Thursday, July 27, 2017

Panzacola H

Plenary Talk:
Vestibular issues in CHARGE syndrome: anatomy, physiology, testing, behavioral outcomes

David Brown and Daniel Choo, MD

Presenter Information

David Brown is a deafblind educational specialist who has been working with children with CHARGE syndrome since 1983. In the United Kingdom he was the Head of Family & Children Services for Sense. He moved to California in 2000 to work with the state deafblind project, based in San Francisco. He has given presentations about CHARGE syndrome in 14 different countries, and in 24 states in the US. His articles about CHARGE syndrome have been translated into at least 12 different languages. In 2005 David was given the Star in CHARGE award by the CHARGE Syndrome Foundation, and in 2013 he received the Lifetime Achievement Award from Deafblind International.

Daniel Choo, MD, obtained his medical degree from the State University of New York Health Science Center at Syracuse, NY, and completed his otolaryngology residency training in Syracuse. Dr. Choo completed fellowships in otology / neurotology at the Ear Research Foundation in Sarasota, Florida and the Neurotology Branch of the National Institute on Deafness and Other Communication Disorders (NIDCD), National Institutes of Health, Bethesda, MD.

Presentation Abstract

One of the most common (but poorly understood) features in children with CHARGE syndrome is absence or malformation of the inner ear vestibular structures (e.g. semicircular canals). These anomalies can impact a child's balance, body control, walking and other complex activities (such as riding a bicycle, sports, use of vision, etc). However, some of the very typical CHARGE behaviors, postures and positions may indeed be related to the abnormal vestibular organs and functions in these children. This presentation offers a primer on inner ear vestibular anatomy and physiology, as well as the current state of the art vestibular testing performed in the clinical setting. The discussion will then extend to correlations of these clinical findings to the behavioral observations from home and school environments. We hope to share our developing knowledge of this aspect of function in CHARGE syndrome, which we believe will provide novel insights into some of the behaviors, postures and positions that we see in children with the syndrome.

Thursday, July 27, 2017

Panzacola H

Plenary Talk: The Neuromuscular Phenotype of Shoulder Deformities in CHARGE Syndrome

prof. C.M.A. van Ravenswaaij, MD, PhD on behalf of Christa (C.M.) de Geus, MD

Presenter Information

Christa de Geus is a medical doctor in training to become a clinical geneticist. Within clinical genetics she has a particular interest in neurology and neuroradiology. In 2014 she joined the research group of prof. Conny van Ravenswaaij as a PhD student. Her PhD focuses on neurological symptoms in CHARGE syndrome.

Conny van Ravenswaaij is a clinical geneticist with a long-lasting experience in genetic and clinical studies on CHARGE syndrome. Since her group discovered CHD7, the gene responsible for CHARGE syndrome, in 2004, she coordinates a multidisciplinary clinic and supervised several PhD research projects dedicated to the syndrome. Her research is mostly based on questions raised by the parents and often results in clinical guidelines. Thus far she has published over 30 papers and four book chapters on CHARGE syndrome.

Christa M. de Geus[1], Renate J. Verbeek[2], Johannes H. van der Hoeven[2], Conny. M.A. van Ravenswaaij-Arts[1], Deborah A. Sival[3]

Affiliations: Department of [1]Clinical Genetics, [2]Neurology and [3]Pediatrics, University Medical Center Groningen, University of Groningen, PO BOX 30001, 9700 RB, Groningen, the Netherlands.

Presentation Abstract

Clinical experience with CHARGE syndrome tells us that many CHARGE patients develop shoulder abnormalities, such as abnormal posture with sloping and anteversion of the shoulders, scapular winging and impaired elevation of the arms.

With the help of many attendees of the 2015 conference, we investigated the prevalence and possible neuromuscular etiology of these shoulder abnormalities. In this presentation, we will present the results of this study.

Thursday, July 27, 2017

Panzacola H

Plenary Talk: Dissecting the functions of CHD7 in brain development using mouse models

M. Albert Basson, PhD

Presenter Information

Albert is a basic scientist with interests in development of the brain, neurodevelopmental disorders and conditions like CHARGE that are caused by mutations in factors that regulate chromatin structure. His laboratory creates and uses genetically modified mouse models to study the role of CHD7 in brain development. Their most recent work has identified several roles for CHD7 in the development of the cerebellum. This work is continuing and they are also looking at other brain regions in our mouse models.

Danielle E. Whittaker[1,2], Kimberley L. Riegman[1], Alex Donovan[1], Christa de Geus[3], Jacob Ellegood[4], Jason Lerch[4], Conor Mohan[1], Cathy Fernandes[5,6], Conny van Ravenswaaij-Arts[3] & M. Albert Basson[1,6].

[1]King's College London, Department of Craniofacial Development and Stem Cell Biology, Floor 27, Guy's Hospital Tower Wing, London, SE1 9RT, UK

[2]Royal Veterinary College, 4 Royal College Street, London NW1 0TU

[3]University of Groningen, University Medical Center Groningen, Department of Genetics, PO Box 30.001, 9700RB Groningen, Netherlands

Presentation Abstract

CHD7 is expressed in proliferating neuronal progenitors in the developing brain. We have deleted CHD7 specifically from these progenitors and identified defects in cell proliferation and differentiation resulting in cerebellar hypoplasia. We identified the Reelin gene as a functional target of CHD7 in these cells and observed mild motor deficits in some of the animals. New studies to identify brain abnormalities in Chd7 heterozygous mice that more closely resemble CHARGE syndrome will be discussed.

Thursday, July 27, 2017

Panzacola H-1/H-2

Breakout Session #1: 1:00-2:30pm

"Taking – too much – CHARGE?"

Wenche Andersen and Eva Seljestad

Presenter Information

Wenche Andersen, Preschool teacher, cand.paed.spec., working with CHARGE s. and children with combined hearing-and vision impairment.

Eva Seljestad, Preschool teacher, teacher of hearing impaired, working with CHARGE s. and children with combined hearing-and vision impairment.

Presentation Abstract

"Taking CHARGE" (2017) is necessary, but we have to ask; are we "Taking –too much – CHARGE? We all want every child to hopefully say, "Hello to the future". We want them to feel that "The sky is the limit (2015)". This is the main reason to organizing big conferences, and the powerful profit of participating. We want to "Experience the Wonder (2013)" and to realize that "Magic Happens Here (2011)" also in 2017.

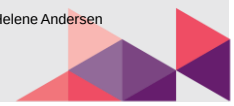
Statped

TAKING CHARGE

TAKING –TOO MUCH – CHARGE?

CHARGE Syndrom Foundation
Professional Day
Orlando, 27th July 2017

Eva Seljestad and Wenche Helene Andersen



Presentation

- 17 years as advisors in The Deafblind System in Norway
- The title: «Taking CHARGE» or «Taking – too much – CHARGE» ?
- Question concerning:
  - Isolation?
  - Identification?
  - Friends?
  - Complexity?

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Reflections

- Good periods
  - Functional communication
  - Participation
- Less good periods
  - In a room with one teacher
  - Isolation
- Independence or «learned helplessness»?
- The difficult balance between necessary and too much facilitation

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Dilemmas

- Paradox
- What includes you in society, may at the same time, exclude you
- Loneliness may follow the technical aid

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The value of the conferences

- Expand the perspective
- Offers a community of shared experiences

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The experiences of a mother

- Learned a lot. New research
- An eye - opener
- «Membership» in a group
- «My gang»

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The Intensions of Conferences

- CHARGE – and all that jazz (2009)
- Experience the wonder (2011)
- Magic happens here (2013)
- The sky is the limit (2015)
- Taking CHARGE (2017)




Summing up

- Taking too much CHARGE/responsibility?
  - Leeds to isolation?
  - Start identifying with the teacher?
  - Children acting like small assitents instead of friends?
  - Is this inevitable?
- No simple answers, but som directions..
  - Longterm perspective
  - Sharing experiences
  - To meet equals

Summing up

Have fun and joy together !

Thursday, July 27, 2017

Panzacola H-1/H-2

Breakout Session #1: 1:00-2:30pm

The CHARGE IEP: What have we learned?

Hailey E. Ripple, M.S. & Kasee Stratton, Ph.D., NCSP

Presenter Information

Hailey is a doctoral student in the school psychology program at Mississippi State University and has been an active member in the Bulldog CHARGE Syndrome Research Lab led by Dr. Kasee Stratton. Hailey's research interests related to CHARGE include investigating IEPs and parent perceptions of the IEP process, behavior, and strategies to raise awareness for CHARGE. Hailey was also one of the first Davenport Fellows.

