

Building Bridges Between Best Practices & Interventions for ASD and Deafblindness

Pennsylvania Training and Technical Assistance Network (PaTTAN)
Webinar April 10, 2018

Julie Maier, MA California Deafblind Services &
San Francisco State University

Plan for this webinar

- Brief review of key takeaways from first webinar presentation
- Describe commonly recognized evidence-based practices often used in autism-focused programs.
- Describe highly recognized effective best practices in the field of deafblind education.
- Compare similarities between some essential practices used by each group of educators.
- Illustrate how a team could tailor practices to better match the unique needs of a learner who is deafblind to provide educational support.
- Identify specific areas that need targeted attention that are unique to learner who is deafblind:
 - Access to curriculum, environment, & social relationships
 - Development of communication, concept development, and self-determination skills.

The seed...

reSources

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California
Deaf-Blind
Services

Why Deaf-Blindness and Autism Can Look So Much Alike

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

You can find this article at our CDBS website [www.cadbs.org](http://files.cadbs.org/200002495-2f170310b5/Belote%20-%20Maier%20reSources%20Fall%202014.pdf) under **Newsletters**:
<http://files.cadbs.org/200002495-2f170310b5/Belote%20-%20Maier%20reSources%20Fall%202014.pdf>

Important reminders

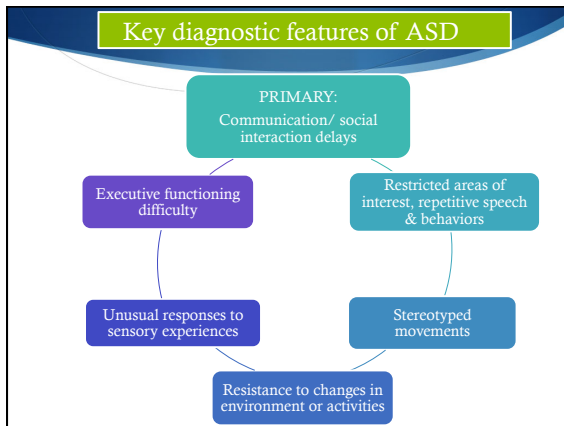
- ◆ Individual with either label are often very puzzling which, in my opinion, is a good thing.
- ◆ A diagnosis, or label, can provide helpful guidance, but should never define a child.
- ◆ Empathy and perspective taking is essential.
- ◆ Really good question to keep in mind: "How does the world right now appear and feel to them?"

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).

Common characteristics shared by students with ASD

- ◆ Communication difficulties
- ◆ Socialization difficulties
- ◆ Movement differences
- ◆ Sensory differences
- ◆ Learning differences
- ◆ Individualized interests and fascinations



A simple definition of deafblindness...

- *"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.*

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.

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.”

Deafblindness & ASD...

- Similarities...
 - Delayed communication and social skills
 - Insistence on routines
 - Repeated stereotypic behavior or interests
 - Difficult with executive function
 - “Meltdowns” or tantrums
- Key difference...
 - Deafblindness occurs due to dual sensory losses — (how eyes & ears function)
 - ASD is a the difference in sensory processing in the brain

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 do **NOT 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.

State of evidence-based practices...

- ◆ 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.
- ◆ Important that practices and interventions selected for a learner are evidence-based and well-matched to that learner.

Good sources for current information evidence-based practices

- ◆ Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fetting, A., Kucharczyk, S., Schultz, T. R. (2014). *Evidence-based practices for children, youth, and young adults with autism spectrum disorder*. Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.
- ◆ Ferrell, K. A., Bruce, S., & Luckner, J. L. (2014). *Evidence-based practices for students with sensory impairments* (Document No. IC-4). University of Florida, Collaboration for Effective Educator, Development, Accountability, and Reform Center.
There is a great webinar at National Center on Deaf-Blindness website (www.nationaldb.org) on the report of this study.

Types of evidence based practices for ASD

Established practices and interventions

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

Summary of Deafblind EBPs

- EBDs or “essential components” were identified by levels of evidence: Strong, Moderate, Limited, and Emerging (*See CEEDAR document*).
- Knowledgeable team members, small instructional groupings
- Use of dynamic, curriculum based, functional, person-centered assessment in natural contexts with family input
- Early identification and intervention
- Child-guided approaches
- Intervention personnel
- Systematic instructional approaches, especially for communication
- Communication development and social interactions emphasized every day in natural contexts

Summary of Deafblind EBPs

- Individualized accommodations for vision & hearing loss and assistive technology
- Orientation and mobility accommodations and focus on development functional life skills (*e.g. expanded core curriculum*)
- Tangible representations for pre-linguistic children
- Functional approach to stereotypic, self-injurious, and aggressive behavior in addition to knowledge of etiology and impact of DB
- Expanded view of literacy, including implementation of hands-on experiences to ground concept of literacy (symbolic representation)
- Placement and services and opportunities for and development of relationships with peers
- Transition (planning and preparation)

