1 **Autism or Deafblindness: Considerations for Assessment and Intervention for Learners with Sensory Losses**

JULIE MAIER, MA
CALIFORNIA DEAFBLIND SERVICES
2025 TEXAS DEAFBLIND SYMPOSIUM
AUSTIN, TEXAS
FEBRUARY 27, 2025

2 **SHARING MY INTENTIONS**

I'm grateful for the opportunity to share my ideas, perspectives and experiences with you.

Much of what I'll share has been acquired from spending time with individuals who are deafblind or autistic and from my mentors in the field. Hopefully, it is useful to your practice.

I expect to learn from your expertise and experiences as well.

3 **OBJECTIVES**

- Understand the difference between a sensory processing difference and sensory losses and explain how certain behaviors demonstrated by an individual may be a response to missing, reduced, or distorted sensory information rather than autism.
- Recognize and explain: 1) the potential benefits and concerns related to dual diagnosis of deafblindness and autism and 2) the limitations and concerns related to exclusive use of evidence-based ASD interventions for a learner.

4 **THE SEED**

In 2013 and 2014 we 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.

5 **IMPORTANT REMINDERS**

- Children and youth who are deafblind or autistic 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?”

6 **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.”

7 **NEURODIVERSITY**

- “Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits.” (Baumer & Fruth. Harvard Health. 2021.)
- Temple Grandin shared, "The focus should be on teaching people with autism to adapt to the social world around them while still retaining the essence of who they are, including their autism."

8 **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

9 **KEY DIAGNOSTIC FEATURES 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

10 **DIAGNOSTIC CRITERIA FOR ASD: THE DSM-V**

This criteria requires that children meet <u>all three of the primary</u>

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

11 **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.

12 CHANGES IN DSM AUTISM DIAGNOSIS (1)
SOURCE: HARKER,C.M. & STONE, W.L. (2014).

1 DSM-V

2 • Terminology: Four previously separate categories now under one umbrella called “Autism Spectrum Disorders” or ASD

- Two categories required for diagnosis:
- Persistent deficits in social communication/interaction *and*
- Restricted, repetitive patterns of behavior

- Sensory issues are now included as a behavioral symptom

3 DSM-IV

4 • The previous categories were: Autistic disorder; Asperger syndrome; Childhood disintegrative disorder; Pervasive developmental disorder-not otherwise specified (PDD-NOS)

- Previously had been three categories
- Social impairment
- Language/communication impairment *and*
- Repetitive/restricted behaviors
- Sensory issues had not been considered before.

13 CHANGES IN DSM AUTISM DIAGNOSIS (2)
SOURCE: HARKER,C.M. & STONE, W.L. (2014).

1 DSM-V

2 • Behavioral criteria requirements in each area:

- Three in social communication and interaction.
- Two in restricted, repetitive patterns of behavior
- A severity assessment scale (levels 1-3) applied to both symptom areas based on level of support needed for daily function.
- Age of onset: Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities).

3 DSM-IV

4 • Formerly had to meet 6 criteria requirements overall across 3 areas.

- Functioning had been determined by category (autistic disorder, Asperger's syndrome, PDD-NOS)
- Delays or abnormal functioning in at least one of the 3 behavioral areas must be present prior to age 3 years.

14 **THE VI AND ASD CONNECTION**

- Multiple studies have found autism is more common among people who are blind/low vision than the general population.
- 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)

15 **BLINDISMS**

- This term is often used to describe stereotypic unusual behaviors exhibited by individuals 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)

16 **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.

17 **THE SPECTRUM OF DEAFBLINDNESS**

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

18 **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.

19 **HOW SIGHTED, HEARING NEUROTYPICAL CHILDREN LEARN**

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

20 **QUIET BACK THERE! I NEED TO WATCH THE ROAD!**

21 **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)

22 **OUR BRAIN: THINK TRAIN**

1 <u>Sensory In</u>

- 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

2 goes IN. <u>Motor Out</u>

- 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.

23 **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.

24 All our life is but a mass of habits.
–William James, philosopher & psychologist

25 Leo Kanner shared that a feature of ASD is an...
"Anxiously obsessive desire for the maintenance of sameness."

26 RESISTANCE TO ENVIRONMENTAL CHANGE

27 RESTRICTED AREAS OF INTEREST

28 DELAY IN SOCIAL INTERACTIONS

29 RESISTANCE TO CHANGE IN DAILY ROUTINES

30 UNUSUAL REPETITIVE BEHAVIOR

31 VIDEO

32 A FEW MINUTES LATER…

33 UNUSUAL RESPONSES TO SENSORY EXPERIENCES

34 QUESTIONS?

35 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. (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*)

36 **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.

37 **ASD: UNUSUAL VISUAL AND AUDITORY CHARACTERISTICS**

1 Visual

2 • 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

3 Auditory

4 • 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

38 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:

a. Social interaction
b. Communication
c. Restricted and repetitive behavior

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

39 Autistic-like behavior in CHARGE syndrome
Hartshorne, 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.

40 **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."

