Saturday, July 29, 2017

Breakout Session #5: 10:45-11:45am
Panzacola F-1/F-2

Sibling Panel

Nancy Salem-Hartshorne, PhD., Aaron Hartshorne, Mallory Beavers, Mindy Braga

Presenter Information

Nancy is a Professor of Psychology, School Psychologist, and mother of Jacob, age 28, who has CHARGE syndrome. Nancy will facilitate the panel composed of siblings of individuals who have CHARGE syndrome.

Additional panelists include: Hannah and Megan Troupe, Rachel Lobaugh, Matt Stanger, Zach Chinicci, Seth Hartshorne, and Sarah Lent

Presentation Abstract

Siblings of individuals with disabilities have unique experiences. Siblings of individuals with CHARGE have even more unique experiences. Within these, there are still more variable experiences, depending on birth order, severity of disability, and parenting styles, among other things. This panel of young adults will describe their experiences, both rewarding and challenging, of being raised with a sibling with CHARGE syndrome. Moderators will then ask specific questions, after which audience questions will be welcomed.

Saturday, July 29, 2017

Breakout Session #5-7:
10:45-11:45am, 1:00-2:00pm, 2:15-3:15pm

Panzacola F-3/F-4

Adult Track

Kasee Stratton, Ph.D., NCSP, Daniel Gadke, Ph.D., NCSP, BCBA, and R. Matthew Coward, MD, FACS

Presenter Information

Dr. Kasee Stratton and Dr. Daniel Gakde are assistant professors of School Psychology at Mississippi State University. Both are also licensed psychologists and nationally certified school psychologists. Drs. Stratton and Gadke completed their doctoral internship and postdoctoral fellowship at Johns Hopkins School of Medicine and the Kennedy Krieger Institute. They specialize in treating challenging behavior and improving adaptive skills for children with developmental disabilities. Dr. Stratton has worked with individuals for CHARGE for over 12 years and Dr. Gadke primarily teaches behavioral assessment and intervention courses.

R. Matthew Coward, MD FACS is an Assistant Professor of Urology and Clinical Assistant Professor of Obstetrics and Gynecology at the UNC School of Medicine, and Director of Male Reproductive Medicine and Surgery at UNC Fertility in Raleigh, NC. He earned his MD with Distinction at UNC, followed by urology residency at UNC, and fellowship in Male Reproductive Medicine and Surgery at Baylor. Dr. Coward's clinical practice focuses in the areas of male reproduction and fertility as well as male sexual dysfunction. Dr. Coward's second of three children, Ryan, is a 4-year-old who has CHARGE syndrome.

Presentation Abstract

This three-session track will provide a series of presentations, discussions, and question and answer formats ***for adults with CHARGE syndrome ages 16+ only***. Sessions will include topics such as sex, sexual dysfunction, sustaining friendships, guidance on drinking, social media skills, advocating on the job and in the community, and question and answer time periods.

Saturday, July 29, 2017

Breakout Session #5: 10:45-11:45am
Panzacola G-1

CHARGE Syndrome and Behavior: Diagnoses and Intervention (Part I)

Tim Hartshorne, David Brown, Megan Schmittel, Shanti Madhavan-Brown, Shelby Muhn

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.

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.

Presentation Abstract

Part one: Diagnosis of behavior. Individuals with CHARGE are often diagnosed with a variety of psychiatric disorders such as autism, OCD, and ADHD. This session addresses the problem of psychiatric diagnoses in children with CHARGE: what are these diagnoses, why are they given to children with CHARGE, and what problems do they create, and are they appropriate?

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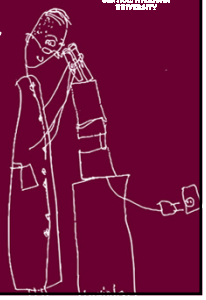
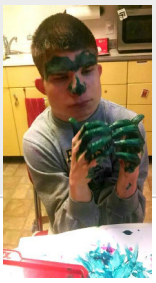
CHARGE Syndrome and Autism, ADHD, ODD, OCD, Et al.

Tim Hartshorne, David Brown, Megan Schmittel, and Shanti Brown



That's weird; must be autistic



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Diagnoses Piled On

- Autism
- ADHD
- OCD
- Tourette
- Etc.

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Problems with these Diagnoses

- Create a reality that may not exist
- Lack explanatory value
- Ignore the uniqueness of the behavior
- Lead to multiple drug treatments

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What are mental disorders?

- Nobody really knows
- There are no blood tests
- Symptom co-variation
  - If you have these behaviors you are likely to have this disorder
- There is no way to confirm
  - Except the agreement of professionals

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What is the cause of mental disorders?

- Probably not evil spirits
- Genetic
- Biological
- Psychological
- Environmental

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Epigenetics – the new direction

- "Certain genes are turned on or turned off, expressed or not expressed, depending on environmental inputs," Richard McNally, PhD, a clinical psychologist at Harvard University

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Diagnosis

- Behavior check lists
- If it looks like a duck, and quacks like a duck

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Diagnosis

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Why do we diagnose mental illness?

- As a guide to treatment

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Can people with CHARGE have mental illness?

- Yes
- So why not just diagnose it?
  - Does it lead to better treatment or outcomes?
  - And is the diagnosis accurate?
- Would we expect that the same behaviors which are co-variant in mental disorders for people ***without*** CHARGE to be co-variant in people ***with*** CHARGE?
- In other words, what would a disorder such as autism look like in a person with CHARGE?
- Or if a child with CHARGE is said to have autistic-like behaviors, does that mean they have autism?

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Autism

- Impairments in social communication
  - Social reciprocity
  - Nonverbal communication deficits
  - Lack of understanding of relationships
- Restricted, repetitive patterns of behavior, interests, or activities
  - Stereotyped or repetitive motor movements
  - Insistence on sameness
  - Fixated interests
  - Reactivity to sensory input

CHARGE Research Lab

Is it autism?

