

WHY DEAFBLINDNESS AND AUTISM SPECTRUM DISORDERS LOOK SO MUCH ALIKE

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Pennsylvania Training and Technical Assistance Network (PaTTAN) Webinar

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Webinar description

- The similarities in the ways that autism spectrum disorders (ASD) and deafblindness present in children have been recognized for a long time, as have diagnostic strategies for differentiating between autism and deafness.
- Families and educators serving children with deafblindness increasingly hear other educators, service providers or medical specialists say that these children seem to act autistic or to have “autistic-like behaviors.”
- The purpose of this webinar is to look closely at the key features of ASD and deafblindness and consider why children who are deafblind might, in some cases, share many of the same features associated with ASD and how vision and hearing loss and other sensory impairments can explain these “autistic-like” features.

In this webinar you will learn...

- The commonly used definitions of deafblindness and diagnostic criteria used for ASD diagnosis.
- The differences between sensory loss or impairment (deafblindness) and sensory processing differences (ASD).
- About some of key diagnostic features of ASD and compare behavioral examples of each feature with same behaviors an individual who with dual sensory loss.
- How neurotypical individuals also show different responses based on sensory processing, sensory regulation, and context.
- About some of the benefits and problems of a dual diagnosis of ASD and deafblindness.

The seed...

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Why Deaf-Blindness and Autism Can Look So Much Alike

by Maurice Belote, CDBS Project Coordinator
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You can find it at our CDBS website www.cadbs.org under **Newsletters**:
<http://files.cadbs.org/200002495-2f170310b5/Belote%20-%20Maier%20reSources%20Fall%202014.pdf>

Important reminders

- ❑ These students are often very puzzling, which is a good thing.
- ❑ A diagnosis, or label, can provide helpful guidance, but should never define a child.
- ❑ Empathy and perspective taking is essential.
- ❑ Really good question to ask yourself: “How does the world right now appear and feel to them?”

Jan van Dijk (2001)



“The multi-sensory impaired person is a unique human being with a unique line of development, who is more dependent on the professional’s willingness to accept this and act accordingly than any other group of disabled persons.”

Deafblindness: Unique Learning Profile

- ❑ Lowest incidence disability
- ❑ Wide heterogeneity in abilities, level of vision and hearing, other support needs, language and culture
- ❑ Requires highly individualized IEP often developed by large teams
- ❑ Effective interventions for other sensory impairments are often not enough
- ❑ It's truly a "Disability of Access"

Federal definition of deafblindness

It may seem that deaf-blindness refers to a total inability to see or hear. However, in reality deaf-blindness is a condition in which the combination of hearing and visual losses in children cause "such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness" (34 CFR 300.7 (c)(2), 2004)

~ Barbara Miles, *An Overview of Deafblindness* (2008)

A simple, useful description...

- *“Deafblindness is a combination of a sight and hearing impairment that affects how you communicate, access information, and get around.”*
(SENSE website)
- Definition used by California Deafblind Services:
Deafblindness is combined hearing and vision problems that are significant enough to require considerations (such as specialized adaptations, modifications, and strategies) when presenting information or interacting with the individual.

Federal definition of autism (2004)

"Autism means a developmental disability significantly affecting verbal and nonverbal communication and social 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."

~ 34 CFR Section 300.8 (c)(1)(i-iii)

Autism spectrum disorders

“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).

DSM-V Diagnostic Criteria for 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 (heightened reaction) or hypo-reactivity (reduced reaction) to sensory input or unusual interests in sensory aspects of the environment

DSM-V Diagnostic Criteria for ASD

In addition, the following are also a part of the DSM-V 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

Problems with vision and hearing

With individuals who are deafblind, 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).

Many individuals who are deafblind may experience both eye and ear issues combined with visual and auditory processing problems.

ASD & Sensory processing difficulties

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.”

~Winnie 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.

Perspective

Many individuals with autism and their family members describe the brains of people with autism as “wired differently” than people without autism, or neurotypicals, and they emphasize the autistic way of thinking as “different”, but not “disordered” or “deficient”.

Our Brain...

Sensory In

- ❑ Messages (input) from all 7 sensory systems travel to the brain on “inbound” tracts of the nervous system.
- ❑ It is a **one-way** street.
- ❑ **Sensory** information only goes **IN**.

Motor Out

- ❑ Messages (output) travel to the muscles on motor pathways, or “outbound” tracts of the nervous system.
- ❑ It is a **one-way** street.
- ❑ **Motor** instructions only go **OUT**.

