reSources

California Deaf-Blind Services

Fall 2014 (Vol. 19 No. 2)

Why Deaf-Blindness and Autism Can Look So Much Alike

by Maurice Belote, CDBS Project Coordinator
and Julie Maier, CDBS Educational Specialist

Why another article on autism?

The similarities in the ways that autism and deaf-blindness present in children have been recognized for a long time, as have diagnostic strategies for differentiating between autism and deafness. Teachers of the deaf-blind often hear people say that these children seem to act autistic or to have "autistic-like behaviors." While it is possible for children to be both deaf-blind and be diagnosed with autism, it is much more likely that a child who is deaf-blind simply appears similar to a child with autism and, conversely, the child with autism might appear to have certain features consistent with deaf-blindness. The purpose of this article is not to consider the incidence of combined deaf-blindness and autism or weigh in on the debate over whether or not it is possible for children and young adults to have this dual diagnosis. The primary purpose of this article is to explain why children who are deaf-blind might, in some cases, share many of the same features associated with autism and how vision and hearing loss can explain these "autistic-like" features.

What exactly is autism?

In a nutshell, autism is a pervasive neurodevelopmental disorder, or difference, that is commonly recognized by the individual's diminished or unusual communication style, difficulty socially interacting successfully with others, desire to be alone, obsessive insistence on sameness and routine, heightened or diminished sensory responses, and in some instances unexpected and unexplainable abilities and skills that do not match skills in other developmental areas (Attwood, 2008). Autism typically appears in the first three years of life, but in some cases may not fully manifest or be recognized until the social demands required in the child's environment exceed his/her limited capacities. Although autism spectrum disorder is a life-long condition, adaptation, compensation, and progress in areas of deficits are possible and very likely (Frith, 2003). Many individuals with autism and their family members describe the brains of people with autism to be "wired differently" than people without autism, or neurotypicals, and they emphasize the autistic way of thinking as "different", but not "disordered" or "deficient".

What are the standard definitions of autism?

There are two other definitions for autism that are often used to ensure eligibility for supports and services—one from the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (2013), or DSM-5, and one from the Individual with Disabilities Education Act, or IDEA (2004). Each is important and each is used for specific purposes.

The DSM-5

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, commonly called the DSM-5, includes the diagnostic criteria for what is now called autism spectrum disorder (ASD). This criteria requires that children meet all three of the primary criteria and at least two of the secondary criteria:

Primary Criteria:

- Deficits in social-emotional reciprocity
- Deficits in nonverbal communicative behaviors used for social interaction
- Deficits in developing, maintaining, and understanding relationships

Secondary Criteria:

- Stereotyped or repetitive motor movements, use of objects, or speech
- Insistence on sameness, inflexible adherence to routines, ritualized patterns, or verbal nonverbal behavior
- Highly restricted, fixated interests that are abnormal in intensity or focus
- Hyper-reactivity (i.e., heightened reaction) or hypo-reactivity (reduced reaction) to sensory input or unusual interests in sensory aspects of the environment

In addition, the following are also a part of the DSM-5 definition:

- Age of onset: Symptoms must be present in the early developmental period.
- Level of impairment: Symptoms must cause clinically significant impairment in social, occupational, or other important areas of functioning.
- Rule-outs: These disturbances are not better explained by intellectual disability or global developmental delay.

Specifiers should also indicate the following comorbidities (i.e., two conditions present in the same individual):

- Presence or absence of accompanying intellectual impairment and or language impairment
- Known medical or genetic condition or environmental factor
- Other neurodevelopmental, mental, or behavioral disorder
- Presence of catatonia (i.e., abnormal movement and behavior associated most typically with schizophrenia)

This new DSM-5 eliminated the previous subcategories that included Asperger's

Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Rett's Disorder, and Child Disintegrative Disorder (CDD) previously recognized in the DSM-4. Now all of these formerly recognized diagnoses are included under the general category of Autism Spectrum Disorder.

IDEA 2004

The Individuals with Disabilities Education Act of 2004 includes its own definition of autism that states in part:

> Autism means a developmental disability significantly affecting verbal and nonverbal interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

Why are there two definitions of autism and autism spectrum disorder?

How, when, and why educational, medical, and social service agencies might apply these definitions are numerous but local educational agencies, such as school districts and county offices of education, are likely to use the definition of autism from the IDEA 2004. Medical personnel, as well as personnel from California's system of regional centers for persons with developmental disabilities, will more likely turn to the DSM-5 for diagnostic criteria.