Presentation Abstract

This presentation will cover what we have learned about Individualized Education Plans (IEPs) for students with CHARGE Syndrome. IEPs (N=30) provided by parents of children with CHARGE will be compared against best practices and quality indicators for students who are deaf-blind. The presenters aim to provide information regarding the most common accommodations provided, variety of services received, and information regarding common areas missing from IEPs.

Thursday, July 27, 2017

Panzacola H-1/H-2

Breakout Session #1: 1:00-2:30pm

Communicative Forms & Functions Used by Individuals with CHARGE Syndrome

Susan M. Bashinski, Ed.D.

Presenter Information

Susan M. Bashinski has 40 years experience with learners who experience multiple disabilities. She has directed numerous federal and state grants in low-incidence disabilities and deaf-blindness, including: personnel preparation, field-initiated research, model in-service training, and assistive technology. Dr. Bashinski has extensive experience in providing professional development and technical assistance nationally and internationally, particularly in the areas of augmentative and nonsymbolic communication for learners who have low-incidence disabilities, including deaf-blindness and CHARGE syndrome. Her research interests and areas of expertise include early communication and language development, augmentative communication, and cochlear implants, with numerous publications and presentations related to these topics. Dr. Bashinski authored the chapter on assessment of prelinguistic communication for the Hartshorne, Hefner, Davenport, and Thelin 2011 book, CHARGE. She has given both paper and platform presentations at the 2009, 2011, and 2015 CHARGE Conferences.

Presentation Abstract

The extant literature base in special education supports the position that development of their child's communication skills is one of the most, if not THE most, critical area of need reported by families of children with CHARGE. This session will present results from a research study conducted during the 2015 International CHARGE Conference held in Chicago. At that conference, 27 families completed individual interviews for this study. Findings will be summarized and possible implications discussed.

COMMUNICATIVE FORMS & FUNCTIONS USED BY INDIVIDUALS WITH CHARGE SYNDROME

CHARGE Professional Day Conference, 2017
Orlando, FL

Susan M. Bashinski, Ed.D.
Missouri Western State University

Barbara A. Braddock, CCC-SLP
Saint Louis University

Christopher A. Neal, Ph.D.
University of Kansas Medical Center

Clarissa Huffman, Graduate Student
Missouri Western State University

Jennifer Heithaus, MD
Saint Louis University

THANK YOU!

The authors express their sincere appreciation to:

- The CHARGE Syndrome Foundation
- Ms. Meg Hefner, Research Coordinator, 12th International CHARGE Conference, Chicago, IL (August 2015)
- ALL the family members who shared their conference time with us, and completed interviews!

Disclosure

No members of the research team have relevant financial or nonfinancial relationships to disclose

Purpose of this Research

1. Describe non-intentional and intentional nonsymbolic communication abilities among a sample of children / young adults with CHARGE syndrome:
   - Communication FORMS utilized
   - Communication FUNCTIONS demonstrated
2. Collect information re: AAC experiences of a sample of children / young adults with CHARGE syndrome, who have little to no conventional speech / sign language.

Definition of Participant Group

Families eligible to participate in this study met all of the following criteria:

- They have a child with CHARGE, who is 29 years of age or younger.
- The child / young adult with CHARGE uses fewer than 50 functional, conventional spoken words or manual signs
- Family members (at least 19 years of age) were willing to be available for a face-to-face interview during the CHARGE Conference

Demographics: Children / Young Adults

Age / Gender	PreK-Kdg Birth – 5 y, 11 m	Elementary 6 yrs – 11 y, 11 m	Jr / Sr High 12 yrs – 17 y, 11 m	Transition 18 yrs – 21 y, 11 m	≥ 22 yrs	TOTAL
MALE	4	5	4	1	2	16
FEMALE	5	4	1	0	1	11

Methodology

All family interviews were conducted:

- face-to-face
- by one member of the research team
- with any number of family members (family's choice)
- at a time chosen by the family
- at a location with which the family was comfortable, but all within the conference hotel
- Following a detailed protocol developed by some members of the research team
- Interview time ranged from 45 minutes to 2 hours

Data Collected: Info re: **P**otential **C**ommunication **A**cts

- Idiosyncratic, *non*-intentional signals
- Idiosyncratic, intentional signals
  - Verbal or nonverbal behavior, which is *interpreted by others* to possibly serve a communicative purpose
  - May include: vocalization, body movement, face/eye movement, change in breathing patterns, challenging behavior, and/or stereotypic movement
- Conventional signals

  Limited use of conventional gestures, words or word approximations, manual signs and other (AAC) forms are also included in the description of PCAs

Overview of the *Inventory of Potential Communicative Acts*

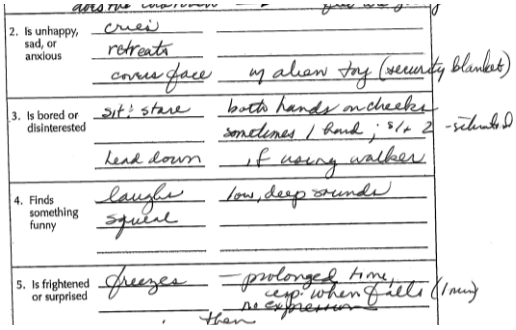
Structure: 41 targeted questions
"Other" option in *each* function category

Interview Format: Completed in-person only
One interviewer + family members

Function Categories: 10

Function Sub-Categories: < 5 each
**exception:* "Comment"

Example: Completed *IPCA* Protocol



2. Is unhappy, sad, or anxious	cries	
	retreats	
	covers face	w/ alicia toy (security blanket)
3. Is bored or disinterested	sits/stare	both hands on cheeks
		sometimes / bends; s/x 2 - schools D
	head down	if using walker
4. Finds something funny	laughs	low, deep sounds
	squeals	
5. Is frightened or surprised	freezes	prolonged time, esp. when fells (new)
		no expression
		then

Results: Communication Forms

Most Frequently Noted Forms
(by ranks)

1. Act on Person – used by ALL 27 (frequently)
1. Act on Object – used by 26 (frequently)
1. Move Toward – used by 26 (frequently by 21)
1. Cries – used by 25 (frequently by 20)
1. Vocalize – used by 23 (2 have trachs)
1. Move Away - used by 21 (frequently by 16)

Results: Communication Forms

Number of UNIQUE forms noted in communication profiles:

Mean = 36.37

Median = 35.00

Mode = 35.00

Range = 13 – 59

***ALL** children / young adults used *some* communication forms *for multiple functions*

Results: Communication Functions

In their communication profiles:

- **ALL 27** children / young adults demonstrated PCAs in the following function categories:

(Number of Forms Demonstrated)

FUNCTION	Mean	Median	Mode	St. Dev.
1. Attention-to-Self	8.33	9.00	4.00	4.28
2. Reject / Protest	11.11	11.00	11.00	4.34
3. Request an Object	6.81	6.00	6.00	3.31
4. Comment	20.00	19.00	15.00	6.77
5. Choice making	5.78	5.00	3.00	2.44

Results: Communication Functions

In their communication profiles:

- **ONLY 16 of 27** children / young adults demonstrated PCAs in the Request Information function category:

(Number of Forms Demonstrated)

FUNCTION	Mean	Median	Mode	St. Dev.
10. Request Information	1.37	1.00	--	1.57

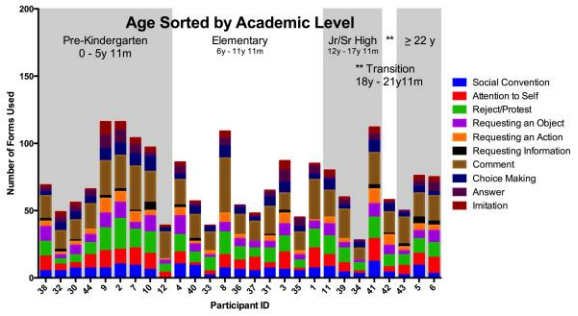
Results: Communication Functions

In their communication profiles:

Participants demonstrated PCAs in the following function categories between *most* and *least:*

6. Social convention (n = 26)
7. Request an Action (n = 25)
8. Answer (n = 25)
9. Imitation (n = 24)

Results: Communication Forms x Functions



Results re: AAC History

Of the child / young adults, whose communication skills were profiled in this study (n=27), **19 have previous / current experience using UNAIDED AAC**:

- primarily *modified* manual signs
- frequently used to supplement spoken language
- signs used as elements of an educational sign system (not ASL)
- primarily used for labeling and directives

Results re: AAC History (con't.)