High rates of ASD have been reported in syndromes such as Cornelia de Lange and Fragile X. However, there is debate about whether the ASD profile of behavours that triggers a Diagnosis in these syndromes is the same as in individuals with idiopathic ASD.

Waite, J., Heald, M., Wilde, L. Woodcock, K., Welham, A., Adams, D., & Oliver, C. (2014). The importance of understanding the behavioural phenotypes of genetic syndromes associated with intellectual disability. Peediatrics and Child Health, 24, 468-472.

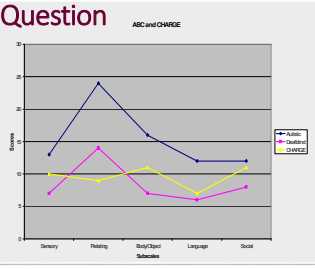
CHARGE Research Lab

Syndromes most often associated with autism

- Fragile X
  - social anxiety, extreme shyness and eye gaze avoidance – not central to autism
  - strong willingness to engage socially with others
- Cornelia de Lange
  - The nature of repetitive behaviors appears to be different compared to those with ASD
- Tuberous Sclerosis Complex
  - Repetitive behaviors are not as frequent as in ASD

CHARGE Research Lab

The Autism Question



Hartshorne, T. S., Grialou, T. L., & Parker, K. R. (2005). Autistic-Like Behavior in CHARGE Syndrome. *American Journal of Medical Genetics, 133A*, 257-261.

CHARGE Research Lab

Autism as an Additional Label

- An array of "symptoms" are seen in CHARGE and Autism, but they differ in function
  - Social: Uninterested vs. not able (Deafblind)
  - Physical: self-stim. vs. regulation
  - Sensory: over-stimulated vs. under-stimulated
  - Communication: immature/uninterested vs. functional
- Autism adds extra label, stops caregivers from finding function for communication

CHARGE Research Lab

Why Add the Label?

- Gives parents feeling that something can be done
- "…our goal has been to identify what is unique about the behavior of children with different genetic disorders, and not what is common. I have no doubt that there is a behavioral phenotype associated with CHARGE. My goal, and that of others, is to better specify that phenotype so that we can develop interventions as well as prevention strategies" –T. Hartshorne
- Does an extra label help? How do we treat them differently?

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Gain Access to Services?

- Add label to get ABA services
- Not always a bad thing – but the child with CHARGE could be misunderstood
- More physiological conditions with CHARGE that contribute to psychological behaviors
- ASD has fewer physical abnormalities
- Clinician needs to understand unique physical needs associated with CHARGE versus reluctance often associated with ASD
- ABA services good for FCT but not for everything
  - Walking on grass: irrational fear or painful experience?

CHARGE Research Lab

Obsessive Compulsive Disorder

- DSM-5 Diagnostic Criteria for Obsessive-Compulsive Disorder (300.3)

Obsessions

Recurrent and persistent thoughts, urges, or impulses that are intrusive and unwanted, and cause marked anxiety or distress. (Typically irrational fears.)

The individual attempts to ignore or suppress such thoughts, urges, or images, or to neutralize them with some other thought or action (i.e., by performing a compulsion).

Compulsions

Repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly.

The behaviors or mental acts are aimed at preventing or reducing anxiety or distress, however, these compulsions are not connected in a realistic way with what they are designed to neutralize or prevent.

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We believe……

- Most individuals with CHARGE syndrome don't have *true* OCD.
- Someone with true OCD has irrational thoughts leading to irrational anxiety.
- The treatment involves exposure to the irrational thought, and prevention of the compulsive response.

- Individuals with CHARGE have TRUE circumstances that lead to UNDERSTANDABLE anxiety!
- In other words, the EXPOSURE is happening all the time, and is unavoidable. The compulsive response is an understandable defense for dealing with the anxiety.

CHARGE Research Lab

OCD-like behaviors seen in CHARGE

- **"Everything must be just right."**
  - Ordering/lining up/making symmetrical
  - Placing/moving to correct place
  - Light switches
  - Doors closed/open
  - Handing cup to caregivers when he sees it
- **Other things reported or seen:**
  - Repetitive question-asking: "What color is your car?" "What color is your house?"
  - Stuffing things into slots—especially into places from which they are difficult to retrieve.
  - Repetitive, idiosyncratic behaviors: Hand movements, tics
  - Rigid inability to switch activities
  - All-consuming focus on one idea, activity, or item, to the point that it's not just a hobby/intense interest—keeping in mind that we ALL have hobbies/interests!
  - What else have you observed?

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"A lot of what looks like OCD in CHARGE is really just a reaction to having multi-sensory impairments"– D. Brown 2015

These are actually very creative responses to abnormal, anxiety-provoking circumstances.

Caveat: Someone with CHARGE syndrome could possibly also develop "actual" OCD, but this is not the norm.

CHARGE Research Lab

Attention-Deficit/Hyperactivity Disorder

- A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development
- Higher incidence among deaf children
  - Sensory integration issue?
  - Limited language exposure?
  - Social-emotional development issue?
  - Visual selective attention?
  - Boredom?
- Consider executive function impacted by sensory impairments

CHARGE Research Lab

Attention Deficit/Hyperactivity Disorder

- Diagnostic Criteria: Inattentive presentation
  - Lacks attention to detail
  - Lacks sustained attention
  - Does not seem to listen
  - Does not follow through on instructions and fails to finish work
  - Difficulty organizing tasks
  - Avoids tasks with sustained mental effort
  - Loses things
  - Easily distracted
  - Forgetful
- Diagnostic Criteria: Hyperactivity/Impulsivity presentation
  - Fidgets
  - Often out of seat
  - Runs or climbs in situations where inappropriate
  - Unable to play quietly
  - Often "on the go"
  - Talks excessively
  - Blurts out answers
  - Difficulty waiting turn
  - Often interrupts others

CHARGE Research Lab

Attention Deficit/Hyperactivity Disorder

- How can these behaviors be better explained by CHARGE syndrome?
  - Deafblindness
  - Difficulties with executive functioning
    - Attending
    - Organizing activities
    - Inhibition
  - Difficulties with self-regulation
  - Sensory needs

CHARGE Research Lab

Attention Deficit/Hyperactivity Disorder

- Example: Bradley, a third grade student with CHARGE syndrome, never seems to be paying attention during math. He spends math class staring up at the lights or inspecting his fingers close to his face.
- ADHD Perspective:
  - Bradley is unable to attend to what his teacher is saying. Bradley is also very fidgety with his fingers.
- CHARGE Perspective:
  - Bradley cannot see the board where his teacher is writing math equations.
  - Bradley cannot hear what the teacher is saying. He also cannot hear what questions his peers are asking.
  - When Bradley flicks his fingers in front of his face, he is getting sensory stimulation from the visual input.
  - Bradley has a hard time transitioning between activities and needs more time to get ready for math.