IDEA uses the term autism, while the new DSM-5 uses the term autism spectrum disorder. For purposes of consistency in this article, we will use the acronym ASD to refer to autism and autism spectrum disorder.

How are deaf-blindness and ASD similar?

Deaf-blindness and ASD may look familiar because they both impact the way an individual accesses and processes sensory information. With children who are deaf-blind, vision and hearing may be:

- missing (i.e., no light perception and profound hearing loss);
- decreased (i.e., legal blindness or low vision and hard of hearing); and/or
- distorted (i.e., cerebral or cortical visual impairment and central auditory processing disorder or auditory neuropathy).

Vision loss can be related to specific conditions related to the complex structure of the eye, but can also be related to the way the information travels along the optic nerves and/or the way the brain processes this sensory information. Similarly, deafness and hearing loss can be related to the ear, in all its complexity, but can also be related to problems with the auditory nerves that

connect the ears and the brain or be related to the brain's ability to make sense of sound. Many children who are deaf-blind may experience both eye and ear issues combined with visual and auditory processing problems.

Individuals with ASD also often have difficulty with processing visual and auditory stimulation, but this is due to sensory processing differences rather than sensory loss. Sensory processing is how we all notice and respond to sensory events in our everyday lives, and the sensory processing patterns that develop affect how a person responds in a particular situation (Dunn, 2008). These differences in processing incoming sensory information and the unique and/or unusual behavioral responses of an individual with ASD are related to how the brain is processing this information. A common area of difficulty is the ability to effectively gather and filter incoming information and then accurately perceive all of the sensory information present in an environment or an interaction with another person. It is often discussed how individuals with autism are highly adept at recognizing patterns and details, but have difficulty "seeing the entire picture". This attention to details, component parts, and/or one sensory aspect over another is neurologically based and is not due to sensory loss. Rather, visual and auditory (and all other senses) are not recognized as the component parts that make up a whole, and instead specific sensory experiences or aspects of an environment or experience are heightened while others are diminished. An example might be a student who cannot understand the directions the teacher is giving because of the humming from an LCD projector and the sunlight crossing through the window blinds making long patterned shadow lines which have more sensory relevance and interest for the student. Another example is the student who screams and cries and drops to the floor when the fire alarm sounds unexpectedly and is not able to calm down and follow through with the action of leaving the building.

What's up with all these "autistic-like" behaviors?

The following chart identifies key features of ASD and how children with deaf-blindness might look similar:

Features Associated with Autism Spectrum Disorder (ASD)	How might this feature be reflected in children with autism spectrum disorder?	Why children with deaf-blindness might appear similar:
Delays in verbal and non-verbal communication	• Reduced initiation of expressive communication • Repetitive vocalizations or sounds • Lack of or delayed response to communicative attempts by other people • Inability to establish and/or maintain eye contact • Difficulties reading the body language, facial expressions, gestures, and other non-verbal cues of others • Heightened attention to objects rather than people (e.g., looking at a light switch on the wall rather than the expression on conversational partner's face)	With little or no access to spoken and/or visual language, children who are deaf-blind will have reduced or sporadic access to language. They may not understand the consequences of their actions or understand that they can control their environment through symbolic and non-symbolic communication. Without access to incidental learning, children must be taught the most basic non-verbal communication, such as facial features (e.g., interpreting a happy or sad face), gestures (e.g., waving the hand towards you to signal "come here", shaking the head side-to-side to communicate "no"), etc.

Features Associated with Autism Spectrum Disorder (ASD)	How might this feature be reflected in children with autism spectrum disorder?	Why children with deaf-blindness might appear similar:
Delays in social interaction	• Challenges with typical back-and-forth communication exchanges and conversations • Challenges with turn-taking activities • Insistence on same greeting and goodbye rituals regardless of context or situation • Difficulty making and maintaining positive relationships and friendships • Challenges with responding using expected and appropriate social behaviors in many situations because the person is not able to understand what the other person may be thinking, feeling, or expecting • Difficulty understanding satire and teasing and other figurative uses of language	For children with typically developing vision and hearing, they learn most of what they know about social skills and personal relationships through incidental learning. For example, children learn playground behavior by watching other children, copying things that other children do that work, and not doing things that don't work for other children. Incidental learning is not like direct teaching; it is learning solely by watching and listening to the world around you. Children who are deaf-blind may not have the vision and hearing to learn incidentally and therefore social interaction skills need to be taught in a more direct way. These children will need help in accessing the world around them so that they can understand the consequences of their interactions. Their lack of social interaction skills—or their perceived lack of these skills—isn't because they can't acquire these skills, but it's simply a matter of lack of visual and auditory access to situations in which to learn about social interactions.