Of the 27 children / young adults, whose communication skills were profiled in this study, **only four have any previous / current experience using an AIDED AAC system**:

1 – (elem.) learning to use Words for Life app for the iPad

1 – (transition) using a Tobii with his family since June 2014

1 – (elem.) scheduled for an AAC evaluation process

1 – (≥ 22 years)used SuperTalker for a time **discontinued**

Comments re: AAC Results

No particular patterns emerged in the data set regarding the children / young adults with CHARGE syndrome with whom **AIDED AAC** has been attempted.

- No apparent correlation with gender
- No apparent correlation with age
- No apparent correlation with overall profile of complex physical / health needs, though NONE of these four have g-tubes (15 of 27 overall do)

Comments re: AAC Results

- **NO** AIDED AAC intervention has been attempted with ANY of the children under 6 years of age (n = 9)
- Even among the 18 children / young adults who were 6 years or older, **only three** are currently involved *in any way* with aided AAC (i.e., 16.7% of this group; **only 11.1% of this entire sample**)

Comments re: AAC Results

A Possible Explanation for Observations Could Be:

- At birth, children with CHARGE are medically fragile
- Typically, at least ten surgeries *prior to the third birthday*
- Critical focus on the child's health, and even survival, can preclude a rich pattern of early language stimulation
- Very limited experiential opportunity early in life, due to medical and motor problems, interferes with typical experience of interacting with the environment
- Multiple anatomical and physiological congenital anomalies often affect chewing, swallowing, & / or the ability to make typical facial movements, affecting the child's ability to communicate nonverbally through facial expressions

Implications of Results for PRACTICE

- The *IPCA* appears to be a strong tool for collecting meaningful data and profiling the communication skills of children with CHARGE, who communicate primarily without the use of conventional symbols
- An inter-professional team, which includes parents / family members, is critical in order for these learners' communication profiles to be fully informed and understood

Implications of Results for PRACTICE

Children and young adults who experience CHARGE syndrome are, as a group, much stronger candidates for AAC evaluation and *possible* implementation than appears to be common belief / practice!

- 55.6% of the participants demonstrated ALL10; 81.5% participants demonstrated 9 of 10 evaluated **communication functions**;

and

- utilized an average number of 36.37 **unique forms** families interpreted as meaningful communication

Implications of Results for PRACTICE

Findings from this study highlight the **need for appropriate AAC evaluation and instruction** for the group of learners who experience CHARGE syndrome.

CONTACT INFORMATION

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Thursday, July 27, 2017

Panzacola H-1/H-2

Breakout Session #1: 1:00-2:30pm

Managing the Sensory Environment

Sarah Bis, MS, OTR/L, C/NDT and Sarah Maust, MOT, OTR/L
Perkins School For The Blind

Presenter Information

Sarah Bis is a registered, licensed occupational therapist currently employed at Perkins School for the Blind's Deafblind Program in Watertown, MA. She has over 6 years of experience working with students with CHARGE Syndrome ages 3-22, in both school and residential settings. Sarah holds certification in Neurodevelopmental Treatment of children with cerebral palsy and other neurologically-based disorders. She also has extensive experience with evaluation and treatment of sensory processing in children with multi-sensory impairment.

Sarah Maust is a registered and licensed occupational therapist currently working at Perkins School for the Blind in the Deafblind Program. Sarah has been practicing for approximately 4 years with a focus in pediatrics from the age of birth to 21 in an outpatient clinic and school settings. She has experience with children with multiple disabilities and multi-sensory impairments. Since beginning her work at Perkins, Sarah has been expanding her knowledge and practice with deafblind children with CHARGE syndrome.

Presentation Abstract

Multi-sensory deficits impact the ability of individuals with CHARGE Syndrome to gather, interpret, and use sensory information across settings. By adapting the sensory environment in which individuals with CHARGE Syndrome live, play, and learn, we can help them better access sensory information and participate in their world. Accommodations and adaptations will be discussed related to the needs of children with CHARGE Syndrome in the educational environment. Participants will leave the session with a list of ideas for sensory-based accommodations that may be implemented at home and in the school setting immediately.

Thursday, July 27, 2017

Panzacola H-1/H-2

Breakout Session #2: 2:45-4:15pm

Assessment and treatment of problematic behavior in students with CHARGE Syndrome

Caleb Davis, M.S., BCBA and Zachary Bird, M.S., BCBA
Perkins School for the Blind

Presenter Information

Caleb Davis is a Board Certified Behavior Analyst (BCBA). Currently, he is a PhD student in the Behavior Analysis program at Simmons College. He received his Master of Science in Applied Behavior Analysis from Western New England University. During graduate school he received his BCBA supervision requirements while working at the New England Center for Children. His research interests include the assessment and treatment of severe problem behavior and errorless learning procedures. Caleb has presented his research at both national and regional conferences. Caleb has worked as a consultant in home and school settings with individuals with disabilities including CHARGE syndrome. He currently works as a behavior analyst in the Deafblind program at Perkins School for the Blind where he works in collaboration with educators to assess and develop treatment plans to reduce problematic behavior.

Zachary Bird is a Board Certified Behavior Analyst (BCBA) who currently works as a Behavior Analyst in the Deafblind program at Perkins School for the Blind. He is currently working on a PhD in Behavior Analysis at Simmons College. He received his Master of Science in Applied Behavior Analysis from Western New England University while working as a teacher at the New England Center for Children. Zach has worked as a consultant nationally and internationally in home and school settings with individuals diagnosed with a variety of disabilities including autism, emotional disturbances, and CHARGE syndrome. His focus is the dissemination of behavior analytic research and principles to the public.

Dr. Yehoash Raphael is Professor of Otolaryngology in the Dept. of Otolaryngology at the University of

Presentation Abstract

This presentation will review several student cases studies. Each student with CHARGE syndrome engaged in problematic behavior that interfered with learning throughout their school day. Presenters will focus on describing the assessment process for each student and how results informed treatment development. In addition, the presentation will describe the three P's of behavior management (i.e., Prevent, Promote, and Provide).

Thursday, July 27, 2017

Panzacola H-1/H-2

Breakout Session #2: 2:45-4:15pm

Who Needs an Intervener?

Beth Kennedy, M.Ed.

Presenter Information

Beth Kennedy currently works as the Director of DeafBlind Central and the new Deafblind Intervener Training Program at Central Michigan University. She has worked in the field of DeafBlindness for over 25 years, holding positions at Perkins School for the Blind, and the Florida and Michigan DeafBlind projects. While her expertise is in deafblindness, she worked directly with children/young adults who have CHARGE Syndrome in previous positions and currently provides consultation and training to many teams who support children/young adults who have CHARGE Syndrome. She earned her Bachelor's Degree from the University of Massachusetts and her Master's from Boston College. Beth is currently earning a doctoral degree in Educational Leadership from Central Michigan University.

Presentation Abstract

Students who have a combined vision and hearing loss have unique educational support needs. Some students require the specialized services of a trained intervener. This session will provide a brief overview of the wide range of students who qualify as deafblind, compare the role of an intervener to that of a paraprofessional and an interpreter, and provide strategies for determining which level of support is appropriate.

Hierarchy of Support Needs for Teams Supporting Students who are DeafBlind

This hierarchy applies to students who have a documented vision and hearing loss that significantly affects their involvement and progress in the educational environment, to an extent that requires accommodations. At each of the 3 levels, the student's team should consider whether providing the services will result in significant change in the student's ability to interact within their educational environment. *Adapted with permission from forms used by the Utah DeafBlind project.

Periodic Consultation from an Expert in the Field of Deafblindness

Student Needs

- Increased access to information through classroom and curriculum material adaptations/modifications (e.g., decrease ambient noise and auditory distractions, increase or decrease amplifications, use of magnification, preferential seating/positioning).
- Use of specialized equipment or services (e.g., glasses, hearing aids, FM systems, interpreters trained in deafblindness, speech or communication devices).
- Support to remain as independent as possible.