CHARGE Research Lab

Borderline Personality Disorder

- A pattern of instability in interpersonal relationships, self-image, and affects, and marked impulsivity
  - Fears of abandonment
  - Extremes of idealization and devaluation of others
  - Unstable self-image
  - Impulsivity
  - Recurrent suicidal behavior
  - Highly reactive emotions
  - Chronic feelings of emptiness
  - Anger difficulties
  - Stress related paranoia
- May be associated with the experience of severe abuse, neglect, parental conflict

CHARGE Research Lab

Tic disorders

- Two types of tics
  - Verbal
  - Motor
- Tourette's Disorder has both
- Worsened by anxiety, excitement, and exhaustion
- About 25% of children will have transient tics
- "Hearing parents and mental health clinicians unfamiliar with typical behaviors of deaf children may have difficulties differentiating the clinical presentation of symptoms of TD from the effects of deafness, as well as in implementing appropriate interventions." (Chovaz, 2013)
- Homemade utterances and gestures may be the result of
  - Language delays
  - Intentional personal entertainment

CHARGE Research Lab

Oppositional Defiant Disorder

- What are the diagnostic criteria?
  - Angry/irritable mood
  - Argumentative/Defiant Behavior
  - Vindictiveness

CHARGE Research Lab

Oppositional Defiant Disorder

- How can these behaviors be better explained by CHARGE?
  - Communication deficits
  - Sensory difficulties
  - Deafblindness
  - Executive Functioning Difficulties
  - Fatigue

CHARGE Research Lab

Opposition Defiant Disorder

- Example:
  - Julie was eating pureed peas for dinner, when all of a sudden, she scooted back her chair and threw the bowl of peas on the ground.
  - ODD Perspective:
    - Julie threw her peas on the ground to defy her caregiver.
  - CHARGE Perspective:
    - Julie was having some gas pain and needed to alert her caregiver that it hurt her stomach to eat.
    - Julie does not like peas and does not want to eat them.
    - Julie cannot stand the texture of pureed peas.

CHARGE Research Lab

Bipolar Disorder

People having a manic episode may:
•Feel very "up," "high," or elated
•Have a lot of energy
•Have increased activity levels
•Feel "jumpy" or "wired"
•Have trouble sleeping
•Become more active than usual
•Talk really fast about a lot of different things
•Be agitated, irritable, or "touchy"
•Feel like their thoughts are going very fast
•Think they can do a lot of things at once
•Do risky things, like spend a lot of money or have reckless sex

People having a depressive episode may:
•Feel very sad, down, empty, or hopeless
•Have very little energy
•Have decreased activity levels
•Have trouble sleeping, they may sleep too little or too much
•Feel like they can't enjoy anything
•Feel worried and empty
•Have trouble concentrating
•Forget things a lot
•Eat too much or too little
•Feel tired or "slowed down"
•Think about death or suicide

CHARGE Research Lab

Dunn Conceptual Model

Arousal of thoughts, behavior, feelings, sensations	PASSIVE Self-regulation Strategies	ACTIVE Self-regulation Strategies
Habituation	Non-reactive Tune it out	Sensation Seeking
Sensitization	Reactive to Stimuli	Sensation Avoiding

Psychotropic Medications

- Have generally not been researched with children
- No idea about impact on sensory systems
- Have numerous side effects – impact on brain?
- Are often prescribed off label
- Use is not often monitored closely with observation
- Side effects may lead to additional prescriptions
- There is a tendency to add drugs, rather than replace
- Goal should be to be weaned off of them
- May take away a form of communication
- Sometimes they are survival for the family

CHARGE Research Lab

The Trouble with Multiple Diagnoses

- Children's functional behaviors may present as symptoms of a mental health condition; however, given the child's multi-sensory impairment, the behaviors are often reasonable choices by the child.
- By classifying these behaviors as a mental health disorder, we may be dismissing the creative strategy the child has come up with to survive within his/her environment.
- Therefore, we need to see these accommodations the child has made as accomplishments for them in creating a world that makes sense to them.

CHARGE Research Lab

Puzzling Behaviors in CHARGE Syndrome

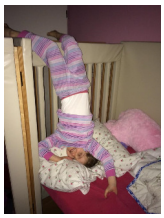
From the FaceBook post:

- Fascinated with fingers/hands (common)
- Laughs at hands
- Plays with hands instead of toys
- Stops what they're doing and touches ground repeatedly
- Knocks on walls/doors before entering a room
- Finger "twiddling" in front of face
- Grinds teeth
- Slaps knees
- Grunts
- Becomes angry when family laughs at jokes/cute things the child says (lunges/hits)
- Violent fits (pulling hair, kicking, punching)
- Constantly touches forehead
- Holds jumper away from stomach
- Leans over to the right
- Bangs elbows on things
- Sticks tongue out a lot
- Touches the inside of eyelids
- Spins in circles
- Bites fingertip with tip of it under tongue
- Obsessively collects things
- Skin picking (lips and fingers)
- Arms crossed
- Lies with one leg over knee
- Chews on things
- Sticks fingers in mouth to the point of gagging
- Spits/puts spit on their hair (or someone else's)
- Spins on floor
- Empties containers/drawers & put everything back
- Hands in fist with thumb tucked in
- Fingers in eyes
- Bangs head on things
- Tongue constantly sticking out
- Fascinated with lights
- Clears bed of anything on it
- Crawls on-top of people lying on the floor
- Flails body when happy
- Hits self in face
- Shakes head from side to side
- Arches back
- Turns on and off lights

CHARGE Research Lab

CHARGE
Research Lab

"CHARGE" is Enough



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Saturday, July 29, 2017

Breakout Session #5: 10:45-11:45am

Panzacola G-2

Creating and Using Nonconventional Signal Dictionaries and Communication Portfolios to Support Individuals who Communicate Primarily without the Use of Symbols

Susan M. Bashinski, Ed.D., Carol Darrah, M.S., Christine Spratling, Ed.S

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.