Features Associated with Autism Spectrum Disorder (ASD)	How might this feature be reflected in children with autism spectrum disorder?	Why children with deaf-blindness might appear similar:
Restricted areas of interest	• Compulsive interest in one or a few topics of conversation (e.g., birthdays, types of horses, air traffic control) • Strong interest in specific objects (e.g., string, yarn, reflective objects, shirt cuffs, clocks, etc.) • Extreme interest in favorite toy or object (e.g., miniature animal, visual stimulation toy, etc.) • Difficulty maintaining conversations about other topics	For children who are deaf-blind, their view of the world around them is shaped by their perceptions. When vision and hearing are decreased and/or distorted or missing altogether, their world might be limited to what can be touched within arms reach. This impacts these children in every possible way. In addition, many children who are deaf-blind experience additional challenges such as physical disabilities and medical conditions. These medical conditions might limit a child's activity and include frequent absences from school and/or hospitalizations. As a result of all of these factors, these children may have fewer life experiences, and perhaps just as critical they may have fewer satisfactory experiences from which to draw a wider range of interests.

Features Associated with Autism Spectrum Disorder (ASD)	How might this feature be reflected in children with autism spectrum disorder?	Why children with deaf-blindness might appear similar:
Repetitive activities and/or speech	• Echolalia (i.e., repeating words and phrases spoken by others) • Using specific "scripts" in certain situations (e.g. greetings, check-out line banter, comments while playing a board game) • Insistence on following steps of an activity or routine in the same order • Restricted imagination and flexibility with play, as well as a lack of interest in new toys, games, or pretend play with others	There are many reasons why a child with sensory issues might engage in echolalia. It might be because the child has limited experiences with the subject matter discussed. Another possible explanation is that the child's receptive communication skills might be more advanced than their expressive skills, so the child wants to be engaged—and maybe is engaged—in the conversation but doesn't yet have the words or language skills to keep up with the conversation. There are also many reasons for repetitive behaviors. Repetitive behaviors might be a "place holder" while the child decides what to do next. It can also be due to a lack of information about how other children engage in the same behavior. Children with typical vision and hearing observe their environment and benefit from this incidental learning in a way that children who are deaf-blind may not.

Features Associated with Autism Spectrum Disorder (ASD)	How might this feature be reflected in children with autism spectrum disorder?	Why children with deaf-blindness might appear similar:
Stereotyped movements	• Rocking body back and forth when sitting and/or standing • Jumping or bouncing up and down • Waving or flapping hands and/or arms • Elaborate sequence of bodily movements repeated over and over • Moving fingers in front of eye(s) • Covering or cupping ears with hands	Stereotypical behaviors are often called self-stimulatory behaviors. These may be due to sensory deprivation or boredom. Many of these behaviors (e.g., rocking, hand flapping) also provide important proprioceptive input about where a child's body is in space and can be used to self-regulate arousal levels. These behaviors might also be used to reduce stress. Anyone who is operating at a heightened level of anxiety and stress is not likely going to be able to learn, try new things, interact with people, or cope with the inevitable unexpected changes that life presents.

Features Associated with Autism Spectrum Disorder (ASD)	How might this feature be reflected in children with autism spectrum disorder?	Why children with deaf-blindness might appear similar:
Resistance to environmental change	• Aggravation if personal possessions or materials in a classroom have been moved from their usual places or are not organized as expected • Insistence that certain objects/possessions be organized and stored in a specific way • Insistence on following the same route when traveling to familiar places • Sensitivity to changes in environment such as lighting, sound, scents, and even people present	Whether it is young children first learning to move about or older individuals with emerging orientation and mobility skills, environmental change can be very distressing for people who are blind or have low vision. It is possible to accomplish everyday tasks in an efficient manner when the environment is consistent and unexpected changes are minimized. Many children who are deaf-blind cling mightily to *order* and the reasons for this are completely understandable. A child who is deaf-blind wants to know that if they set an object down, it will still be there—in the same shape and condition—the next time they want it. Lilli Nielsen's concept of the Little Room is based on this idea: that objects will be in a predictable place so that the child can learn to anticipate. Without this sense of order, children who are deaf-blind might perceive their world as descending into a chaotic, stressful mess.