Teacher Supports

- Ideas on how to present information to the student with the dual sensory loss.
- Strategies on how to best integrate the deafblind student into the educational experience (e.g., academic and social activities).
- Ideas on how to adapt or modify the educational environment and curriculum materials.

Frequent Consultation from an Expert in the Field of Deafblindness

Student Needs

- Needs are significantly greater than those noted above.
- Help organizing and responding to information fragmented by severe vision and hearing loss (e.g., use of recorder, brailler, computer day planner, class organizer, or other calendaring device; use of appropriate communication devices).
- Help receiving and using incoming information (e.g., use of appropriate sensory modalities, receiving and recording devices, interpreters, educational strategies for using/applying received information).
- Help interacting within the educational environment with peers and staff (teaching appropriate interaction and engagement skills, cues, and behavior).
- May need occasional prompts or guidance from a classroom assistant on the above.

Teacher Supports

- Strategies on how to best integrate instruction into functional routines for the student.
- Ideas on ways to reduce student's isolation in the social and educational process.
- Ideas on how to decrease student's feelings of dependency and increase student's confidence and independence.
- Help integrating/understanding responses from the student.

Frequent Consultation from an Expert in the Field of Deafblindness and an Intervener

Student Needs

- Needs are significantly greater than those noted above.
- Support to develop trusting relationships in the school environment.
- Help developing and using anticipatory skills and access to information through the establishment and use of routines throughout the educational day.
- Development of and reciprocal use of an appropriate, predictable communication system (e.g., gestures, signs, pictures, object cues).
- Signs, cues, and materials presented tactually or within a 3 foot space.
- Daily help in the educational setting in order to communicate, explore, and access information from that environment, and to act upon and respond to the information.

Teacher Supports

- An intervener assigned to the student so that the student can access instruction, social relationships, and environmental information.
- Access to information on working with an intervener.

Comparison of Possible Supports for Students Who Are DeafBlind

An intervener, paraprofessional, and/or interpreter can play a critical role in meeting the educational needs of a student who is DeafBlind. Every student who is DeafBlind has unique needs, so supports necessary to provide access will vary from student to student. Think about the student's support needs. Do the support needs change in different environments? If so, the level of support necessary could vary across environments. Below, each position is briefly described. The boxes in the columns below the given role outline the student support needs that might be satisfied by each one.

The team may want to reference "Are Intervener Services Appropriate for Your Student With Deaf-Blindness? An IEP Discussion Guide," available through the National Center on Deaf-Blindness.

Intervener: A person who has specialized training in deafblindness; provides 1:1 support to a student who is DeafBlind by facilitating communication, language, and concept development, providing access to auditory and visual information	**Paraprofessional:** A person who may have some training for specific job duties; provides support in a small group or 1:1 capacity; may be assigned to a student or a classroom	**Interpreter:** A person who is trained to interpret English to American Sign Language (or another manual system) and ASL to English; may have training to accommodate for vision loss/ deafblindness; may serve as a language model for the student
Student has both a vision and a hearing loss, necessitating specialized one on one support to participate in/provide access to activities, instructional and non-instructional, on and off site	**Student** functions well in small groups, may occasionally require 1:1 assistance	**Student** requires translation of information, from one language to another. The student is able to process the information and determine key points with minimal support.
Student support needs necessitate ready accommodations by a person trained in deafblindness in order to participate	**Student** support needs can be met by someone with basic training in deafblindness	**Student** requires the skill level of a nationally or state certified interpreter, who can provide appropriate accommodations for access (e.g. restricted field, tactile, etc.)
Student requires support for communication, language, interactions, concept development, curricular modifications, sensory losses, etc.	**Student** requires only minimal adaptations of classroom materials that can easily be accommodated by the team	**Student** is able to access interpreted information independently, and is able to seek information or clarification as needed independently
Student requires support to connect with and interact with others	**Student** requires only minimal support when interacting with peers and others	**Student** interacts independently, with the support of an interpreter, as needed
Student needs prompts and individualized support to attend/participate	**Student** requires occasional prompts and support to attend/ participate	**Student** is able to attend for long periods of time with little to no redirection
Student performance is significantly improved by support provided by a consistent, trusted person	**Student** interacts with and performs comparably with a variety of people	**Student** performance is typically not impacted by presence or absence of specific people
Student requires support to enhance her/his independence	**Student** requires occasional support/ prompts to work independently	**Student** is able to function independently, and makes independent decisions without prompts

References: 1. "What is My Role?" A Comparison of the Responsibilities of Interpreters, Interveners, and Support Service Providers (Susanne Morgan, MA, CI, CT) and, 2. Alsop, L., Robinson, C., Goehl, K., Lace, J., Belote, M., & Rodriguez-Gil, G. (2007). *Interveners in the classroom: Guidelines for teams working with students who are deafblind*. Logan, UT: SKI-HI Institute.

Developed by Beth Kennedy, DB Central: Michigan's Training and Resource Project, 2016
Special thanks for contributions by: John Miller (Gratiot-Isabella RESD), Nancy Mosher and Debra Belavek (Bloomfield Hills Deaf and Hard of Hearing Program), Jennifer Bigelow-Stambaugh (DB Central), and editing by Susanne Morgan-Morrow (New York Deaf-Blind Collaborative)

Who Needs an Intervener?

Beth Kennedy, M.Ed.

Central Michigan University

CHARGE 2017- Professional Day

Who Qualifies as Deafblind?

- People who have both a documented vision loss and a documented hearing loss
- Consider acuity and field loss
- People who do not respond to visual and auditory information due to a significant intellectual disability

What is an Intervener?

The National Center on Deaf-Blindness (NCDB) definition:

“Interveners…provide access to information and communication and facilitate the development of social and emotional well-being for children who are deaf-blind.”

NCDB recommends that interveners have training that is based on the CEC competencies for interveners.

July 2013

Full definition available on www.nationaldb.org.

What Is a Paraprofessional?

- May have some training, often from school or district
- Training is specific to job duties
- Provides support in small groups, sometimes 1:1
- Often assigned to the classroom, many programs resist assigning 1:1

What Is an Interpreter?

- Trained to interpret English to American Sign Language (ASL), and ASL to English
- Understands hearing and Deaf cultures
- May have training specific to accommodating clients who are DeafBlind
- May work with one or many clients simultaneously

Where Did Interveners Get Started?

- Long story short, Canada, but…
- Longitudinal research conducted in 1994, over the course of three years
- Focused on interveners working in Utah with children ages 0-3
- Found children with like needs in other states, tracked progress
- Children who have interveners make more progress

Who Needs an Intervener?

A student must:

- Have a vision and a hearing loss
- Not readily access activities
- Require adaptations and accommodations in order to participate

Who Needs an Intervener? (con’t)

The student requires support for:

- Communication
- Language
- Interactions
- Concept development
- Curricular modifications

Who Needs an Intervener? (con’t)

- The student requires:
- Support to connect with others
- Prompts and individualized supports to participate
- Support to enhance level of independence
- Consistency
- Support from a familiar, trusted person

Three Tools to Help You Decide

- Hierarchy of Support Needs for Teams Supporting Students who are DeafBlind
- Comparison of Possible Supports for Students Who Are DeafBlind
- Are Intervener Services Appropriate for Your Student With Deaf-Blindness? An IEP Team Discussion Guide

The National Credential

- Offered through the National Resource Center for Paraeducators (NRCPara)
- Requires the completion of a higher education program
- Candidates submit a portfolio demonstrating the competencies identified for interveners by the Council for Exceptional Children (CEC)
- Pay $100 processing fee

Other Ways to Train

- Some states are offering workshop-style training
- May have their own curriculum
- May use the Open Hands Open Access (OHOA) intervener training modules
- This type of training may or may not follow the CEC competencies
- People can earn the new national certificate

Will Interveners Be Mandated?

- The Alice Cogswell Anne Sullivan-Macy Act
- Introduced to Congress in September 2015 (H.R. 3535)
- Has bipartisan support
- In February, the bill was re-introduced as H.R. 1120
- Interveners are included
- Some states have passed policies or legislation ahead of a federal law

Contact Me

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References

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Are Intervener Services Appropriate for Your Student With Deaf-Blindness?

An IEP Team Discussion Guide

If you have questions or comments, please contact:
National Center on Deaf-Blindness
info@nationaldb.org

Are Intervener Services Appropriate for Your Student With Deaf-Blindness? An IEP Team Discussion Guide

Purpose of the Guide

The purpose of this discussion guide is to help IEP teams make informed decisions about whether intervener services are appropriate for a particular student.

