"HMMM, IT LOOKS LIKE AUTISM TO ME": UNDERSTANDING THE SIMILARITIES BETWEEN THE PROFILES OF LEARNERS WITH AUTISM AND LEARNERS WITH SENSORY LOSSES

JULIE MAIER, MA

CALIFORNIA DEAFBLIND SERVICES

TSBVI COFFEE HOUR

FEBRUARY 26, 2024

THE SEED

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

In 2013 and 2014 my colleague and I started hearing many questions and stories from families and professionals about dual diagnosis of deafblindness and autism. We decided to share our thoughts about it.

All our life is but a mass of habits.

–William James, philosopher & psychologist

IMPORTANT REMINDERS

- Individual with deafblindness, visual impairments, or autism 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.
- A 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."

AUTISM SPECTRUM DISORDER (ASD)

Autism is a complex, lifelong neurodevelopmental disability that typically appears during early childhood and can impact a person's social skills, communication, relationships, and self-regulation.

Autism is defined by a certain set of behaviors and is a "spectrum condition" that affects people differently and to varying degrees.

Source: The Autism Society

KEY DIAGNOSTIC CHARACTERISTICS OF ASD

- Communication and social interaction delays
- Restricted areas of interest
- Stereotyped movements
- Resistance to changes in the environment or activities
- Unusual responses to sensory experiences
- Executive functioning difficulties

DIAGNOSTIC CRITERIA FOR ASD: THE DSM-V

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

ADDITIONAL CONSIDERATIONS

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.

DEAFBLINDNESS

- Deafblindness refers to the combination of hearing differences and vision loss that significantly limits an individual's ability to receive information from their surroundings and the people in their surroundings.
- This can lead to developmental delays in areas of language and communication, concept development, social skills, and mobility, but doesn't necessarily limit the individual's learning potential.
- Fundamentally, deafblindness is a **disability of access.**

THE SPECTRUM OF DEAFBLINDNESS

The range and types of vision loss and hearing levels is expansive, however a common denominator is **the struggle to acquire the information** available to sighted and hearing people.

With learners 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).

THE VI AND ASD CONNECTION

- Multiple studies have found autism is more common among people who are blind/low vision than the general population, studies show.
- Children with autism also are more often diagnosed with significant vision disorders than neurotypical children. Including refractive errors, strabismus, and amblyopia.
- Since vision is how most neurotypical children learn social skills, a visual condition might explain some of the autistic behaviors. Visual skills like making eye contact or directing eye contact toward another person's gaze and "reading", or understanding, another person's facial expressions and body language are often indicative of autism. Deweerdt, S. (2020)

BLINDISMS

- This term is often used to describe stereotypic unusual behaviors exhibited by individual who are blind/low vision.
- The behaviors include: rocking back and forth, spinning, head swaying and rhythmic bouncing.
- The intensity and persistence of these behaviors may indicate autism rather typical behaviors associated with blindness.
- It is important to consider the purpose of the behaviors to provide the appropriate response to the behavior and intervention for the child.
- (Gense, M. & Gense, J., 2005)

ASD: UNUSUAL VISUAL AND AUDITORY CHARACTERISTICS

Visual

- Little to no eye contact or difficulty maintaining eye contact.
- Does not visually follow other people's movements in environment or visually imitate
- Does not mimic or react to facial expressions
- Peripheral side viewing
- Isolate on certain visual details, especially lights or spinning objects

Auditory

- Child often appears Deaf to others
- Doesn't respond to name or spoken language used by others
- Doesn't respond to loud sounds
- Doesn't meet language milestones for babbling or early speech
- Uses visual or physical means to communicate

WHY DOES THE QUESTION OF ASD ARISE?

- First, many of the behaviors look very familiar.
- Lack of knowledge about deafblindness and certain types of vision impairments by both medical and educational professionals.
- More awareness and experience with individuals with ASD than with deafblindness and visual impairments.
- 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.

IMPACT OF LIMITED DISTANCE SENSES

- Typically developing children gather information through all of their senses, but especially hearing and vision.
- Moment to moment, vision and hearing provide them with the information they need to continuously expand their conceptual knowledge and interact with the world around them.