Features Associated with Autism Spectrum Disorder (ASD)	How might this feature be reflected in children with autism spectrum disorder?	Why children with deaf-blindness might appear similar:
Resistance to change in daily routines	• Preference for rigid, consistent schedules and routines • Extreme distress at unexpected changes in schedules or anticipated activities • Difficulty transitioning between activities of the day or changing from one activity to another	When access to sensory information is decreased, distorted, or missing altogether, children who are deaf-blind may cling desperately to familiar routines. This allows them to maintain some control over what they must often perceive as a chaotic, confusing world of people, things, and activities that come and go and stop and start without warning or explanation. Think about children with typical vision and hearing: if a child is engaged in a favorite activity and you tell the child she has to stop, the child will want to know what is going to happen next by noticing visual and auditory clues about the next activity. A person with vision and hearing loss does not receive this information incidentally and instead relies on predictability and routines for understanding.

Features Associated with Autism Spectrum Disorder (ASD)	How might this feature be reflected in children with autism spectrum disorder?	Why children with deaf-blindness might appear similar:
Unusual responses to sensory experiences	• Diminished or heightened responses to very loud or very quiet sounds • Extreme responses to certain sounds • Extreme responses to and/or preference for certain textures (e.g., aversion to clothing labels, strong preferences for specific clothing fabrics) • Strong interest in lights and reflective objects • Enjoyment of squeezing into small, tight spaces or receiving deep pressure squeezes or massage • Heightened or diminished reaction to extreme temperatures or pain • Inattentiveness to certain sensory information while extreme focus on other sensory input (e.g. doesn't appear to hear the teacher talking because a florescent light in the classroom is flickering)	Many children who are blind or visually impaired have something that has been called tactile defensiveness. This aversion to certain textures and experiences might be due to a lack of reliable information about what is about to happen, or it might be a result of more complicated neurological factors. Perhaps a better term for this tactile defensiveness is tactile selectiveness, because we all seek out preferred textures and avoid aversive textures. This is true for the clothes we wear, the surfaces we touch, and the food we eat. Plenty of people with typical vision and hearing avoid putting their hands into slimy textures or choose to wear clothing that isn't rough and itchy.

Features Associated with Autism Spectrum Disorder (ASD)	How might this feature be reflected in children with autism spectrum disorder?	Why children with deaf-blindness might appear similar:
Difficulties with executive function skills (e.g. self-regulation of behavior, controlling inhibition, planning and organization, working memory, and problem solving)	• Difficulty completing tasks or activities without additional reminders • Difficulty calming self when agitated or upset or frustrated • Heightened emotional responses, either positive or negative, that may be inappropriate for the setting • Inability to initiate action, especially in novel situations, and waiting for additional prompts/reminders from another person • Difficulty recalling and using information previously learned at a later time, especially in a different context	Since executive function skills need to be learned, this is another area that students with deaf-blindness very often have not had any or enough opportunities to learn these associated skills. Many of these learned skills are refined and finally acquired with input from others' reactions and responses, which most of us see or hear in another's gestures, facial expressions, vocal praise, or annoyance. This information is not fully available to an individual with vision and hearing losses. Perhaps the individual has not been given enough opportunities to regulate their own behaviors or reactions based on others' responses or to solve a novel problem, often because another person with intact vision or hearing does this for them. Due to lack of environmental or contextual information, it can also be difficult for people with vision and hearing loss to recognize that a situation or environment is novel and new and then consider using previously learned executive function skills. This is why orientation and mobility and every day life skills are such important areas of focus for students with deaf-blindness. Planning and successfully navigating environments and the daily tasks in life need to be taught, practiced, and supported with appropriate tools and assistive technology.

Don't many people have features of ASD to some degree?

It might be helpful to consider that many features of ASD are evident in people who don't have ASD and/or deaf-blindness. When it comes to the following features, our own behavior often falls on a spectrum of some kind:

Communication and social interaction delays: Our ability to engage in natural, back-and-forth communication exchanges can be impacted by factors such as stress, lack of confidence, sensory overload, and fear of saying something wrong. Some conversations just don't go well and sometimes we just can't seem to communicate effectively with certain people.

Restricted areas of interest: Sometimes we end up in situations in which we don't have anything to add to conversations because we don't know anything about the topics being discussed. Some of us are only interested in a few topics and are masters of steering conversations back to these topics of interest.

Stereotyped movements: Almost everyone engages in frequent self-stimulatory behavior throughout the day (e.g., sitting in a rocking chair, playing with our hair, twirling rings and bracelets, chewing gum, wearing strong cologne). We also use familiar activities to regulate our levels of arousal, both to increase arousal (e.g., stretching, listening to loud music, standing during meetings) and to decrease arousal (e.g., meditation, sitting in a quiet room with low lighting, massage).