Carol Darrah is the Early Childhood Coordinator for the Georgia Sensory Assistance Project, which supports children and youth with combined vision and hearing loss. Carol focuses her efforts on early identification and referral, supporting families and early intervention providers, and assisting with transition from early intervention to school services. She earned her Bachelor's and Master's degrees in Child and Family Development from the University of Georgia and has worked in the field of Early Intervention for more than 18 years.

Christine is the Technical Assistance Specialist with the Georgia Sensory Assistance Project.

Presentation Abstract

For individuals at the earliest, non-symbolic stages of communication development, the implementation of consistent communication strategies enhances their participation in interactions and promotes their ongoing communication development. Learn how to build receptive and expressive Nonconventional Signal Dictionaries (written scripts and video clips) and to create Communication Portfolios (pictures and written descriptions) to support children as they enter new learning settings, participate in community activities, meet new service providers, and interact with family members and friends.

Saturday, July 29, 2017

Breakout Session #5: 10:45-11:45am

Panzacola H-1/H-2

Who Needs an Intervener? And A Day in the Life! A Case Study of 2 Adults with CHARGE and their Intervenor Services

Beth Kennedy, M.Ed., Leah Cameron, Cullen Drew

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.

Leah Cameron is Director of Services with the Canadian Deafblind Association Ontario Chapter leads a team of Managers and Intervenor Service Coordinators that support residential programs across the province of Ontario. Leah had the opportunity to attend a CHARGE Conference in California in 2007 and describes the experience as life changing! Leah is thrilled to have the opportunity to present at the 2017 conference and share what the Canadian Deafblind Association is doing to support individuals with CHARGE with their everyday life planning and accomplishing life goals both big and small!

Cullen Drew is an Intervenor Services Coordinator with the Canadian Deafblind Association Ontario Chapter and supports three individuals at CDBA's new apartment complex in Paris, Ontario. Two of the gentlemen he supports are deafblind due to CHARGE Syndrome; Jason and his roommate Nicholas. Cullen attended the CHARGE Conference in Chicago with Jason and it was an experience he will never forget.

Presentation Abstract

Beth will discuss students who have a combined vision and hearing loss and their 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. This will be followed by Leah and Cullen's presentation, which will feature a case study of 2 adults with CHARGE whom are currently supported by CDBA Ontario through Adult Intervenor Services. CDBA Ontario's vision is that all people who are deafblind will live rich meaningful lives.

Interveners Make a Difference

Overview and Real Life Examples

Beth Kennedy
Leah Cameron
Drew Cullen

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

References

- National Center on Deaf-Blindness. (2013). Intervener services and interveners in educational settings. Retrieved from https://nationaldb.org/library/page/2266.
- National Resource Center for Paraeducators. (n.d.). National Intervener Credential. Retrieved October 11, 2016, from http://www.nrcpara.org/intervener.
- Watkins, S., Clark, T., Strong, C., & Barringer, D. (1994). The effectiveness of and intervener model of services for young deafblind children. *American Annals of the Deaf*, *139*(4), 404-409.

A Day in the Life of Jason and Nicholas

Meet Jason Hotte

He has been with CDBA Ontario since 2003

I.A.M Jason Hotte

Appreciations

- Patience
- Clear communication
- Flexible and adaptable
- Handshakes
- Space and independence

How Best to Support Me

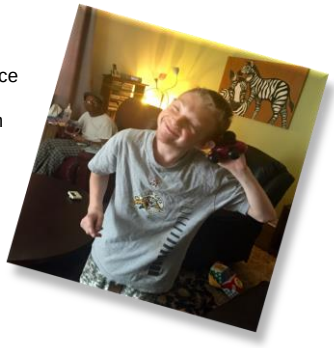
- Learn my language
- Proper sighted guide technique
- Give me choices
- Give me space to reflect

What Makes me Happy

- Visiting family – cottage
- Fishing
- Movies
- Historical deceased people
- The Simpsons
- Numbers on computer
- Friends
- Pudding
- Animals
- My calendar
- History

Meet Nicholas Fice

He has been with CDBA Ontario since 2016



I.A.M Nicholas Fice

Appreciations

- Physical contact when he initiates it
- Repeating information and signing slowly
- Positive feedback and attention
- Patience

How Best to Support Me

- Give me time to process information
- Communication in adapted ASL
- Positive reinforcement
- Approach me with a relaxed energy
- Use clear and precise communication
- Assist me in making independent choices: Do with me, not for me

What Makes me Happy

- Dogs
- Going for walks outside
- Spinning
- Playing musical instruments
- Vibrating handheld toys
- Attention
- Socks
- Visiting my family
- Colouring

CDBA Ontario's Apartment Complex

What

- It's About Me profile – snapshot of the individual
- Art of My Life – a visual/tactile representation of what's important to that person
- Individual goals – based on a person's needs, wants and dreams
- Everyday Life – incorporating goals into daily life

Why

- Improved quality of life
- Independence
- Empowerment & excitement
- Sense of achievement
- Enhanced community involvement

When

- Process begins with intake
- Goals reviewed every 3 months at minimum
- It's About Me reviewed annually

How

- Development of plan led by individual, families and Intervenor Services Coordinator

Who

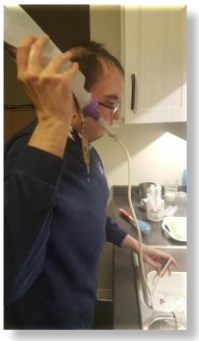
- Individual who is deafblind
- Family
- Friends
- Intervenor services team
- Significant others

It's My Life Planning Process

Jason's SMART Goal

What is your goal in one sentence?
- Jason will clean his food bag independently after his last meal of the day.