Focus area for deafblind instruction

- ◆ Communication development
- ◆ Functional vision use and use of assistive devices
- ◆ Accommodations to support hearing
- ◆ Orientation and mobility
- ◆ Strategies to help regulate emotions
- ◆ Need for additional sensory input AND need for sensory breaks
- ◆ Age-appropriate, motivating, activity-based curriculum
- ◆ Social relationships with peers

Important deafblind practices

- ◆ Follow the child or child-guided approaches
- ◆ Direct experiences and instruction
- ◆ Pacing and allowing time for processing
- ◆ Planned and expected transitions and routines
- ◆ Focus on communication everywhere and all of the time
- ◆ Frequent breaks related to sensory needs
- ◆ Attention to visual and auditory environments
- ◆ Trusting, positive relationships with intervener
- ◆ Promotion and support of positive social relationships
- ◆ Self-determination skill development

Concerns about 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 deficits needs
- ◆ Accessibility of visual and auditory cues and supports

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-guided and are implemented in natural contexts.
- ◆ Sensory needs must be considered and responded to —ACCESS, SUPPORTS, PREFERENCES
- ◆ Consult with deafblind specialists for training and resources
- ◆ Provide families with accurate and complete information about ASD features and interventions

ASD: Individualized supports & services

- ◆ **Considering family preferences** when determining the goals to be taught and the methods by which instruction will be delivered.
- ◆ **Incorporating the child's preferences and special interests** into the instructional program.
- ◆ **Focusing on the child's strengths and needs** to determine the most appropriate intensity and level of instruction to meet the child's individual goals.

DB: Child-guided practices

- ◆ Motivation is key to engagement & 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

ASD: Systematic Instruction

- ◆ Identifying valid educational goals
- ◆ Carefully outlining instructional procedures
- ◆ Implementing the instructional procedures
- ◆ Evaluating the effectiveness of instruction--and adjusting instruction based on evaluation data
- ◆ Providing a plan for generalization and maintenance of learned skills

DB: 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.
- ◆ This development of skills and concepts needs to be supported by observant and supportive partners.
- ◆ Breaking down activities and tasks into steps is very effective.
- ◆ Using materials, activities, routines present in the child's home and classroom provide the concrete and meaningful reference point for the child.

DB: Pacing and practice

- ◆ Children who are deafblind 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
- ◆ Pay attention to AND provide the time needed in the communication loop with the child

ASD: Comprehensible/Structured Learning Environments

- ◆ The curriculum (activities, schedule, environment) is clear to both the student and the educational staff.
- ◆ Visual cues, priming, and other supports are used to organize the instructional setting including:
 - ◆ Schedule of activities to create predictability and facilitate flexibility with change;
 - ◆ Labeling of areas of the classroom and school settings (visual with print or icon or photo)
 - ◆ Carefully planned choice-making opportunities
 - ◆ Facilitation of transitions

DB: Environmental Adaptations

- ◆ Organized learning spaces
- ◆ Presence of and access to materials of high interest
- ◆ Intriguing materials 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

DB: Planned transitions and routines

- ◆ Consistency and predictability provide reassurance, sense of security, and reduces stress.
- ◆ Allows the child to initiate more.
- ◆ Allows child to develop independence
- ◆ Maintain consistency but also provide variety & novelty
- ◆ Use visual markers and predictable auditory cues and wait time during transitions
- ◆ Use tactile object or visual calendars and schedules
- ◆ Let child know of changes in advance

DB: Attention to visual & auditory environment

- ◆ Consider and minimize visual and auditory clutter in environment
- ◆ Maximize salient visual and auditory information & cues
- ◆ Organized and easily navigable spaces
- ◆ Use of assistive technology devices to enhance auditory or visual information
- ◆ Present information in multiple formats

Incorporating multiple senses in instruction and interactions

- ◆ Intriguing materials you can feel, smell, taste to enhance interest and motivation
- ◆ Information presented in visual, auditory, and tactual modes
- ◆ Variety of seating options
- ◆ Encourage exploration through touch and use of touch to communicate
- ◆ Hand under hand support
- ◆ Respecting child's preferences and sensitivity to touch
- ◆ Light touch to alert child and deeper, slower touch or massage to calm child

ASD: Specialized Curriculum Content

- ◆ Is based on an individualized assessment of student and should consider the family's preference for targeting goals.
- ◆ Targets functional skills that...
 - ◆ are most likely to be useful in the student's life to control his or her environment.
 - ◆ will increase the student's independence and quality of life.
 - ◆ will increase the student's competent performance.
- ◆ Includes assistive technology and augmentative and alternative communication systems

DB: Concept Development

- ◆ Experience through direct contact, interaction, and communication allows the child with deaf-blindness to **develop concepts** about the world around.
- ◆ This process needs to be supported and taught because natural interaction and incidental learning can be greatly limited in this population.

DB: Concept Development

A concept is a mental representation, image or idea of tangible and concrete objects (e.g., a chair, a dog) and intangible ideas and feelings (e.g., colors, emotions) that gives meaning to the world.