Resistance to changes in the environment and daily activities: We find comfort in the familiar. This is one of the reasons why chain restaurants and stores are so popular. In fact, we depend on routines to minimize stress so that we are better prepared for the inevitable unexpected. Doing things the same way over and over isn't bad. In a sense, it allows us to save our creativity for times when it is truly needed.

Unusual responses to sensory experiences: We all seek out preferred sensory experiences (e.g., getting into bed, the smell of baking, going out into nature) and avoid aversive sensory stimuli (e.g., wearing rough/itchy fabrics, touching or eating gooey textures, unpleasant sounds).

Executive function difficulty: We use past successful experiences to navigate life on a daily basis using executive function skills. For example, we make our lunch and set our alarm clock the night before a work day, get the kids off to school on the way to work, attend planned and unplanned duties at work, and finally figure out a new way home when traffic is bad. We also use many tools to assist in these daily tasks such as planners and calendars, to-do lists, graphic organizers, self-talk to navigate stressful or unexpected situations, and yoga, mediation, or crossword puzzles to either quiet or activate our minds.

Discussion

As you can see from the chart, there are numerous similarities between specific features and behaviors often attributed to ASD and behaviors often observed in individuals who are deaf-blind. Many of them have to do with diminished or distorted sensory information or very different perception or understanding of the available and incoming sensory information (i.e. sensory processing). In the case of individuals with ASD, there are evidence-based interventions and accommodations that can allow the individual to adapt and compensate in specific skill areas related to communication, socialization, restricted areas of interests, and sensory processing. How the individual with ASD processes incoming sensory information likely will not change, but there are environmental, interactional, and self-regulatory changes or adaptations that can adjust the sensory demands to allow for greater participation and more successful interactions.

With individuals who are deaf-blind, the focus needs to be on the effects of the combined vision and hearing loss. It is important to identify the effect the vision and hearing loss has on incoming information and whether it limits or distorts the information. Next, one must determine if visual and auditory information is still viable and can be magnified (e.g. through contrast, large print, FM system) or if the individual needs to receive information through other senses (e.g. tactile communication, object calendar, specific positioning and support to enhance vestibular or proprioceptive sense, use of white cane to travel, or tasting or smelling food). From there the team can plan proper instructional strategies and adapted materials or assistive technologies that will allow the student to learn relevant skills. It is also critical to remember that some of the behaviors we discussed are already effective adaptations that the student has figured out work to provide the sensory input s/he needs, and in those cases the self-directed behavior should be acknowledged and supported rather than changed or "fixed" (Brown, 2011).

Resources

American Psychiatric Association (2013). DSM-5. Autism Spectrum Disorders Classification in Diagnostic and Statistical Manual of Mental Disorders (5th edition), p. 50-59.

Attwood, T. (2008). An overview of autism spectrum disorders. In Buron Dunn, K. & Wolfberg, P. (Eds) (2008) Learners on the Autism Spectrum: Preparing Highly Qualified Educators. Shawnee Mission, Kansas: Autism Asperger Publishing Company

Brown, D. (2011). Deaf-blindness, self-regulation, and the availability for learning: Some thoughts on educating children with CHARGE syndrome. California Deaf-Blind Services reSources, 16(3), 1-7. [Available at: http://www.cadbs.org/articles-by-subject/school/]

Dunn, W. (2008) Sensory processing: Identifying patterns and support strategies. In Buron Dunn, K. & Wolfberg, P. (Eds) (2008) Learners on the Autism Spectrum: Preparing Highly Qualified Educators. Shawnee Mission, Kansas: Autism Asperger Publishing Company.

Frith, U. (2003). Autism: Explaining the enigma. (Second Edition). Oxford: Blackwell Publishing.

Gense, M. & Gense, D.J. (2005). Autism Spectrum Disorders and Visual Impairment: Meeting Students' Learning Needs. New York: American Foundation for the Blind Press.

Harker, C.M., & Stone, W.L. (2014). Comparison of the diagnostic criteria for autism spectrum disorders across the DSM-5, DSM-IV-TR, and the Individuals with Disabilities Act (IDEA) Definition of Autism. Nashville, TN: The Iris Center, Vanderbilt University. [Available at http://iris.peabody.vanderbilt.edu/wp-content/uploads/2014/09/ASD-Comparison-092214.pdf]

Individuals with Disabilities Education Act of 2004, 20 U.S.C. §1400 et seq. (2004).