The benefits of achieving this goal will be…
- Improve daily living skills, increased responsibility and independence.



Specific
- What exactly will you accomplish?
  - A clean food bag.

Measurable
- How will you (and others) know when you have reached your goal?
  - When Jason cleans his food bag independently for a month.

Attainable
- Is attaining this goal realistic with effort and commitment? Do you have the resources to achieve this goal? If not, how will you get them?
  - Yes.

Relevant
- Why is this goal important to you? Hone in on why it matters
  - Health and independence.

Time-bound
- When will you achieve this goal?
  - 3 months.

Nicholas' SMART Goal

What is your goal in one sentence?
- To complete a load of laundry

The benefits of achieving this goal will be…
- Promote independence and life skills

Specific

- What exactly will you accomplish?
  - A clean load of laundry.

Measurable

- How will you (and others) know when you have reached your goal?
  - When Nicholas is able to put a load of laundry into the washing machine.

Attainable

- Is attaining this goal realistic with effort and commitment? Do you have the resources to achieve this goal? If not, how will you get them?
  - This goal is attainable with consistency and commitment. We have the resources and materials to achieve this goal.

Relevant

- Why is this goal important to you? Hone in on why it matters
  - This goal is promoting independence and teaching Nicholas a life skill.

Time-bound

- When will you achieve this goal?
  - September 2016.

Jason taking money out of the bank during the day and Line Dancing at night

Nicholas supply shopping during the day and Line Dancing at night

Saturday, July 29, 2017

Breakout Session #5: 10:45-11:45am

Panzacola H-3/H-4

Teaching Strategies: Building Bridges Between Home and School

Sharon Stelzer, M.Ed.

Presenter Information

Sharon Stelzer has been teaching students who are Deafblind and with CHARGE Syndrome for over thirty years at Perkins School for the Blind. Sharon has worked with students from the ages of six to twenty-one years old. She loves brainstorming and working with parents and other teachers/professionals in the areas of teaching strategies, communication strategies, literacy development and functional academics. Sharon has worked both nationally and internationally with professionals and families sharing ideas and techniques.

Presentation Abstract

For this presentation the presenter will share teaching strategies that work for children with CHARGE Syndrome. She will present how these strategies are used in school. With input from families of children with CHARGE Syndrome Sharon will link strategies that work at home to strategies that educators use in the classroom. She will discuss the importance of using similar vocabulary in the IEP process and methods to share strategies with the school team.

Saturday, July 29, 2017

Breakout Session #6: 1:00-2:00pm

Panzacola F-1/F-2

Personal Reflections on Transition Supporters in Baseball Parody Format: Take Me Out to The Ballgame

Christopher Sence, BFA
L. Kathleen Sheriff, Ed.D.

Presenter Information

Chris Sence is a 35-year-old man born with CHARGE syndrome. He has his Bachelor of Fine Arts degree from Sam Houston State University in Texas with a major in technical theatre. Mr. Sence is active in the Texas Chargers, volunteers at the Texas School for the Blind, and is an advisory board member for the Helen Keller National Center in New York. He is an avid baseball fan and had the opportunity to work as a baseball team manager in high school and in summer leagues leading to his love of the game. He dreams of watching a baseball game played in every major baseball stadium in the United States.

L. Kathleen Sheriff is the mother of Chris Sence and is a professional special educator. Her doctorate is in Special Education from Texas Tech University with certification in Dual Sensory Impairment. She has taught thousands of children in special education classrooms and currently is on the faculty at Stephen F Austin State University in Texas training pre-service special education teachers.

Presentation Abstract

Chris Sence, a 35-year-old man born with CHARGE syndrome, reflects on his personal transition support system in parody format emphasizing teaming together as a baseball team program to ultimately win at the game of life. He and his mother, Dr. Kathleen Sheriff, share his story of transition supporters matched with baseball program positions from little league to adulthood regarding the choices of majoring on the majors in life. Chris hopes this personal reflection adds to the lives of younger children with CHARGE syndrome and their supporting parents and transition teams.

Saturday, July 29, 2017

Breakout Session #5-7:
10:45-11:45am, 1:00-2:00pm, 2:15-3:15pm

Panzacola F-3/F-4

Adult Track

Kasee Stratton, Ph.D., NCSP, Daniel Gadke, Ph.D., NCSP, BCBA, and R. Matthew Coward, MD, FACS

Presenter Information

Dr. Kasee Stratton and Dr. Daniel Gakde are assistant professors of School Psychology at Mississippi State University. Both are also licensed psychologists and nationally certified school psychologists. Drs. Stratton and Gadke completed their doctoral internship and postdoctoral fellowship at Johns Hopkins School of Medicine and the Kennedy Krieger Institute. They specialize in treating challenging behavior and improving adaptive skills for children with developmental disabilities. Dr. Stratton has worked with individuals for CHARGE for over 12 years and Dr. Gadke primarily teaches behavioral assessment and intervention courses.

R. Matthew Coward, MD FACS is an Assistant Professor of Urology and Clinical Assistant Professor of Obstetrics and Gynecology at the UNC School of Medicine, and Director of Male Reproductive Medicine and Surgery at UNC Fertility in Raleigh, NC. He earned his MD with Distinction at UNC, followed by urology residency at UNC, and fellowship in Male Reproductive Medicine and Surgery at Baylor. Dr. Coward's clinical practice focuses in the areas of male reproduction and fertility as well as male sexual dysfunction. Dr. Coward's second of three children, Ryan, is a 4-year-old who has CHARGE syndrome.

