



Saturday, August 3, 2019

Breakout Session C16 • 2:45-3:45 pm • Chantilly Ballroom East

Autism or CHARGE?

Why Autism and CHARGE syndrome Can Look So Much Alike and Identifying Effective Educational and Behavioral Interventions for These Learners

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San Francisco State University**

Presenter Information

Julie Maier is an Educational Specialist for California Deafblind Services providing technical assistance and training to families of children with deafblindness and their school teams. She currently serves many children and teens with CHARGE syndrome. Julie has been involved in the field of special education since 1987, including as a faculty member in the Special Education Department at San Francisco State University since 1999 and teaches courses in deafblindness, autism spectrum disorders, inclusive education, and assessment and curricular design for learners with extensive support needs. She was the project liaison for an OSEP funded personnel preparation project in deafblindness at SFSU. Julie has presented at many conferences on a variety of topics related to deafblindness and effective educational practices, including the 2018 DbI Conference of the Americas, the 2015 & 2017 International CHARGE Syndrome Conference, the 2016 German CHARGE Syndrome Conference, and the 2018 CEC Conference. She has written or co-authored several published articles on assessment, self-determination, autism and deafblindness, and social supports.

Maurice Belote is a graduate of the federally-funded teacher training program in deafblindness at San Francisco State University and has worked exclusively in the field of deafblindness for 37 years. Mr. Belote has served as an Educational Specialist and Project Coordinator for California Deafblind Services (CDBS) since 1992. During that time, CDBS pioneered the inclusion of family members as full and equal partners on the state deafblind project. Prior to joining the state technical assistance and training project, he served for ten years as a teacher of the deafblind at the California School for the Blind, where he met his first student with CHARGE syndrome in 1984. Mr. Belote is a frequent presenter at state, national, and international conferences and has written extensively on educational issues specific to children and youth with deafblindness. He represents students with deafblindness on numerous state and national groups and organizations, including as the specialist in deafblindness for California Transcribers and Educators of the Blind and Visually Impaired. He has also served for the past five years as Co-Chair of the National Coalition on Deafblindness, where he has advocated for the addition of interveners to IDEA as a related service.

Presentation Abstract

There have been a lot of questions and discussion in the past several years about individuals with CHARGE also receiving a diagnosis of autism. During this presentation we will take a look at profiles of learners with autism spectrum disorders (ASD) and learners with CHARGE syndrome, point out similar characteristics in both profiles, and share a brief explanation of how vision and hearing loss and other sensory impairments can explain these “autistic-like” features.


This presentation is NOT a discussion about the problems or merits of a dual diagnosis, but instead we will consider which educational and behavioral interventions can be most effective and helpful for learners with this profile. The majority of our presentation will focus on information about evidence-based practices in the field of autism and highly recognized field-based best practices related to deafblind education. We will offer families and educators suggestions for how to match and tailor several evidence-based ASD practices with deafblind practices when planning instruction and supports that provide the most beneficial outcomes for a learner with CHARGE.

Learning Objectives

- Learn several key features common in CHARGE syndrome that may also meet the medical and educational diagnosis for autism (ASD).
- Identify several effective evidence-based educational practices related to ASD and field-based practices in deafblindness.
- Increase knowledge of how to share information about CHARGE syndrome features and effective educational & behavioral interventions with educational and medical professionals who propose an ASD diagnosis for learners with CHARGE syndrome.


Autism or CHARGE?

Why autism and CHARGE syndrome can look so much alike and what effective practices can help





Julie Maier & Maurice Belote
California Deafblind Services

2019 international CHARGE Syndrome Conference
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The seed...


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

You can find it at our CDBS website www.cadbs.org under Newsletters:
http://bit.ly/Belote_Maier_DB_ASD_LookAlike

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.”

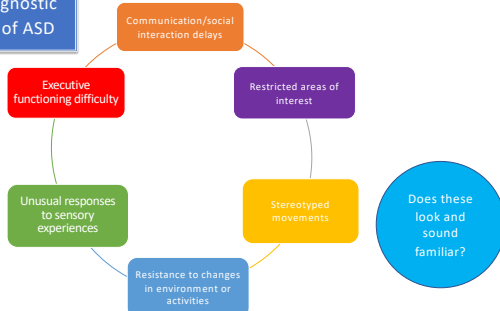
Children and youth with CHARGE are...

- Curious
- Intelligent
- Resilient
- Adaptive
- Persistent
- Mischievous
- Socially interested
- Particular about order and routine

Autism spectrum disorders (ASD)

"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).

Key diagnostic features of ASD



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

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" 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.