Why Intervener Services May Be Needed

Students who are deaf-blind have absent, partial, or distorted vision and hearing. Deaf-blindness severely limits access to visual and auditory information that forms the basis for learning and communication and creates challenges for educational systems mandated to provide a free and appropriate education in the least restrictive environment. Intervener services are a way to meet the challenge of providing students who are deaf-blind with access to information they are unable to gather via vision and hearing and to help them compensate for the difficulties with communication and concept development that occur as a result of sensory deprivation.

How the Need for Intervener Services Is Determined

There are currently no accepted or standardized criteria to determine if a student requires intervener services. The decision is highly individualized based on the needs of a particular student as determined by the student's IEP team. This guide should be used within the context of developing a student's IEP. Its specific intent is to determine if intervener services should be provided to a student as part of his or her "related services and supplementary aids and services" [34 CFR 300.320(a)(4)]. IEP teams may find, however, that it also informs broader IEP discussion and planning in a number of areas including: (a) review of evaluation data [CFR 300.324(a)(1)(iii)]; (b) consideration of the communication needs of a child who is deaf or hard of hearing [34 CFR 300.324(a)(2)(iv)]; and (c) present levels of academic achievement and functional performance, particularly related to how deaf-blindness affects the child's "involvement and progress in the general education curriculum" [34 CFR 300.320(a)(1)(i)].

In order to make an informed decision, the team must clearly understand:

1. How the student's deaf-blindness affects his or her access to information, communication, social relationships, and conceptual learning. Combined vision and hearing loss typically substantially limits access in each of these areas.
2. The supports and accommodations needed by the student to obtain access in those areas.

Before You Begin

Before the IEP team considers whether an intervener is appropriate and needed for a particular student, the team members must:

- have a common understanding of what intervener services are and what interveners do,
- assure that someone on the student's IEP team has expertise in deaf-blindness, and
- assure that appropriate evaluation data, including data by evaluators with expertise in deaf-blindness, are available to the team.

IEP Team Discussion Guide Flow Chart

Preliminary Steps

- Understand what an intervener does
- Identify team member with deaf-blind expertise
- Review student evaluation data

Final Steps

- Summarize Discussion
- Make Decision
- Record Rationale

Preliminary Steps

Step 1: Assure that all involved in the discussion and decision-making have a common understanding of what intervener services are and what interveners do.

The following definition is from *Intervener Services and Interveners in Educational Settings*:[1]

Interveners, through the provision of intervener services, provide access to information and communication and facilitate the development of social and emotional well-being for children who are deaf-blind. In educational environments, intervener services are provided by an individual, typically a paraeducator, who has received specialized training in deaf-blindness and the process of intervention. An intervener provides consistent one-to-one support to a student who is deaf-blind (age 3 through 21) throughout the instructional day. While working under the guidance and direction of a student's classroom teacher or another individual responsible for ensuring the implementation of the student's IEP, an intervener's primary roles are to:

- *provide consistent access to instruction and environmental information that is usually gained by typical students through vision and hearing, but that is unavailable or incomplete to an individual who is deaf-blind;*[2]
- *provide access to and/or assist in the development and use of receptive and expressive communication skills;*[2]
- *facilitate the development and maintenance of trusting, interactive relationships that promote social and emotional well-being;*[2] *and*
- *provide support to help a student form relationships with others and increase social connections and participation in activities.*

An intervener does not work in isolation. Instead, he or she:

- *participates as an active member of the student's educational team,*
- *attends and participates in IEP meetings,*
- *attends regularly scheduled planning and feedback meetings with the teacher and other team members,*
- *is actively supervised and supported by the classroom teacher and other professionals responsible for the child's IEP, and*
- *receives ongoing support from professional educators with expertise in deaf-blindness.*

Step 2: Ensure that the student's IEP team has a member with expertise in the education of students who are deaf-blind.

Due to the low incidence of deaf-blindness, many teachers and related service providers have little to no experience with students who are deaf-blind and a limited understanding of their unique needs. Therefore, the IEP team should include a member with expertise in the education of students who are deaf-blind. If the student's team does not currently include an individual with this specific knowledge or training, your state deaf-blind project may be able to provide or assist you in finding one. You can obtain contact information for your state deaf-blind project at: https://nationaldb.org/members/list?type=State+Project

1. National Center on Deaf-Blindness. (2013). *Intervener services and interveners in educational settings*. Available at https://nationaldb.org/library/page/2266

2. Alsop, L., Blaha, R., & Kloos, E. (2000). *The intervener in early intervention and educational settings for children and youth with deaf-blindness*. Monmouth, OR: Western Oregon University, Teaching Research, National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind. Available at https://nationaldb.org/library/page/1320

Preliminary Steps (Continued)

Step 3: Review the student's evaluation data.

In order to have a knowledgeable discussion about a student's need for intervener services, the team must have the following information about the student. If it is not available from existing evaluation data, it should be gathered prior to the IEP meeting.

- Use of vision, hearing, and other senses to access information.
- Communication modes and skills.
- Analysis of the student's behavior as a form of communicative intent.
- Concept development and learning needs.
- Learning media and assistive technology needs.
- Daily living skills.
- Orientation and mobility needs.
- Opportunities to interact with others, including family members, peers, and service providers.

Additional information about assessment of children who are deaf-blind can be found at https://nationaldb.org/library/list/32

Using this Discussion Guide

The remainder of this document is organized as a guide for the IEP team to address six specific topics:

1. The student's use of residual vision.
2. The student's use of residual hearing.
3. How the student accesses information.
4. The student's communication modes and needs.
5. The student's social interactions and relationships.
6. The student's understanding of concepts and concept development.

The first two topics provide an opportunity to discuss the extent (if any) of a student's residual vision and hearing and the supports needed to maximize their use.

The remaining four topics address domains for which a student may need intervener services support.

Important: Download and save a copy of this form before completing.

Use of Residual Vision

Does the student have residual vision?

☐ Yes ☐ No

How do you know this?

☐ Medical report

☐ Functional vision evaluation

Other:

(If you answered "no" above, continue to page 7)

Describe how he or she uses vision to access information

☐ Must be very close to objects and people

☐ Must be a specific distance away from objects and people to accommodate for a narrow field of vision

☐ Relies on particular visual fields (describe)

☐ Relies on a combination of visual and tactual input

☐ Other:

Use of Residual Vision (Continued)

List supports and accommodations the student requires to maximize the use of vision (e.g., vision devices, alternative materials) and who is responsible for their use or delivery.

Type of Support or Accommodation	***Personnel Responsible***
Vision Devices (describe, e.g., eyeglasses, magnifier):	
Alternative Materials (describe, e.g., larger print, slant board):	
Environmental Accommodations (describe, e.g., preferential seating, supplemental light):	
Other:	

Use of Residual Hearing

Does the student have residual hearing?

☐ Yes ☐ No

How do you know this?

☐ Medical report

☐ Functional hearing evaluation

Other:

(If you answered "no" above, continue to page 9)

Describe how he or she uses vision to access information

☐ Requires other sensory input to make sense of auditory information

☐ Must be very close to people and sound sources

☐ Hears best when background noise is minimized

☐ Other:

Use of Residual Hearing (Continued)

List supports and accommodations the student requires to maximize the use of hearing and who is responsible for their use or delivery.

Type of Support or Accommodation	***Personnel Responsible***
Hearing Devices (describe, e.g., hearing aids, cochlear implants, FM system):	
Environmental Accommodations (describe, e.g., preferential seating, reduced background noise):	
Other:	

Access to Information

The left-hand column lists characteristics a student may have as a result of combined vision and hearing loss. Read each of these characteristics carefully and check those that apply to your student. In the right-hand column, for each checked item, describe the supports and accommodations the student requires and who is responsible for their delivery.

Student Characteristics	***Supports and Accommodations and Personnel Responsible***
Relies on close vision and/or hearing to obtain information ☐	
Relies on touch to obtain information ☐	
Requires support to locate and understand items in the environment ☐	
Requires support when moving within environments ☐	

Examples of these supports may include but are not limited to:

- Close-up instruction
- Tactile Learning
- Access to information presented during group instruction
- Assistance anticipating upcoming activities
- Assistance transitioning from one activity to another
- Orientation to and exploration of the environment

Access to Information (Continued)

The left-hand column lists characteristics a student may have as a result of combined vision and hearing loss. Read each of these characteristics carefully and check those that apply to your student. In the right-hand column, for each checked item, describe the supports and accommodations the student requires and who is responsible for their delivery.

