

## Why Autism and Deafblindness Can Look So Much Alike

Maurice Belote & Julie Maier   
 California Deafblind Services  
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 Students with Deafblindness  
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## The seed...

Article:

Belote, M. & Maier, J. (2014). Why deaf-blindness and autism can look so much alike. *reSources: California Deaf-Blind Services Newsletter*, 19(2).

In 2013 and 2014 we started hearing lots of questions and stories from families and professionals about dual diagnosis of deafblindness AND autism. We decided to share our thoughts about it.



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We never really grow up,  
we only learn how to act that  
way in public.

–Bryan White, Musician



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Age-appropriateness  
vs.  
Age-respectfulness



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All our life is but a mass of habits.  
–William James, Philosopher & Psychologist



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## Key diagnostic features of ASD

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



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## Executive function

Harvard University describes executive functioning as “mental processes that enable us to plan, focus attention, remember instructions, and juggle multiple tasks successfully.”

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## Important reminders

- Children with deafblindness or Autism Spectrum Disorders 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?”



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## 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.”



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## 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.



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## 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.



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## Changes in DSM Autism Diagnosis (1)

Source: The Iris Center, Harker & Stone, 2014.

DSM-V	DSM-IV
<b>Terminology:</b> Four previously separate categories now under one umbrella called “Autism Spectrum Disorders” or ASD	The previous categories were: Autistic disorder; Asperger syndrome; Childhood disintegrative disorder; Pervasive developmental disorder-not otherwise specified (PDD-NOS)
<b>Two categories required for diagnosis:</b> <ul style="list-style-type: none"> <li>• Persistent deficits in social communication/interaction <i>and</i></li> <li>• Restricted, repetitive patterns of behavior</li> <li>• Sensory issues are now included as a behavioral symptom</li> </ul>	Previously had been three categories <ul style="list-style-type: none"> <li>• Social impairment</li> <li>• Language/communication impairment <i>and</i></li> <li>• Repetitive/restricted behaviors</li> </ul> Sensory issues had not been considered before.



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### Changes in DSM Autism Diagnosis (2)

Source: The Iris Center, Harker & Stone, 2014.

DSM-V	DSM-IV
<p><b>Behavioral criteria requirements in each area:</b></p> <ul style="list-style-type: none"> <li>• Three in social communication and interaction.</li> <li>• Two in restricted, repetitive patterns of behavior</li> </ul>	Formerly had to meet 6 criteria requirements overall across 3 areas.
<p><b>A severity assessment scale (levels 1-3)</b> applied to both symptom areas based on level of support needed for daily function.</p>	Functioning had been determined by category (autistic disorder, Asperger's syndrome, PDD-NOS)
<p><b>Age of onset:</b> Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities).</p>	Delays or abnormal functioning in at least one of the 3 behavioral areas must be present prior to age 3 years.



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### 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 mapping 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)



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### Resistance to Environmental Change

Leo Kanner: A feature of ASD is an...  
 "Anxiously obsessive desire for the maintenance of sameness."



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### Restricted Areas of Interest



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### Delay in Social Interactions



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### Resistance to Change in Daily Routines



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## Unusual, repetitive behavior



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## 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)



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### Why the focus on autism?

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

- 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.



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### Research:

***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**.

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## 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."



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## Deafblindness and Autism...

### Similarities...

- Insistence on routines
- Repeated stereotypic behavior or interests
- Difficult 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.



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## Why does dual diagnosis occur?

- First, many of the behaviors look very familiar.
- Lack of knowledge about deafblindness by both medical and educational professionals.
- 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.



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## Dual Diagnosis

### Potential benefits include:

- 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.



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## Dual Diagnosis

### Potential problems include:

- 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 additional label limits the educational opportunities offered to a student.



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## 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.
- 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?



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## Evidence based practices (EBPs)

- 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.



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## Established practices and interventions for individuals with ASD

1. Discrete, systematic instruction
2. Comprehensible and/or structured environments
3. Functional communication skills
4. Modeling
5. Naturalistic responses
6. A functional approach to problem behaviors
7. Social skills interventions
8. Peer-mediated interventions
9. Technology-aided instruction or intervention

Wong et. al. (2014)



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### 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.



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### 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. (Probst & Borders, 2017)



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### Bridging ASD & DB Practices

- Always look at 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.



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### Questions? Comments?

Maurice Belote  
California Deafblind Services  
Project Coordinator  
[mbelote@sfsu.edu](mailto:mbelote@sfsu.edu)  
415-405-7558 (VM only)

Julie Maier  
California Deafblind Services  
Educational Specialist  
[jmaier@sfsu.edu](mailto:jmaier@sfsu.edu)  
415-405-7559 (VM only)

Website: [www.cadbs.org](http://www.cadbs.org)

Follow us on Facebook and Instagram and Twitter @CADeafblind



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