Kate Beals, OT CHARGE Syndrome Conference July 2015

Sensory Systems

- ❑ Job of our sensory systems is to **provide information** to the brain.
- ❑ This sensory information is transmitted to the brain for two reasons: 1) **generate awareness** and (arousal/alerting) and 2) **gather information** for making a map of one’s self and environment (discrimination and mapping).
- ❑ In most cases these two reasons **typically complement each other**, but in **individuals with ASD arousal input frequently overpowers discriminating input** and this creates unusual behavior as person tries to manage the distorted information.

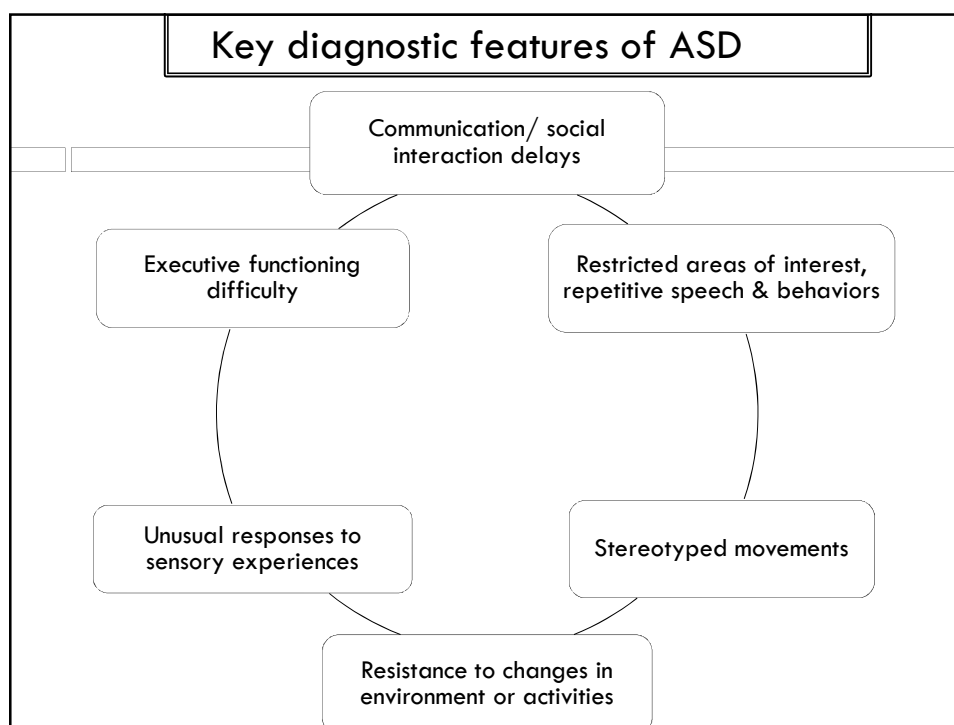
~Winnie Dunn (2008)

“Missing the forest for the trees.”

- Central coherence theory (Frith, 2003)
- Common area of difficulty is gathering, filtering, and then accurately interpreting incoming sensory input.
- Visual and auditory (and all other senses) are not recognized as the component parts that make up a whole.
- Instead specific sensory experiences or aspects of an environment or experience are heightened, while others are diminished.

Belote & Maier (2014)

Simply put, deafblindness and ASD may look similar because they both significantly impact the way an individual **accesses** and **processes** the **sensory information** in their environment.



Delays in verbal and non-verbal communication	
Possible behaviors of a person with ASD	Reasons someone with deafblindness might appear similar:
<ul style="list-style-type: none"> • Little or absent initiation of expressive communication • Repetitive vocalizations or sounds • Lack or delayed responses to others' communicative attempts • Inability to establish or maintain eye contact • Difficulties reading other people's body language, facial expressions, gestures, and other non-verbal cues • Heightened attention to objects rather than people 	<ul style="list-style-type: none"> • Reduced or no access to spoken or visual language. • May not understand consequences of communicative actions they engage in or attempt. • May not understand they can control their environment through symbolic and non-symbolic communication. • Have not learned the most basic non-verbal communication due to lack of incidental learning opportunities and/or sensory losses. • Often will not notice others present in their environment unless they are very close by.

Delays in developing social interaction skills

Possible behaviors of a person with ASD	Reasons someone with deafblindness might appear similar:
<ul style="list-style-type: none"> • Challenges with typical back-and-forth communication exchanges • Challenges with turn-taking activities • Insistence on same greeting or goodbye rituals regardless of context • Difficulty making and maintaining positive relationships and friendships • Challenges with responding using expected and appropriate social behaviors in many situations because difficulties with understanding others' behaviors or perspectives • Difficulty understanding satire & teasing or figurative language 	<ul style="list-style-type: none"> • People learn about social skills & personal relationships through incidental learning. • Incidental learning is acquired solely by watching and listening to the world around you. • People who are deafblind may not have the vision and hearing to learn incidentally and need direct instruction to learn social interaction skills. • Their lack of social interaction skills—or perceived lack of these skills—isn't because they can't acquire these skills, but it's the lack of visual and auditory access to situations in which to learn about social interactions.

