.htm