Student Characteristics	***Supports and Accommodations and Personnel Responsible***
Requires support to know what will happen next ☐	
Requires support to participate in group instruction ☐	
Requires support to transition between activities (this refers to the cognitive and emotional aspects of transitions as well as physical support) ☐	
Requires support to explore and understand his or her surroundings ☐	

Examples of these supports may include but are not limited to:

- Close-up instruction
- Tactile Learning
- Access to information presented during group instruction
- Assistance anticipating upcoming activities
- Assistance transitioning from one activity to another
- Orientation to and exploration of the environment

Access to Information (Continued)

Summarize Your Responses

With your responses to the questions about student characteristics and required supports in mind, discuss the following questions:

☐ Yes ☐ No Are current supports meeting the student's needs for appropriate access to information?

☐ Yes ☐ No Do current personnel have the specialized skills needed to provide what the student requires? If not, is an intervener needed to deliver the supports? If the team decides an intervener is not needed, a plan to provide appropriate access to information should be specified.

Documentation

List the sources of information that helped you respond to the questions above (e.g., specific evaluation reports, staff or family knowledge).

Access to Communication

The left-hand column lists characteristics a student may have as a result of combined vision and hearing loss. Read each of these characteristics carefully and check those that apply to your student. In the right-hand column, for each checked item, describe the supports and accommodations the student requires and who is responsible for their delivery.

Student Characteristics	***Supports and Accommodations and Personnel Responsible***
Uses sign language or signed communication ☐	
Uses *tactile* sign language or signed communication ☐	
Uses other tactile communication methods (e.g., informal touch systems, touch cues, tactile symbols, object cues) ☐	
Requires a slow pace of communication ☐	
Requires support to get someone's attention ☐	

Examples of these supports may include but are not limited to:

- Instruction in the student's preferred mode of communication
- Facilitation of direct communication between the student and others (including peers)
- Ensuring that supplemental communication aids are functioning and being used
- Hand under hand instructional techniques
- Consistent use of communication systems
- Calendar systems
- Consistent use of supplemental communication aids
- Altered pacing of instructional and other activities
- Providing extended time for the student to respond
- Multiple communication partners proficient in primary communication mode

Access to Communication (Continued)

The left-hand column lists characteristics a student may have as a result of combined vision and hearing loss. Read each of these characteristics carefully and check those that apply to your student. In the right-hand column, for each checked item, describe the supports and accommodations the student requires and who is responsible for their delivery.

Student Characteristics	***Supports and Accommodations and Personnel Responsible***
Requires support to express needs ☐	
Requires support to make requests ☐	
Requires support to understand what others are communicating ☐	
Requires support to understand curricular content ☐	
Requires others to be in close proximity to communicate ☐	

Examples of these supports may include but are not limited to:

- Instruction in the student's preferred mode of communication
- Facilitation of direct communication between the student and others (including peers)
- Ensuring that supplemental communication aids are functioning and being used
- Hand under hand instructional techniques
- Consistent use of communication systems
- Calendar systems
- Consistent use of supplemental communication aids
- Altered pacing of instructional and other activities
- Providing extended time for the student to respond
- Multiple communication partners proficient in primary communication mode

Access to Communication (Continued)

Summarize Your Responses

With your responses to the questions about student characteristics and required supports in mind, discuss the following questions:

☐ Yes ☐ No Are current supports meeting the student's needs for appropriate access to communication?

☐ Yes ☐ No Do current personnel have the specialized skills needed to provide what the student requires? If not, is an intervener needed to deliver the supports? If the team decides an intervener is not needed, a plan to provide appropriate access to communication should be specified.

Documentation

List the sources of information that helped you respond to the questions above (e.g., specific evaluation reports, staff or family knowledge).

Access to Trusting Relationships and Social Interactions

The left-hand column lists characteristics a student may have as a result of combined vision and hearing loss. Read each of these characteristics carefully and check those that apply to your student. In the right-hand column, for each checked item, describe the supports and accommodations the student requires and who is responsible for their delivery.

Student Characteristics	***Supports and Accommodations and Personnel Responsible***
Needs support to interact with peers (this includes providing information and support to peers) ☐	
Often expresses emotions in socially inappropriate ways ☐	
Has difficulty establishing trusting relationships with educators and peers ☐	
Becomes frustrated or confused when interacting with educators and peers ☐	

Examples of these supports may include but are not limited to:

- Functional analysis of communicative intent and perceived inappropriate behavior
- Formal or informal social skills training
- Teaching initiation and interaction strategies to peers and staff
- Facilitating social interactions with staff and peers using the student's primary modes of communication
- Assistance locating and identifying staff members and peers
- Assistance orienting to new people
- Provision of additional information when transitioning between individuals and activities

Access to Trusting Relationships and Social Interactions (Continued)

Summarize Your Responses

With your responses to the questions about student characteristics and required supports in mind, discuss the following questions:

☐ Yes ☐ No Are current supports meeting the student's needs for appropriate access to relationships?

☐ Yes ☐ No Do current personnel have the specialized skills needed to provide what the student requires? If not, is an intervener needed to deliver the supports? If the team decides an intervener is not needed, a plan to provide appropriate access to relationships should be specified.

Documentation

List the sources of information that helped you respond to the questions above (e.g., specific evaluation reports, staff or family knowledge).

Access to Conceptual Learning

The left-hand column lists characteristics a student may have as a result of combined vision and hearing loss. Read each of these characteristics carefully and check those that apply to your student. In the right-hand column, for each checked item, describe the supports and accommodations the student requires and who is responsible for their delivery.

Student Characteristics	***Supports and Accommodations and Personnel Responsible***
Does not understand concepts used in instruction or conversation (e.g., up, down, over, below, stop, go) ☐	
Does not understand concepts used in grade-level standards work ☐	
Lacks understanding of the concepts of time (minute, hour, month, year, today, tomorrow) ☐	
Lacks understanding of concepts associated with objects (e.g., function, use) ☐	
Does not understand concepts used in daily routines ☐	

Examples of these supports may include but are not limited to:

- Pre-teaching, review, and repetition
- Hands-on experiences to build concepts
- Direct and incidental teaching
- Generalization training
- Activity-based instruction
- Meaningful and relevant activities
- Attaching language to all experiences

Access to Conceptual Learning (Continued)

Summarize Your Responses

With your responses to the questions about student characteristics and required supports in mind, discuss the following questions:

☐ Yes ☐ No Are current supports meeting the student's needs for appropriate access to conceptual learning?

☐ Yes ☐ No Do current personnel have the specialized skills needed to provide what the student requires? If not, is an intervener needed to deliver the supports? If the team decides an intervener is not needed, a plan to provide appropriate access to conceptual learning should be specified.

Documentation

List the sources of information that helped you respond to the questions above (e.g., specific evaluation reports, staff or family knowledge).

Final Steps

Putting It All Together

The information generated by the discussion above should inform the team's development of the statement of "special education and related services and supplementary aids and services" required as part of the student's IEP. **On the next page, you will record your conclusions.** As you summarize what you have learned from the preceding discussion and make a determination about the student's need for intervener services, consider the following questions.

1. Are current supports and accommodations sufficient to provide appropriate access in all of the areas above—information, communication, trusting relationships/social interactions, and conceptual learning?
2. Do current personnel have the knowledge and skills needed to consistently deliver those supports and accommodations?
3. Are the supports, accommodations, and associated personnel adequate for access across all school environments?
4. Is the current system for providing supports, accommodations, and associated personnel sustainable for the school year?
5. Finally, as you determine the related services and supplementary aids and services that will be provided to the child, consider whether intervener services are appropriate in order to enable the child to meet the following requirements as specified in 34 CFR 300.320(a)(4):
   - To advance appropriately toward attaining the annual goals;
   - To be involved in and make progress in the general education curriculum . . . and to participate in extracurricular and other nonacademic activities; and
   - To be educated and participate with other children with disabilities and nondisabled children.

Team Conclusions

The team has determined that the student's deaf-blindness affects his or her access to information, communication, trust and social relationships, and/or concept development in the following ways:

Based on discussion, the team has determined that the student needs the following supports and adaptations:

Is an intervener recommended to provide the identified supports and accommodations?
(If yes, describe the rationale and include information about this decision on the student's IEP. If no, describe why.)

