



Sunday, August 4, 2019

Breakout Session E26 • 10:45-11:45 am • Grand Ballroom C

Meeting the Needs of Students with CHARGE Syndrome with Proficient Communication Skills in General Education

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Presenter Information

Robbie Blaha has served students with DeafBlindness including those with CHARGE Syndrome and their families for 48 years. She been a classroom teacher for students with DeafBlindness as well as a consultant on the Texas DeafBlind Outreach Project.

Presentation Abstract

The field of deafblindness has appropriately focused on learners with emerging language and multiple disabilities. This is a result, in part, of the Rubella epidemic that was foundational in the development of the field we have today. In the past, academic students with deafblindness were typically those with Usher Syndrome.. Currently, as an effect of significant changes in etiology and quality of medical interventions, there is a growing population of congenital students with CHARGE who have formal language. These students are undergoing and presenting considerable challenges to local districts that serve them. Though many of the essential strategies and best practices in our field do not address their needs, the underpinnings of the deafblind learning style: significant and ongoing lack of incidental information, concept development and social issues are very much at play with these students. These academic children and youth with deafblindness need our attention and support to assure that there are new and unique strategies that address the needs of this growing academic population.

Learning Objectives

- Increased awareness of the needs of and effective strategies to serve this population.

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Rubella Pandemic

- This marked the beginning of our field as we know it today.
- Our intervention strategies were developed to serve this population of children.

A shift in our field

Things were changing - clues

- Referrals for on-sites began to increase slightly for academic kids population

Who are we talking about

The onsite visits began to show a trend in student characteristics:

No intellectual disability onsite observations began to show a trend

Regular or Modified General Curriculum (not alternative)

- “Kinda” informal until the census was sorted by state tests
- 23.6% of our National Child Count were taking regular state test with their peers or with accommodations.

Responding to the clues

- Included in our current grant
- Formed an advisory board that gave recommendations for products
- Gathered information and formed into characteristics/needs for programming
- Shared at training events

3 Implications for Learning with Deafblindness

- Access to information
 - Concept development
 - Pacing
-
- The students were really struggling

Characteristics

- Build a list of characteristics that were important for the IEP team to consider
- We now have 12 that we are sharing in our handouts

6. Consider the student's technology needs.

- How does the student use technology during a lesson?
- Does technology need to be repurposed?
- What are the logistical issues related to the student's technology?
 - *For Jessy's team, the intervener assisted Jessy with real time coordination of technology.*
 - *Some of Jessy's low-vision devices needed to be repurposed.*
 - *The intervener assisted in the transportation and set-up of Jessy's technology.*

7. Monitor indicators of stress.

- How does the student show that he or she is becoming stressed?
- How does the team assist the student in reducing or managing stress?
 - *For Jessy, he would start acting silly. Sometimes he would become deeply depressed if very overwhelmed.*
 - *Jessy did not have a physical demonstration of his stress.*
 - *Interventions reduced Jessy's stress.*
 - *Intervener*
 - *Additional individual time during the school day*

3. Build time into the day for individual and small group work.

- How can you extend the learning day for the student?
 - *Jessy's team identified that Jessy was –*
 - *Not having a cohesive experience of his lessons*
 - *The team added two periods for individual and small group work.*
 - *The teacher of the deaf and the intervener worked together to decide what would be covered during those two periods.*

The Plan

- IEP list of considerations: validation,
- Development of evaluation protocols materials/strategies
- Developing a definition
- Reaching out to the field for collaboration