Concept development requires interaction and communication.

DB: Focus on Communication

- ◆ Most children with deafblindness benefit from a total communication approach
- ◆ Modes for each child are highly individualized and require everyone to consistently implement plans across all settings.
- ◆ Some students with good assistive listening devices have success understanding spoken language for receptive communication and at the same time might use signed communication and gestures for expressive communication.
- ◆ Many also benefit from visual forms of communication to aid or augment their understanding or to clarify their communication.

ASD: Functional Approach to Behavior

- ✓ Determining contextual function of behavior (Carr & Durand, 1985)
 - Social attention
 - Tangible/Intangible reward
 - Escape/Avoidance
 - Sensory stimulation
- ✓ Identifying communicative intent
- ✓ Consideration of sensory processing difficulties
- ✓ Adaptations to environment, activities, schedule, support person
- ✓ Identifying more appropriate replacement behavior that serves same function
- ✓ Consistent systematic instruction of replacement behavior with reinforcement systems

DB: Functional Approach to Behavior

- In addition to ABA principles consider...
 - the impact of deafblindness on behaviors
 - etiology specific behaviors (Hartshorne, Hefner, & Davenport, 2000)
- May be more difficult to identify exact function of behavior (*evidence still at emerging level*)
- 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 result of an unmet need (*e.g child lying on floor in order to maintain visual and vestibular functioning*)
- Consider behaviors as creative adaptations (Brown, 2005)
- Replacement behaviors taught and practiced in natural contexts

DB: Sensory breaks

- ◆ Many individuals with deafblindness are often functioning at their maximum sensory threshold.
- ◆ Need for frequent sensory “breaks” in order to continue to be able to attend and perform and interact with others.
- ◆ The sensory break provides opportunity to calm down, refocus, and reduce fatigue and stress.
- ◆ Many spaces, materials, and activities can be helpful.
- ◆ A flexible schedule is essential.
- ◆ Teachers, aides, interveners, and therapists will need to “read” the child well and anticipate the need for a break.

ASD: Social supports for students

- ◆ **Difficulties with social behavior vary** among individual students and learners with ASD often have **difficulty generalizing new skills** to novel settings, people, or materials.
- ◆ In 2001 National Research Council recommended that students with ASD be **taught skills in the natural context** they would be used.
- ◆ It is **critical that social supports are included** in the design of program or educational plan for a student with ASD.
- ◆ Evidence based interventions include systematic instruction, peer modeling, use of social stories, and integrated playgroups.

DB: Trusted intervener and peer relationships

- ◆ Respectful, reciprocal interactions
- ◆ Joint attention in activities and to materials
- ◆ Basis for healthy social, emotional, and communication development
- ◆ Necessary to feel safe and confident and develop positive self-image
- ◆ Informed peers who are provided encouraging coaching and support.
- ◆ Knowledgeable support staff & service providers
- ◆ Consistency in support is essential

Review: 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

Questions? Comments?

Julie Maier
 California Deafblind Services, Educational Specialist
 San Francisco State University, Course instructor
jmaier@sfsu.edu
 415-405-7559 * Please feel free to contact me.

References

- ◆ Attwood, T. (2008). *An overview of autism spectrum disorders*. In Baron Dunn, K. & Wolfberg, P. (Eds). (2008). *Learners on the Autism Spectrum: Preparing Highly Qualified Educators*. Shawnee Mission, Kansas: Autism Asperger Publishing Company.
- ◆ 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.
- ◆ Carr, E.G. & Durand, V.M. (1985). Reducing problem behavior through functional communication training. *Journal of Applied Behavior Analysis*, 18, 111-126.
- ◆ Ferrell, K. A., Bruce, S., & Luckner, J. L. (2014). *Evidence-based practices for students with sensory impairments* (Document No. IC-4). Retrieved from University of Florida, Collaboration for Effective Educator, Development, Accountability, and Reform Center website: <http://cedar.education.ufl.edu/tools/innovation-configurations/>

References

- ◆ Hartshorne, T. S., Hefner, M. A., & Davenport, S. L. H. (2000). Behavior in CHARGE syndrome: Introduction to the special topic. *American Journal of Medical Genetics, Part A*(133A), 228-231.
- ◆ Hartshorne, T.S., Stratton, K.K., Brown, D., Madhavan-Brown, S., Schmittl, M.C. (2017). Behavior in CHARGE syndrome. *American Journal of Medical Genetics Part A*(175C):431–438.
- ◆ SENSE Definition of Deafblindness, Retrieved 3/15/18
<https://www.sense.org.uk/get-support/information-and-advice/conditions/deafblindness/>
- ◆ Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fetting, A., Kucharczyk, S., Schultz, T. R. (2014). *Evidence-based practices for children, youth, and young adults with autism spectrum disorder*. Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group. Retrieved from
<http://autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/files/2014-EBP-Report.pdf>