Presentation Abstract

This three-session track will provide a series of presentations, discussions, and question and answer formats ***for adults with CHARGE syndrome ages 16+ only***. Sessions will include topics such as sex, sexual dysfunction, sustaining friendships, guidance on drinking, social media skills, advocating on the job and in the community, and question and answer time periods.

Saturday, July 29, 2017

Breakout Session #6: 1:00-2:00pm
Panzacola G-1

CHARGE Syndrome and Behavior: Diagnoses and Intervention (Part II)

Tim Hartshorne, David Brown, Megan Schmittel, Shanti Madhavan-Brown, Shelby Muhn

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.

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.

Presentation Abstract

Part two: Interventions for challenging behavior. This session describes interventions that can help to reduce the behaviors that often lead to psychiatric diagnoses. These interventions follow the principle that the behaviors are functional for the child given their various impairments. The interventions address issues of pain, sensory processing, and anxiety.

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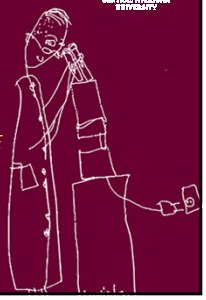
So what the h_ll are we supposed to do?

Coping with the behavior of people with CHARGE

Tim Hartshorne, David Brown, Megan Schmittel and Shanti Brown



One way of sorting and categorizing varied behaviors would be to list them in increasing order of urgency for intervention in the form of the following questions:

1.Is this a behavior that just bugs you personally, so that it can be accepted and ignored?
2.Is this a behavior that seems to help the child to function in a positive way, so that it can be accepted and ignored?
3.Is this a behavior that seems to help the child to function in a positive way, but should be reduced, or replaced by another, better behavior over time?
4.Is this a behavior that is undesirable and needs to be reduced or replaced fairly quickly?
5.Is this a behavior that needs to be prevented immediately?

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Jane bangs her head against the side of the bathtub while taking a bath.
Alan flaps his arms and hands wildly when he is excited.
Megan sticks her hands in her food at some meals.
Bill refuses to get out of bed some mornings, but will just lie there and laugh.
April will sometimes press her fingers into her eyes.
John wants to pull the fire alarm whenever he sees one.
Amber interrupts the class with noisy outbursts.
Tim will drop to the ground sometimes when out on walks or excursions.
Hayley will often make clucking noises that go on and on.
Jason often rocks his body while sitting at the table.
Emily pushes people when they are in her way.
Trevor will sometimes hit and scratch people who are near him.
Heather will bite her fingers until they bleed.
Jared repeatedly checks where his cup and plate are at meals.
Nancy likes to hang upside down on her chair or couch.
TJ will put his hands behind him and grab feces and smear it over his face.
Toni likes to throw her toys after she has played with them.
Ray likes to look at lights and will hold a light close to his eyes.
Jacob will play with people's shows and likes to lick the bottoms of them.
Lauren will have a temper tantrum if anything in her schedule changes.

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Interventions

- Always consider pain first!
- Figure out why
- Co-regulation – what do you do to stay basically in control?
- Yoga or Tai Chi
- Sensory breaks
- Calendar systems
- Social stories
- Experience books
- Respect communication
- Managing transitions
- Adapt the environment

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PAIN?

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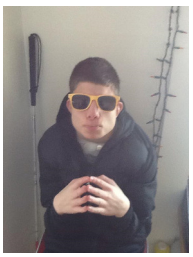
Understand behavior first



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This is normal viewing posture…

…when you have no vestibular sense, upper visual field loss, poor tactile & proprioceptive perception, & low muscle tone.

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Co-Regulation

What works for you in managing

- Your thoughts and motivation
- Your feelings and emotions
- Your actions and behaviors
- Your physical state

How do we teach this to our children who do not learn passively?

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Supporting self-regulation

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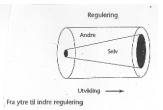
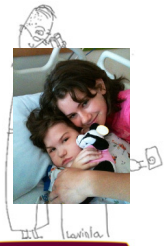
- Because self-regulation skills are hard for children with significant disabilities to develop
- We provide the external support for what will become an internal self-regulatory process





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Fun Chi

Reduced stress
Reduced anxiety
Reduced depression
Increased self-esteem
Increased energy/focus/concentration
Increased positive mood
Better balance
Improved sleep
Improved immune system

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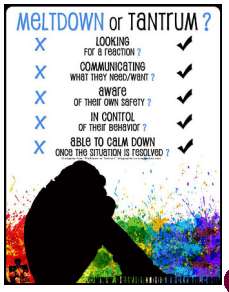
Sensory breaks



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Calendar systems

- Anxiety due to a lack of predictability
- Utilize an informed calendar intervention
- Increase self-regulation and predictability
- Reduce anxiety and anxiety related behaviors

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Social Stories

Short, simple, to the point, easy to make, personalized

Conveys social situation and explains how someone would react or what to do

Repetition makes the message stronger

Can help teach a lesson visually

Potty training, sharing, handling anger, change in routine, etc.

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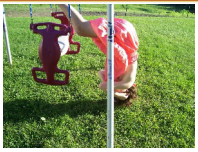
Respect communication



Communication vs. compliance: Jessica

Jessica will only sit in her chair for about 10 minutes at school before she wants to get down.

When she is told that she must stay in her chair longer she tantrums and has a meltdown.

One day she scratched her intervener and then flung herself from the chair and ran to a corner of the room where she lay down on the floor.

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Jacob and the bath

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Managing Transitions

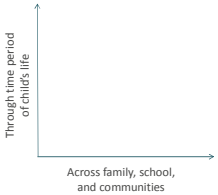
"Goal of a successful transition process is the child's success in the next environment." (Rouse, Hallam, Harbin, McCormick, & Jung, 2007)

Types of Transitions

Between daily activities

Life events

Changes in setting



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Managing Transitions

- Visual and auditory cues
- Visual and tactile daily and weekly schedules
- Explicit teaching on procedure for transitions
- Extra time for processing directions
- Reminders
- Social Stories
- Calendar systems
- Visit and explore new settings

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We know that external factors in the environment can have a profound impact on a child's behavior, so one way we can modify what the child is doing is to change features of the environment.