HOW SIGHTED, HEARING NEUROTYPICAL CHILDREN LEARN

- Vision ~85%
- Hearing ~12%
- Taste, touch, smell ~3%

OUR SENSORY SYSTEM

The 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)

OUR BRAIN: THINK TRAIN

Sensory In

- Messages (input) from all 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.**

Source: Kate Beals, OT, 2015 International CHARGE Conference

AUTISM & DEAFBLINDNESS

Similarities:

- Insistence on routines
- Repeated stereotypic behavior or interests
- Difficulty with executive function
- Delayed communication and social skills
- Sensory and emotional regulation difficulties

Key Difference:

- Sensory processing differences (ASD) vs. sensory systems not functioning properly.

LET'S TAKE A DEEPER DIVE

- Resistance to environmental change
- Restricted areas of interest
- Delay in social interactions
- Resistance to change in daily routines
- Unusual repetitive behavior
- Unusual responses to sensory experiences

WE ALL FALL SOMEWHERE ON THE SPECTRUM

CHICKEN OR THE EGG?

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

Why the focus on autism?

Dammeyer (2014) found that there are three essential behavioral domains where similarities between learners with ASD and deafblindness have been reported:

- Social interaction
- Communication
- Restricted and repetitive behavior

This indicates that the suspicion or diagnosis of ASD is based on observations focused on person's behavior rather than internal and external factors affecting the person with dual sensory loss.

AUTISTIC-LIKE BEHAVIOR IN CHARGE SYNDROME
*H*ARTSHORNE, GRIALOU, & PARKER (2005)

- **Language and social engagement:** People with CHARGE syndrome are **more** socially engaged and have **better** language or communication skills than those with **people with ASD.**
- **Sensory related movements and behaviors (rocking, whirling, flapping):** People with CHARGE syndrome engage **more** in these behaviors more than **other people who are deafblind.**
- **Coping with stressful demands from the environment:** Responses are **similar** to those with **ASD**.

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."

Concerns about using primarily autism-focused interventions

- Intervention and instruction is adult-directed and initiated.
- Strong focus on behavioral model.
- Inflexibility of some ASD interventions.
- Focus on communication and reciprocal social skill delays without consideration of child's multisensory needs.
- Accessibility of visual and auditory cues and supports.

POTENTIAL BENEFITS OF DUAL DIAGNOSIS

- Structured educational environments that include predictable routines & transitions.
- Diagnosis may provide access to helpful and effective intervention and services.
- Individualized services, supports, accommodations, and instruction 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.

POTENTIAL PROBLEMS WITH DUAL DIAGNOSIS

- Student who is deafblind doesn't "fit" with the autism-focused program or interventions.
- Intervention approaches are purely behavioral and don't adequately address unique multisensory and communication needs of a student who is deafblind.
- The autism diagnosis is primary and serves as a barrier to a team acquiring knowledge and skills about deafblindness.
- The additional diagnosis may not provide additional helpful information to team, and the additional label limits the educational opportunities offered to a student.

FINAL THOUGHTS ON DUAL DIAGNOSIS

- Critical to identify if the “autistic” characteristics or behaviors can be attributed to dual sensory or multi-sensory loss or impairments.
- For a child with vision and hearing losses, assessment for ASD must include a person with knowledge and experience in deafblind education.
- What does an additional label offer?
- Are evidence-based instructional methodologies and practices related to ASD most appropriate for this deafblind learner?

QUESTIONS? COMMENTS?

Contact Information:

Julie Maier

California Deafblind Services

Project Coordinator

jmaier@sfsu.edu

415-405-7558

REFERENCES

- Belote, M. & Maier, J. (2014). Why deaf-blindness and autism can look so much alike. *reSources: California Deaf-Blind Services Newsletter, 19*(2). California Deafblind Services, San Francisco, CA.
- Brown, D. (2005). CHARGE Behaviors: Challenges of adaptations? *American Journal of Medical Genetics, Part A*(133A), 268-272.
- Dammeyer, J. (2014). Symptoms of Autism Among Children with Congenital Deafblindness. *Journal on Autism and Developmental Disorders. 44:* 1095. https://doi.org/10.1007/s10803-013-1967-8.
- Deweerdt, S. (2020). Eyeing the connection between autism and vision. *Spectrum.* Retrieved 2/5/24 https://www.spectrumnews.org/features/deep-dive/eyeing-the-connection-between-autism-and-vision/
- 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.
- Hartshorne, T.S., Grialou. T.L. Parker, K.R. (2005). Autistic-like behavior in CHARGE syndrome. *American Journal of medical genetics. 133*A. 257-261.