Guide Development Process

This guide was developed from draft and internal documents on determining the need for an intervener that were developed by the following state deaf-blind projects:

- Texas Deafblind Project (primary source)
- Utah Deaf-Blind Project
- DB Central: Michigan's Training & Resource Project
- Georgia Sensory Assistance Project
- Arizona Deafblind Project

We also reviewed the following manual and structured the present guide to align with its categories of access related to information, communication, and social and emotional well-being: Alsop, L., Berg, C., Hartman, V., Knapp, M., Lauger, K., Levasseur, C., Prouty, M., & Prouty, S. (2012). *A Family's Guide to Interveners for Children with Combined Vision and Hearing Loss*. Logan, UT: SKI-HI Institute, Utah State University. Available at http://intervener.org/wp-content/uploads/2012/06/A-Familys-Guide-to-Interveners.pdf

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If you have questions or comments, please contact:
National Center on Deaf-Blindness
info@nationaldb.org

Evaluation
If you would like to provide feedback after using the guide, please go to this survey: www.surveygizmo.com/s3/1950701/IEP-Guidelines-Evaluation
Your input will help us improve future versions.

Thursday, July 27, 2017

Panzacola H-1/H-2

Breakout Session #2: 2:45-4:15pm

The Behavior Triangle for CHARGE Syndrome

Timothy S. Hartshorne, Ph.D.

Presenter Information

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafbind in Michigan. Much of his work is influenced and motivated by his son Jacob, who was born in 1989 with CHARGE syndrome. Tim's particular interests include understanding the challenging behavior exhibited by many individuals with deafblindness, CHARGE, and related syndromes, and also how severe disability impacts the family. He is the lead developer of a deafblind intervener training module on behavior for the National Center on Deaf-Blindness. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. His research was recognized in 2009 with the Central Michigan University President's Award for Outstanding Research. He is a frequent presenter on CHARGE and deafblindness.

Presentation Abstract

Having considered issues around challenging behavior in individuals with CHARGE for many years, I have come to the conclusion that that the behavior has three primary sources: pain, sensory issues, and anxiety. This presentation will address what we know about each of these, and then discuss the development of self-regulation skills as a prime intervention.

Thursday, July 27, 2017

Panzacola H-1/H-2

Breakout Session #2: 2:45-4:15pm

The CHARGE Syndrome Research Lab at Central Michigan University

Timothy S. Hartshorne, Ph.D.

Presenter Information

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafbind in Michigan. Much of his work is influenced and motivated by his son Jacob, who was born in 1989 with CHARGE syndrome. Tim's particular interests include understanding the challenging behavior exhibited by many individuals with deafblindness, CHARGE, and related syndromes, and also how severe disability impacts the family. He is the lead developer of a deafblind intervener training module on behavior for the National Center on Deaf-Blindness. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. His research was recognized in 2009 with the Central Michigan University President's Award for Outstanding Research. He is a frequent presenter on CHARGE and deafblindness.

Co Presenters: Megan Schmittel, Bree Kaufman, Shanti Madhavan-Brown, Anna Weatherly, Shelby Muhn, Rachel Wilson, Gretchen Imel, Blair Tieso, Aaron Hartshorne

Presentation Abstract

The CHARGE Lab at Central Michigan University began about 1999 when Tim Hartshorne began to study behavior in children with CHARGE. This presentation provides a bit of history, and then describes the research of the current lab members.

Thursday, July 27, 2017

Panzacola H-3/H-4

Breakout Session #1: 1:00-2:30pm

A new feeding scale for use in CHARGE syndrome

Alexandra Hudson, MD Candidate 2018
Dr. Kasee Stratton and Dr. Kim Blake

Presenter Information

Alexandra is a medical student at Dalhousie University in her third year of study. Prior to attending medical school, she completed my Honors Bachelor of Science at the University of Toronto in human biology, physiology, and psychology. She is currently studying CHARGE syndrome and its associated eating and gastrointestinal issues, under the supervision of Dr. Kim Blake at the I.W.K. Hospital in Halifax, Nova Scotia.

Presentation Abstract

Feeding issues are a major cause of morbidity and mortality in CHARGE syndrome. The feeding difficulties are unique and are not accurately captured with current validated feeding scales. This study designed a new feeding scale specific for CHARGE syndrome, and tested its validity and reliability in 100 individuals. This new scale can be used to assess an individual's current severity of feeding difficulties, track their oral feeding progress, and can alert to areas of concern that need clinical intervention.

Thursday, July 27, 2017

Panzacola H-3/H-4

Breakout Session #1: 1:00-2:30pm

Cochlear implants for CHARGE patients: sound present and better future

Brandi Griffin, Au.D. and Yehoash Raphael, Ph.D.
University of Michigan, Ann Arbor

Presenter Information

Dr. Griffin is a clinical audiologist in the Cochlear Implant Program. She has been working with pediatric and adult cochlear implant patients for more than 15 years. She received her undergraduate and master's degrees in Audiology from the University of North Texas and her clinical doctorate in audiology (Au.D.) from Arizona Health Sciences Center in Phoenix, Arizona. Dr. Griffin has special interest in working with children with disabilities in addition to hearing loss, and has managed the audiological needs of several children with CHARGE who have received cochlear implants.

Dr. Yehoash Raphael is Professor of Otolaryngology in the Dept. of Otolaryngology at the University of Michigan. His background is in Audiology and Embryology (Tel Aviv University). Work in the lab is aimed at developing novel technologies applicable for prevention and cure of inner ear disease. Dr. Raphael is applying his research efforts towards diseases caused by both environmental and hereditary factors, with manifestation in both auditory and vestibular parts of the inner ear. He is studying the development and function of the normal ear, and the cellular and molecular aspects of diseases affecting hearing and balance. Dr. Raphael designs novel experimental therapies aimed at prevention of hearing loss, regeneration of hair cells in the auditory and vestibular systems, and enhancing the functions of ears that receive cochlear implants.

Presentation Abstract

This presentation will answer many questions you may have about cochlear implants, including who is a candidate, and what tests are used to determine if someone is a candidate for a cochlear implant. We will review how a cochlear implant works, and discuss the kinds of outcomes that can be expected when a patient with CHARGE receives a cochlear implant. We will review recent developments in cochlear implants that will include a description of hearing preservation, electrode arrays, and new developments in speech processors. The presentation will include a discussion of factors that impact performance, and things that can be done to enhance performance. You will learn about novel biological approaches for making the ear a better recipient of the implant.

Thursday, July 27, 2017

Panzacola H-3/H-4

Breakout Session #1: 1:00-2:30pm

External Quality Assessment Clinical Genetics: CHARGE syndrome as an educational case

Conny van Ravenswaaij-Arts, MD, PhD

Presenter Information

Conny van Ravenswaaij is a clinical geneticist with a long-lasting experience in genetic and clinical studies on CHARGE syndrome. Since her group discovered CHD7, the gene responsible for CHARGE syndrome, in 2004, she coordinates a multidisciplinary clinic and supervised several PhD research projects dedicated to the syndrome. Her research is mostly based on questions raised by the parents and often results in clinical guidelines. Thus far she has published over 30 papers and four book chapters on CHARGE syndrome.

Conny van Ravenswaaij-Arts[1], Livia Garavelli[2], Alain Verloes[3], Kim Blake[4], Simon Howard[5], Ros Hastings[6]

[1]University Medical Center Groningen, Netherlands; [2]S. Maria Nuova Hospital, Reggio Emilia, Italy; [3]Hopital Robert Debre, Paris, France; [4]IWK Health Centre, Halifax, Nova Scottia, Canada; [5]UK CHARGE Family Support Group; [6] CEQAS, Oxford University Hospitals NHS Foundation Trust, Oxford, UK

Presentation Abstract

In 2013 a project was started to develop an External Quality Assessment (EQA) scheme for Clinical Genetics. The aim of EQA is to improve quality and harmonization of genetic services. Each year four cases are presented to the participating centers within different categories. The 2016 dysmorphology case was on CHARGE syndrome. From this scheme it can be learned what the gaps in knowledge of CHARGE syndrome are and it also creates awareness among clinical geneticists.