Restricted areas of interests

Possible behaviors of a person with ASD	Reasons someone with deafblindness might appear similar:
<ul style="list-style-type: none"> • Compulsive interest in one or a few topics of conversation (e.g., breeds of horses, birthdays, rail systems) • 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 	<ul style="list-style-type: none"> • With decreased and/or distorted or missing vision and hearing, your world might be limited to what can be touched within arms reach. • Many individuals who are deafblind experience additional challenges such as physical disabilities and medical conditions which limit access and opportunities. • In addition to fewer life experiences, these individuals may have fewer satisfactory experiences from which to draw a wider range of interests.

Use of repetitive speech or engaging in repetitive activities or routines

Possible behaviors of a person with ASD	Reasons someone with deafblindness might appear similar:
<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Limited experiences with the subject matter/topic discussed. Receptive communication skills may be more advanced than their expressive skills, so the person wants to be engaged in the conversation but doesn’t yet have the language skills to keep up with the conversation. Repetitive behaviors might be a “place holder” while the person decides what to do next. Lack of information about how others engage in the same behavior due to difficulty with incidental learning & need for direct instruction.

Stereotyped movements or behaviors

Possible behaviors of a person with ASD	Reasons someone with deafblindness might appear similar:
<ul style="list-style-type: none"> 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 body movements repeated over and over Moving fingers in front of eye(s) Covering or cupping ears with hands 	<ul style="list-style-type: none"> Stereotypical behaviors are often called self-stimulatory behaviors. These might 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. Often used to self-regulate arousal levels. These behaviors might also be used to reduce stress.

Resistance to environmental change

Possible behaviors of a person with ASD	Reasons someone with deafblindness might appear similar:
<ul style="list-style-type: none"> • 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 the environment such as lighting, sound, scents, and even people present 	<ul style="list-style-type: none"> • For children or older individuals who are blind or low vision with emerging orientation and mobility skills, environmental change can be very distressing. • Accomplishing everyday tasks in an efficient manner is easier when the environment is consistent and unexpected changes are minimized. • Order makes life and our world less chaotic and more predictable which reduces stress.

Resistance to change in daily routines

Possible behaviors of a person with ASD	Reasons someone with deafblindness might appear similar:
<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • Familiar routine allows a person 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. • A person who is deafblind depends on routines and predictable transitions to provide the information the visual and auditory cues they are missing provide.

Unusual responses to sensory experiences

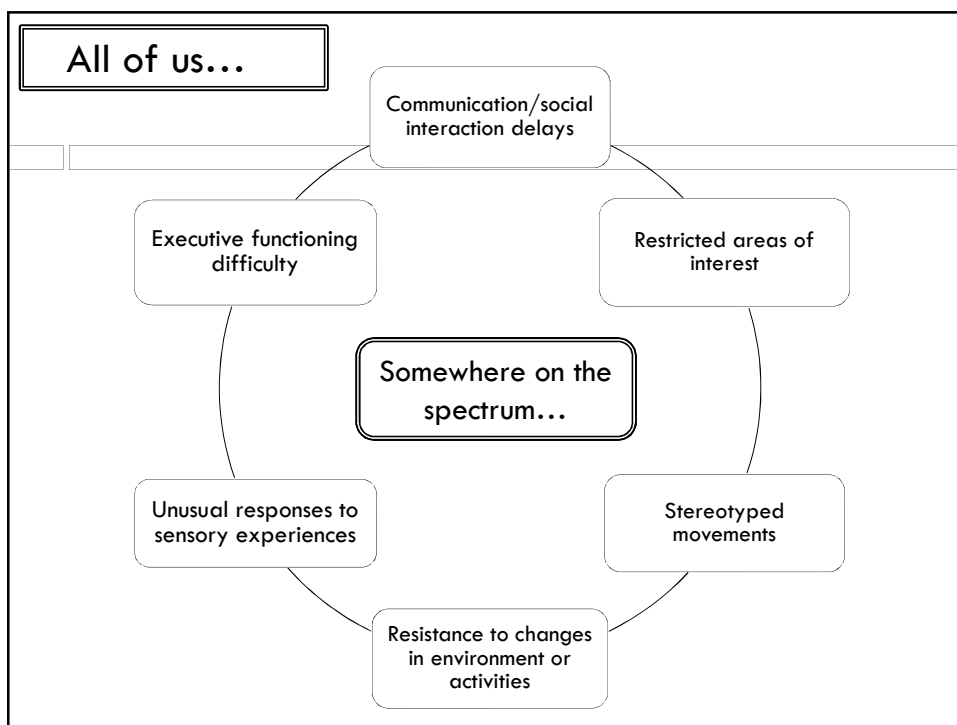
Possible behaviors of a person with ASD	Reasons someone with deafblindness might appear similar:
<ul style="list-style-type: none"> • Diminished or heightened responses to very loud or very quiet sounds or to certain sounds • Extreme responses to and/or preference for certain textures • Strong interest 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 	<ul style="list-style-type: none"> • Tactile selectiveness—seeking out preferred tactual inputs and avoiding those that aren't preferred—makes sense if one has missing or diminished vision. • Seeking tight spaces, clothing, and deep pressure is likely the need for proprioceptive input to help regulate their body in space. • Medical and physiological issues can make interpreting pain and body temperature extremely difficult. • Missing, diminished, and distorted vision and hearing can lead to unusual and unexpected responses to sensory information that others react to or are able to ignore.