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Key Elements in Environment

- People
- Time
- Space

Tony Best (1998, July) Structuring the Environment. *Dbl Review*, 4-9

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People

- Limited in number
- Available
- Responsive
- Not overburdened with non-child tasks
- Consistent
- Engaged
- Skilled observers
- Familiar
- Identifiable (personal markers)

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Time

- Sequences
- Consistency
- Number
- Calendars/ schedules
- Survey past, and anticipate & plan future
- Repetitions (with concrete markers)
- Adapted timepieces

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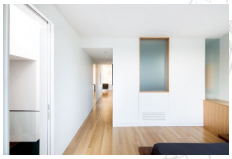
Space/Place

- Markers to identify areas by use/function
- Accessible
- Consistent
- Responsive
- Uncluttered
- Routes
- Landmarks



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Remember that a child's behaviors can indicate what is wrong/missing from their environment, and can also sometimes point you towards the solution to the problem.

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Minimize tactile distractions

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Provide the necessary physical supports for postural security

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Utilize and allow the most effective postures for attention and comfort

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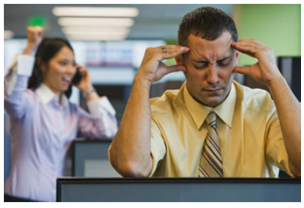
Minimize ALL distractions!



CHARGE Research Lab

Keep smell & taste inputs pure and separate

CHARGE Research Lab

Position and support for optimum attention, comfort, and functioning

CHARGE Research Lab

Managing the environment to prevent behavior problems

Consider what you could do to make the environment of your child safe and secure to enable their optimal development, and to avoid challenging behaviors

- Familiar – how could you create an environment that feels safe and secure to the child?
- Regular – how could you create an environment that is predictable to the child?
- Responsive – how could you create an environment that anticipates and responds to the behavior of the child?
- Meets basic needs – how could you create an environment that anticipates and responds to the needs of the child?

For each question, consider the impact of people, time, and space, and sensory impairment.

CHARGE Research Lab

Resources

- Barrey-Grassick. S. (2011).Sign Chi: signing a way to relaxation and stress reduction. *DeafBlind International 47, 11-13.*
- Tony Best (1998, July) Structuring the Environment. DbI Review, 4-9
- Calendars: For Students With Multiple Impairments Including Deafblindness -- Blaha, Robbie. Austin: Texas School for the Blind and Visually Impaired. (2001)
- Lewis, S., & Tolla, J. (2003). Creating and using tactile experience books for young children with visual impairments. *Teaching Exceptional Children*, vol. 35, No. 3, pp. 22-28, Jan/Feb 2003
- Hartshorne, T. S. (2003). Positive behavioral supports and social relationships. *Deafblind International Review.* July-December, Number 32, 4-6.
- Ramirez, M. A., Hartshorne, T. S., & Nicholas, J. (2014, January). Self-regulation in individuals with CHARGE syndrome. *DbI Review, 52,* 43-47.

CHARGE Research Lab

Saturday, July 29, 2017

Breakout Session #6: 1:00-2:00pm

Panzacola G-2

Quality Adapted Physical Education and Recreation for Individuals with CHARGE Syndrome

Dr. Elizabeth (Beth) Foster, CAPE

Presenter Information

Dr. Beth Foster is a Certified Adapted Physical Educator. She worked as an Elementary Adapted Physical Educator in Pennsylvania for 6 years then was an APE consultant in Texas for 4 years. During her time teaching in Pennsylvania, Beth was named the 2012 adapted physical education teacher of the year. Beth has been involved in Camp Abilities, a developmental sports camp for individuals who are blind, visually impaired, or deafblind for the past 12 years. She is currently the assistant director for Camp Abilities in Pennsylvania and Texas. From her experience at Camp Abilities, she developed a passion and determination to be knowledgeable within the field of deafblindness. Beth has presented on various topics about deafblindness across the U.S. She completed intervener training at the Minnesota Deafblind Project. Beth has been involved with the Texas Chargers for the past 3 years providing physical activities for individuals with CHARGE Syndrome at their annual retreat and has directed the Camp Abilities at the past two International CHARGE Conferences. Beth received her PhD in May 2016 by completing research related to children with CHARGE Syndrome and walking. Currently Dr. Foster is an assistant professor at Cal Poly Pomona in California in adapted physical education.

Presentation Abstract

Many individuals with CHARGE Syndrome do not have the same movement opportunities in their schools and in their communities. Come to this session to learn about the federal laws and advocacy skills to obtain a quality physical education or an adapted physical education program for your child at their school. Learn about the motor assessment process and proper Individual Education Programs (IEPs) related to movement and motor skills. Participants will also leave with valuable information to assist in the inclusion of their child in recreation activities within their community.

Saturday, July 29, 2017

Breakout Session #6: 1:00-2:00pm

Panzacola H-3/H-4

Taking CHARGE of Your Gastrointestinal Issues

Dr. Kim Blake, Alexandra Hudson

Presenter Information

Dr. Kim Blake has researched CHARGE Syndrome for 30 years, with over 100 publications: including; post-operative airway events, sleep apnea, bone health, cranial nerve anomalies; gastrointestinal and feeding disorders. Recently her clinical understanding of CHARGE Syndrome has given her the ability to ask research questions that can be investigated with a Zebra Fish model. Dr. Blake's goal is to understand more about the cranial nerves associated with CHARGE Syndrome with respect to gastrointestinal and feeding issues. Dr. Blake has taught thousands of students and residents about CHARGE Syndrome and is involved in active research mentoring.