CHARGE Syndrome Behavioral Phenotype

| |
|---|
| Normal to low cognitive functioning |
| Very goal directed and persistent with sense of humor |
| Socially interested but immature |
| Repetitive behaviors that increase under stress |
| High degree of sensory seeking |
| Under conditions of stress and sensory overload find it difficult to self-regulate and easily lose behavioral control |
| Difficulty shifting attention and moving onto to new things; easily lost in own thoughts. |

Hartshorne, 2011

Research Findings

Autistic-like behavior in CHARGE syndrome Hartshorne, Grialou, & Parker (2005)

"A picture begins to emerge of children with CHARGE being (1) generally more socially engaging and having better language and communication skills than children who are autistic, (2) engaging in more sensory related behaviors and more rocking, whirling and flapping than others who are deafblind, and (3) being similar to those with autism in trying to cope with the stressful demands of their environment, such as changes in routine. This, in turn, causes them to attend more to inanimate objects, to withdraw, or even to lose control in the form of tantrums, biting, hitting, kicking, etc."

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, 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 ☒

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, OT (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.

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.”

This certainly includes individuals with CHARGE

CHARGE Syndrome and Autism...

Similarities...

- ☐ Insistence on routines
- ☐ Repeated stereotypic behavior or interests
- ☐ Difficult with executive function
- ☐ Delayed communication and social skills
- ☐ Meltdowns or tantrums

Key Difference:

- ☐ Sensory processing differences (ASD) vs. multi-sensory impairments (CHARGE)

Why does dual diagnosis occur?

- First, many of the behaviors are very familiar.
- Lack of knowledge about deafblindness and CHARGE syndrome by both medical and educational professionals.
- More awareness and experience with individuals with ASD than with deafblindness or CHARGE syndrome.
- 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:

- ☐ 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 include:

- ☐ Student with CHARGE 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 with CHARGE.
- ☐ The autism diagnosis is primary and serves as a barrier to a team acquiring knowledge and skills about CHARGE syndrome
- ☐ The additional diagnosis may not provide additional helpful information to team, and 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.
- Assessment for ASD must be completed by 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 a child with CHARGE?

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.

Evidence base for ASD, Deafblindness, & CHARGE



Good sources for current information on EBPs

- 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.

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)

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 deficits needs
- Accessibility of visual and auditory cues and supports

"Students cannot benefit
from interventions they do
not experience."

~Dean Fixsen



Combining EBDs for ASD and Deafblindness

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

(Probst & Borders, 2017)

Instructional focus areas for children and youth with deafblind

- 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-appropriate, motivating, meaningful curriculum, both academic and functional
- Social relationships with others, especially peers
- Self-determination

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, ideally someone who understands CHARGE syndrome well
- Provide families with accurate and complete information about ASD features and interventions

ASD:
Individualized
Supports &
Services

CHARGE: 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

ASD:
Systematic
Instruction

CHARGE: 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.

ASD:
Individualized
Supports &
Services

CHARGE: Pacing and practice

- Children with CHARGE 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

ASD:
Comprehensible,
structured
learning
environments

CHARGE: Environmental Adaptations

- Organized learning spaces
- Presence of and access to materials of high interest
- Intriguing materials and activities that rotate to enhance interest and motivation
- Use of a calendar or schedule system
- 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

ASD:
Comprehensible,
structured
learning
environments

CHARGE: Planned transitions and routines

- Consistency and predictability provides reassurance, sense of security, and reduces stress and anxiety.
- 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 object or visual calendars and schedules
- Let child know of changes in advance

ASD:
Specialized
Curriculum

CHARGE: Meaningful Curriculum

- Age-appropriate curriculum with adaptations—don't underestimate student's abilities
- Functional-activity and lessons that will serve a useful purpose in the future
- Attention to concept development
- Focus on communication
 - Most children with CHARGE benefit from a total communication approach (spoken, visual, tactile)
- Active vs. passive participation-alternate between seated activities and those that require movement

ASD:
Functional
approach to
behavior

Specific CHARGE Considerations

- In addition to traditional Applied Behavior Analysis principles you need to consider...
 - the impact of deafblindness and multi-sensory on behaviors
 - etiology specific behaviors (Hartshorne, Hefner, & Davenport, 2000; Hartshorne, 2011)
- 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

ASD:
Functional
approach to
behavior

CHARGE: Need for Sensory Breaks

- Most individuals with CHARGE 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, stress, and anxiety.
- 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

CHARGE: Trusted intervener and peer relationships

- Respectful, reciprocal interactions
- Consistency in support is essential
- 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 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.

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?



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Resources:

- CEDAR Report on EBPs for Deafblindness:
http://cedar.education.ufl.edu/wp-content/uploads/2014/09/IC-4_FINAL_03-30-15.pdf
- ASD EBPs Report:
<http://cidd.unc.edu/Registry/Research/Docs/31.pdf>
- Belote & Maier article on Similarities between ASD and Deafblindness:
http://bit.ly/Belote_Maier_DB_ASD_LookAlike
- CHARGE Foundation Educator Packet:
http://bit.ly/CHARGE_Educator_Packet
- Perkins CHARGE Webcasts:
<http://www.perkinselearning.org/videos/webcast>

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