Difficulties with executive function skills

Possible behaviors of a person with ASD	Reasons someone with deafblindness might appear similar:
<ul style="list-style-type: none"> • 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 • Difficulty recalling and using information previously learned at a later time, especially in a different context 	<ul style="list-style-type: none"> • Lack of opportunities to learn or practice these skills or 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. • Many of these skills are learned and refined through visual input received from others facial expression and gestures. • Without visual and auditory environmental or contextual information, it can also be difficult for someone to recognize that a situation or environment is novel and new and use previously learned skills.

Chicken or the Egg?

- For over four decades researchers have identified and documented many typically autistic behaviors in congenitally deafblind children.
- Necessary to consider if the barriers caused by congenital deafblindness, especially in relation to communication, language and social skill development, and sensory isolation, contribute to the development of autistic-like behaviors. (Danmeyer, 2014; Hartshorne, 2005).
- It's also interesting to ponder why a behavior is termed "autistic" rather than "deafblind".



Pop Quiz

- ☐ How many of you have been swinging your legs or uncrossing and crossing your legs during this presentation?
- ☐ Biting your nails?
- ☐ Twisting your hair?
- ☐ Rocking in your chair?
- ☐ Fiddling with your watch or jewelry?

Pop Quiz

- ☐ How many cringe or jump at the sound of fireworks or sirens?
- ☐ Sometimes walk out of a restaurant before seated because the cooking smells bother you?
- ☐ Get headaches from going to the mall?
- ☐ Cut tags out of new clothes before you can wear them?

Pop Quiz

- ☐ How many of you avoid sidewalk cracks?
- ☐ Need to have your desk “just so” before you can work?
- ☐ Carry a certain “lucky” item most or all of the time?
- ☐ Try to sit in the same seat in class, park in the same space at work every day?

Why does dual diagnosis occur?

- ☐ First, many of the behaviors are very familiar.
- ☐ Lack of knowledge about deafblindness by both medical and educational professionals, especially related to particular syndromes in which autistic-like behaviors are present or part of the syndrome.
- ☐ More awareness and experience with individuals with ASD than with deafblindness.
- ☐ Many school systems have invested in training, materials, and services specific to ASD.
- ☐ Labels often provide services and supportive resources, so families or support providers seek a diagnosis of autism.

Dual Diagnosis

□ Potential benefits include:

- ▣ Educational environments might be more structured and include predictable routines and transitions.
- ▣ Diagnosis may provide access to particular helpful and effective intervention and services.
- ▣ Services, supports, accommodations, and instruction may be more individualized and focused on communication and social skill development with particular attention to sensory processing issues.
- ▣ Families may find valuable social and informational support through connections to other families with children with similar challenges and support needs.

Dual Diagnosis

□ Potential problems include:

- ▣ Student with deafblindness doesn't "fit" into autism-focused program or interventions used in that program.
- ▣ Intervention approaches are purely behavioral and don't adequately address unique multisensory and communication needs of the student with deafblindness.
- ▣ The autism diagnosis is primary and serves as a barrier to a team acquiring knowledge and skills about deafblindness or a particular etiology (e.g. CHARGE syndrome, Rubella syndrome, Down syndrome)
- ▣ The additional diagnosis may not provide additional helpful information or add anything to the educational program, and may actually limit the educational opportunities offered to a student with an additional label.

Additional resources for further study:

- ❑ Danmeyer, J. (2014). Symptoms of autism among children with congenital deafblindness. *Journal of Autism & Developmental Disorders*, 44(5).
- ❑ Hartshorne, T., Grialou, T., and Parker, K. (2005). Autistic-like behaviors in CHARGE syndrome. *American Journal of Medical Genetics* 133 A: 257–261.
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- ❑ Capone, G. (n.d.) Down Syndrome and Autistic Spectrum Disorder: A Look at what we know. Adapted from *Disability Solutions*, Vol. 3(4/5).

Questions? Comments?

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