41 **POTENTIAL BENEFITS OF DUAL DIAGNOSIS**

1. Structured educational environments that include predictable routines & transitions.
2. Diagnosis may provide access to helpful and effective intervention and services.
3. Individualized services, supports, accommodations, and instruction focused on communication and social skill development with particular attention to sensory processing issues.
4. Families may find valuable social and informational support through connections to other families with children with similar challenges and support needs.

42 **POTENTIAL PROBLEMS WITH DUAL DIAGNOSIS**

1. Student who is deafblind doesn't "fit" with the autism-focused program or interventions.

2. Intervention approaches are purely behavioral and don't adequately address unique multisensory and communication needs of a student who is deafblind.
3. The autism diagnosis is primary and serves as a barrier to a team acquiring knowledge and skills about deafblindness.
4. The additional diagnosis may not provide additional helpful information to team, and the additional label limits the educational opportunities offered to a student.

43 **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?

44 **QUESTIONS?**

45 **EVIDENCE BASED PRACTICES (EBP)**

In educational settings, *"evidence-based practices"* are effective intervention strategies that are supported by rigorous research and evidence specific to the particular group of learners with whom the interventions are implemented.

It is critical that the practices and interventions selected for a learner are evidence-based and well-matched to that learner.

46 EVIDENCE BASE FOR ASD AND DEAFBLINDNESS AND VISUAL IMPAIRMENTS

47 Concerns about using primarily autism-focused interventions

- Intervention and instruction is adult-directed and initiated.
- Strong focus on a 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.

48 **COMBINING EVIDENCE-BASED PRACTICES**

FOR ASD AND DEAFBLINDNESS

- Need for further research to identify EBPs for learners who are deafblind.
- One direction is to use EBPs for ASD with modifications.
- Caution that some EBPs may not be appropriate for learners who are deafblind.
- Any interventions with a learner who is deafblind must be individualized and matched to their needs.
- Crucial that consequences of sensory losses be considered.
- Assessment should include a professional knowledgeable in deafblindness.

49 **IDENTIFICATION DETOURS**

Language delay
Motor delay
Lack of facial expression
Language delay
Lack of eye contact
OCD-like features

50 *ESTABLISHED* PRACTICES AND INTERVENTIONS

FOR CHILDREN AND YOUTH WITH ASD (WONG ET AL. 2015)

- ☐ Behavioral Interventions
  - Cognitive Behavioral Intervention Package
  - Comprehensive Behavioral Treatment for Young Children
  - Language Training (Production)
  - Modeling
- ☐ Natural Teaching Strategies
  - Parent Training
  - Peer Training Package
  - Pivotal Response Training
  - Schedules
  - Scripting
  - Self-Management
  - Social Skills Package
  - Story-based Intervention

51 **SENSORY PROFILE**

- Deafblind children and youth often experience issues with many other sensory systems in addition to visual and auditory systems.
- Identifying a learner's interests, preferences, and aversions in each sensory area, as well as in movement and positioning, must be strongly considered when determining the most appropriate intervention practices.

52 **ZONES OF PROXIMAL DEVELOPMENT**

- Zone 1: Current understanding and skills. Needs no assistance
- Zone 2: Learns through scaffolding and guidance
- Zone 3: Out of reach, even if guided

53 Sensory Profile Assessment Tool:

Likes/ Dislikes from the Washington DeafBlind Program

54 Use of Sensory Channels Form
WA Deafblind Project (2005)

55 THE CHECKLIST OF EDUCATIONAL NEEDS OF INDIVIDUALS WITH CHARGE SYNDROME

Developed by Dr. Lily Slavin while a doctoral student at Central Michigan University. (Slavin, L. & Hartshorne, T., 2019).

Purpose: The checklist is a tool that can be used by school teams and early intervention specialists to help guide educational services for individuals with CHARGE syndrome.

56 **INSTRUCTIONAL FOCUS AREAS FOR CHILDREN & YOUTH WITH DEAFBLINDNESS**

- Communication and concept development
- Functional use of vision and appropriate assistive devices
- Accommodations to support auditory input
- Orientation and mobility
- Strategies to help regulate emotions
- Need for additional sensory input AND need for sensory breaks
- Age-respectful, motivating, meaningful curriculum, both academic and functional
- Social relationships with others, especially peers
- Self-determination

57 **BRIDGING ASD & DEAFBLIND PRACTICES**

- Always look at the individual and their needs first.
- Select interventions that fit the child's learning profile, skills, and needs.
- Select practices and approaches that are child-led and are implemented in natural contexts.
- Sensory needs must be considered and responsive to—ACCESS, SUPPORTS, PREFERENCES.
- Consult with deafblind specialists for training and resources.
- Provide families with accurate and complete information about ASD features and interventions.

58 **DEAFBLINDNESS: CHILD-GUIDED PRACTICES**

- *"Follow the child"*. Motivation is key to learning.
- Respect the child's preferences.
- Embed their interests into activities and instruction.
- Join the child in activities, play, work they select or initiate.
- Build upon the child's initiations, actions, language.
- Provide meaningful and motivating choices that allow learner to feel in control.
- Partial vs. full participation to ensure student success rather than failure.