Thursday, July 27, 2017

Panzacola H-3/H-4

Breakout Session #1: 1:00-2:30pm

Dissecting the causes of frontal cortex abnormalities in a mouse model for CHARGE syndrome

Alex P A Donovan

Presenter Information

Alex Donovan is a first-year PhD student at King's college London studying the developmental origins of executive functioning deficits in CHARGE syndrome. Alex has a neuroscience bachelor's degree from KCL, and is now working under Dr. Albert Basson, focusing on the role of the chromatin remodeling factor CHD7 in the development of the frontal cortex, and the consequence of its disruption in CHARGE syndrome.

Presentation Abstract

Many individuals with CHARGE syndrome have been reported to have deficits in executive functioning, often associated with a diagnosis of an autism spectrum disorder. The neurodevelopmental and neuroanatomical underpinnings of these deficits are not yet known. However, functional studies have identified the prefrontal cortex as the primary brain region governing executive functions. I report studies on a Chd7+/- mouse model to investigate the impact of Chd7 heterozygosity on the development and function of the frontal cortex.

Thursday, July 27, 2017

Panzacola H-3/H-4

Breakout Session #2: 2:45-4:15pm

Putting Genetics in CHARGE

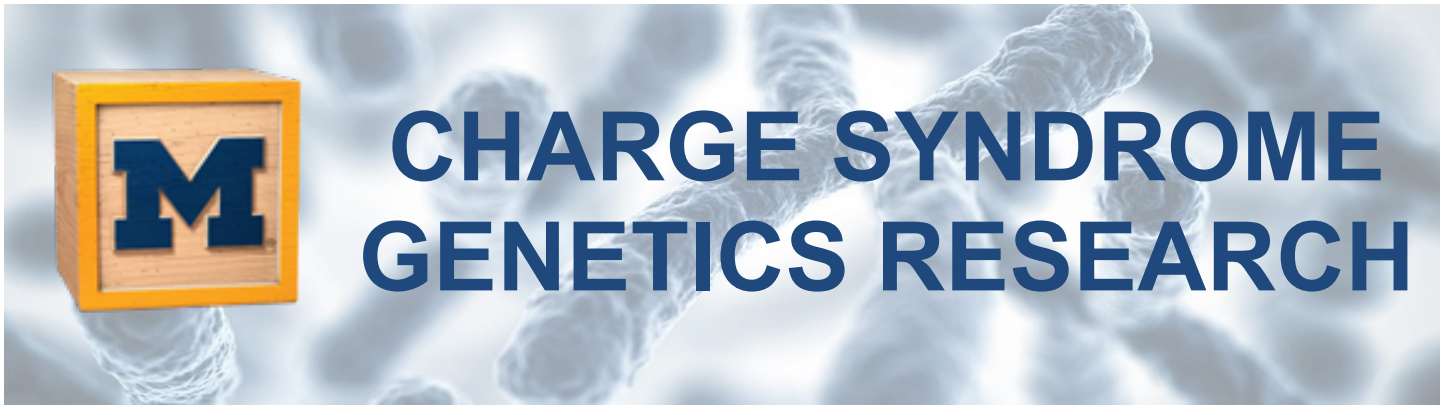
Amanda Moccia, MS

Presenter Information

Amanda Moccia is currently in pursuit of her doctorate degree in Human Genetics at the University of Michigan. Her research focuses on studying the genetic etiology and mechanisms of neurodevelopmental diseases. Under the supervision of Dr. Stephanie Bielas and Dr. Donna Martin, Amanda has sought the opportunity to better understand the etiology of CHARGE syndrome. One of her research projects consists of generating a cohort of individuals with features of CHARGE syndrome who do not have a genetic diagnosis. The hope is to identify novel causes of CHARGE that are not explained by CHD7 mutations to better understand the mechanism of CHARGE, improve clinical diagnostics, medical management and surveillance.

Presentation Abstract

Although CHARGE syndrome has been classified as a monogenic disorder, not all individuals test positive for CHD7 mutations. This finding is suggestive that there are additional genetic etiologies for CHARGE outside of CHD7 exons or coding regions in the genome. Here we report on our progress of generating a CHARGE cohort, our results from Whole Exome Sequencing, and our analysis of regulatory regions in the genetic etiology of CHARGE.



Purpose of the study

Not all cases of CHARGE Syndrome are caused by mutations in the *CHD7* gene. We are interested in finding new genetic causes of CHARGE.

Participation Requirements

1. At least one individual in the family must have clinical features of CHARGE Syndrome.
2. Adults and children of any age can participate (we have cheek swabs for individuals who may have difficulty producing enough saliva).

Nature of participation

We are collecting saliva samples from individuals with clinical features of CHARGE Syndrome and their parents and siblings. DNA is collected from the saliva samples and sequenced. We are also asking families to participate in a CHARGE Syndrome database so we can obtain clinical information to understand the natural history of CHARGE Syndrome.

Time involved

The requirements to participate in this genetic study can be completed in a single session of approximately 30 minutes at our booth during the conference. Each family will be asked to complete a clinical history questionnaire (15 - 20 minutes), and each participating family member will be asked to donate a saliva sample (5 - 10 minutes).

Contact information

If you have any questions regarding this genetic study, please visit our booth during the conference or contact Dr. Donna Martin 734.645.3564/donnamm@umich.edu, Dr. Stephanie Bielas 734.647.8890/sbielas@umich.edu or Ms. Amanda Moccia 734.647.8852/moccia@umich.edu.

Thursday, July 27, 2017

Panzacola H-3/H-4

Breakout Session #2: 2:45-4:15pm

Rapid drug discovery in genetic models of CHARGE syndrome

Kessen Patten, Phd

Presenter Information

Dr. Patten is an Assistant Professor and was the first to describe a zebrafish model of CHARGE Syndrome. He has obtained a pilot grant from the CHARGE Syndrome Foundation with Dr. Schmeisser and Dr. Parker and our labs are addressing the role of CHD7 in a translational approach using the nematode C. elegans and the zebrafish D. rerio.

Co-presenters:

Kathrin Schmeisser[1], Betelhem Kassa[2], Jodey Alex Parker[1]

[1]CRCHUM and Department of Neurosciences, University of Montreal

[2]INRS-Institut Armand Frappier

Presentation Abstract

CHARGE Syndrome (CS) is a genetic disorder characterized by a complex array of birth defects, for which there are no cure. We have developed C. elegans and zebrafish models of CS and used them for a phenotypic drug screen of 3850 clinical-approved molecules. We have identified several small molecules that can suppress the dysfunctional phenotypes caused by mutation in the CS gene, CHD7. Our findings may assist in accelerating the development CS therapeutics.

Thursday, July 27, 2017

Panzacola H-3/H-4

Breakout Session #2: 2:45-4:15pm

Genetic epistasis contributes to inner ear and neuronal development via regulation of chromatin remodeling and retinoic acid synthesis

Hui Yao, PhD.

Presenter Information

Hui Yao is a postdoctoral fellow in the Pediatrics Department at The University of Michigan working in the laboratory of Dr. Donna Martin. She has been studying basic mechanisms of CHARGE syndrome since November 2014. She received her PhD in Biochemistry and Molecular Biology from the National Institute of Biological Science in Beijing in 2011. Her work focuses on the role of CHD7, the chromatin remodeling protein mutated in CHARGE, in embryonic stem cell and neuronal development. She uses cell culture models of developing neurons and biochemical assays to better understand the basic processes by which CHD7 promotes neuronal development and differentiation. Dr. Yao attended the CHARGE conference in Chicago in July 2015 and looks forward to participating again this summer.

Co-presenters:

Jennifer M Skidmore[1], Ethan D Sperry[2,4], Donald L Swiderski[3], Shigeki Iwase[2], Peter Scacheri[5] and Donna M Martin[1,3,4]; Departments of Pediatrics[1], Human Genetics[2], and Otolaryngology[3], and the Medical Scientist Training Program[4], The University of Michigan, Ann Arbor, MI and Department of Genetics[5], Case Western Reserve University, Cleveland, OH

Presentation Abstract

Abnormal retinoic acid (RA) signaling during embryogenesis mimics CHARGE syndrome, suggesting CHD7 and RA cooperate to regulate gene expression. Here we show results of biochemical and genetic studies on CHD7- and RA-mediated inner ear and neuronal development. We show that Chd7 acts in a genetic pathway upstream of the RA synthesis gene Aldh1a3 in the inner ear, and that epistasis between Chd7 and Aldh1a3 may explain phenotypic similarities observed in CHARGE and RA embryopathy.