59 **DEAFBLINDNESS: PACING AND PRACTICE**

- Children with deafblindness often need more time than their peers to gather information, learn new concepts and skills, and respond to others.
- Plan transitions well and provide prompts and alerts.
- Provide child time to practice and participate at their own pace—don't rush them.
- Use of an activity-based curriculum that allows opportunities for movement, breaks, different positions.
- PAUSE and provide the time needed for child to be ready and comfortable with response.

60 **DEAFBLINDNESS: DIRECT, SYSTEMATIC, HANDS-ON INSTRUCTION**

- Children with vision and hearing loss do NOT learn about the world incidentally.
- Concepts, knowledge and skills are developed through repeated, direct experiences.
- Model steps in a task or activity for learner.
- Task Analysis: Break down activities and tasks into smaller steps so learner is successful.
- Focus on clear Beginning-Middle-End in each activity and lesson.
- Using materials, activities, routines present in the child's home and classroom provide the concrete and meaningful reference point for the child.

61 **DEAFBLINDNESS: ENVIRONMENTAL ADAPTATIONS**

- Organized learning spaces. Use of a calendar or schedule system.
- Access to materials of high interest.
- Intriguing materials and activities that rotate to enhance interest and motivation.
- Information presented in visual, auditory, and tactual modes.
- Attention to visual and auditory clutter and lighting.
- Variety of seating options.
- Safe space for child to relax and recharge.

62 **DEAFBLINDNESS: PLANNED TRANSITIONS AND ROUTINES**

- Consistency and predictability provide reassurance, sense of security, and reduces stress and anxiety.
- Promotes child's initiation & independence.
- Maintain consistency but also provide variety & novelty.
- Use visual markers and predictable auditory cues and wait time during transitions.
- Use object or visual calendars and schedules.
- Let child know of changes in advance.

63 **DEAFBLINDNESS: MEANINGFUL CURRICULUM**

- Age-respectful curriculum with adaptations. *Don't underestimate a student's abilities!*
- Functional activities and lessons that will serve a useful purpose in the future.

- Attention to concept development.
- Focus on communication.
    - Many children with deafblindness benefit from a total communication approach (spoken, visual, tactile).
- Active vs. passive participation. Alternate between seated activities and those that require movement.

64 **SPECIFIC DEAFBLIND CONSIDERATIONS**

- In addition to traditional Applied Behavior Analysis principles consider…
    - The impact of deafblindness and multi-sensory issues.
    - Etiology specific behaviors (Hartshorne, Hefner, & Davenport, 2000; Hartshorne, 2011).
- May be more difficult to identify exact function of behavior.
- Consideration of pain, stress and anxiety, and sensory deficits related to proprioception and vestibular function (Hartshorne et. al., 2017; Brown, 2005).
- Communicative intent may be the result of an unmet need.
- Consider behaviors as creative adaptations (Brown, 2005).
- Replacement behaviors taught and practiced in natural contexts.

65 **BEHAVIOR=COMMUNICATION**

- Unusual and unexpected behaviors are often misunderstood labeled as “attention-seeking” and perhaps a better description is “connection-seeking”.
- External communication intent:
    - Connecting and responding to others
- Internal communication intent:
    - Connecting and responding with your body or senses
- Important to recognize the difference and respond accordingly.

66 **DEAFBLINDNESS: NEED FOR SENSORY BREAKS**

- Most individuals with deafblindness are often functioning at their maximum sensory threshold.
- Necessity for frequent sensory “breaks” so that child can attend, perform, and interact with others.
- A flexible schedule is essential.
- The sensory break provides opportunity to calm down, refocus, and reduce fatigue, stress, and anxiety.

- Many spaces, materials, and activities can be helpful.
- Teachers, aides, interveners, and therapists will need to “read” the child well and anticipate the need for a break.

67 **USEFUL PRACTICE: CATEGORIZING BEHAVIOR**

1. Does this behavior just annoy you personally? Can it be accepted and ignored?
2. Does this behavior seem to help the child function in a positive way? Can it be accepted and ignored?
3. Does this behavior seem to help the child function in a positive way, but should be reduced or replaced by another, better behavior over time?
4. Is this a behavior that is undesirable and needs to be reduced or replaced fairly quickly?
5. Is this a behavior that needs to be prevented immediately?

Source: Open Hands, Open Access Deafblind Learning Module: Behavior and Environmental Supports

68 **DEAFBLINDNESS: TRUSTED INTERVENER AND PEER RELATIONSHIPS**

- Respectful, reciprocal interactions and consistency in support is essential.
- Basis for healthy social, emotional, and communication development.
- Joint attention in activities and to materials.
- Necessary to feel safe and confident & develop positive self-image.
- Informed peers are provided encouraging coaching and support from knowledgeable support staff & service providers.
- Specific instruction and practice in natural contexts to learn turn-taking, negotiation, sharing, and listening to others may be needed.

69 **QUESTIONS? COMMENTS?**

Contact Information:

Julie Maier, California Deafblind Services, Project Coordinator
jmaier@sfsu.edu or 415-405-7558

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