Presentation Abstract

Gastrointestinal (GI) symptoms and feeding difficulties are highly prevalent but are often a neglected area of diagnosis, treatment and research. In this presentation a young adult will report on her ongoing story with gastrointestinal problems, we will review what is known in the literature and treatment options; some of which have been gathered from you as parents, and from individuals with CHARGE syndrome.

Gastrointestinal (GI) and Feeding Issues in CHARGE Syndrome

Dr. Kim Blake, Professor Pediatrics
IWK Health Centre and Dalhousie University
kblake@dal.ca

Alexandra Hudson & MacKenzie Colp

Guess the Birds Names

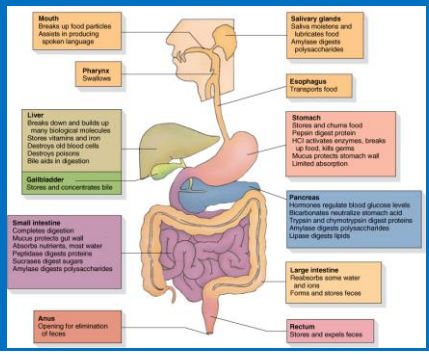
Objectives

After this presentation, you will have a greater understanding of:

1. A young adults struggle with gastrointestinal (GI) symptoms and eating challenges.
2. The breadth of gastrointestinal (GI) issues in CHARGE syndrome.
3. A new feeding scale for CHARGE syndrome.

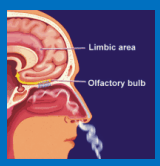
MacKenzie's Story

What We Know



Sense of Smell

- Olfactory bulb absence or hypoplasia has been reported as high as 100% in CHARGE syndrome.
- Reduced or complete absence of sense of smell.



https://www.sense.org.uk/sites/default/files/Puberty_and_smell_in_CHARGE.pdf

Craniofacial Abnormalities

- Cleft palate/lip can interfere with feeding, particularly in infancy
- Children with choanal atresia/stenosis have significantly more GI symptoms than those without this feature

Macdonald M, Hudson A, Ratcliffe E, Bladon A, Blake K. Experiences with feeding and gastrointestinal motility in children with CHARGE syndrome. 12th international CHARGE syndrome conference proceedings. 2016. AJMG.

Salivation

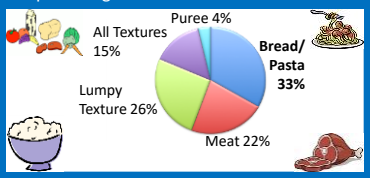
- Excessive salivation and secretions can be a problem
- Treatment options:
  - Botox injection into salivary gland every 3-5 months
  - Combine surgeries together if possible to reduce intra-operative risks (have to suction airway for excess saliva)
- Thin liquids can be a problem too

FIG. 1. Botox injections into the submandibular gland using ultrasound guidance.

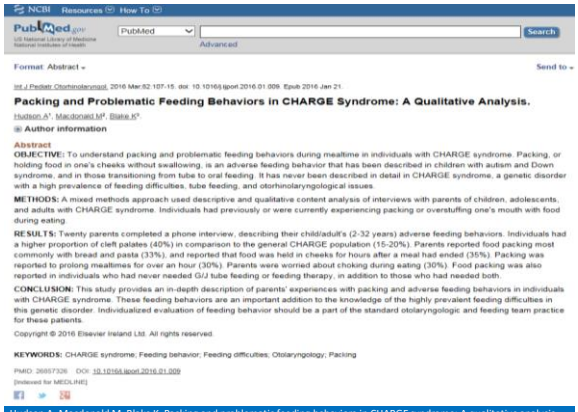
Mouth overstuffing and pocketing food into cheeks

- Can prolong mealtime for > 1 hour
- Parents are concerned about choking

Types of food pocketing occurs with:



Hudson A, Macdonald M, Blake K. Packing and problematic feeding behaviors in CHARGE syndrome: A qualitative analysis. AJMG. 2016



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Int J Pediatr Otorhinolaryngol. 2016 Mar;82:107-15. doi: 10.1016/j.ijporl.2016.01.009. Epub 2016 Jan 21.

Packing and Problematic Feeding Behaviors in CHARGE Syndrome: A Qualitative Analysis.

Hudson A[1], Macdonald M[2], Blake K[3].

Author information

Abstract

OBJECTIVE: To understand packing and problematic feeding behaviors during mealtime in individuals with CHARGE syndrome. Packing, or holding food in one's cheeks without swallowing, is an adverse feeding behavior that has been described in children with autism and Down syndrome, and in those transitioning from tube to oral feeding. It has never been described in detail in CHARGE syndrome, a genetic disorder with a high prevalence of feeding difficulties, tube feeding, and otorhinolaryngological issues.

METHODS: A mixed methods approach used descriptive and qualitative content analysis of interviews with parents of children, adolescents, and adults with CHARGE syndrome. Individuals had previously or were currently experiencing packing or overstuffing one's mouth with food during eating.

RESULTS: Twenty parents completed a phone interview, describing their child/adult's (2-32 years) adverse feeding behaviors. Individuals had a higher proportion of cleft palates (40%) in comparison to the general CHARGE population (15-20%). Parents reported food packing most commonly with bread and pasta (33%), and reported that food was held in cheeks for hours after a meal had ended (35%). Packing was reported to prolong mealtimes for over an hour (30%). Parents were worried about choking during eating (30%). Food packing was also reported in individuals who had never needed G/J tube feeding or feeding therapy, in addition to those who had needed both.

CONCLUSION: This study provides an in-depth description of parents' experiences with packing and adverse feeding behaviors in individuals with CHARGE syndrome. These feeding behaviors are an important addition to the knowledge of the highly prevalent feeding difficulties in this genetic disorder. Individualized evaluation of feeding behavior should be a part of the standard otolaryngologic and feeding team practice for these patients.

KEYWORDS: CHARGE syndrome; Feeding behavior; Feeding difficulties; Otolaryngology; Packing

PMID: 26857326 DOI: 10.1016/j.ijporl.2016.01.009

[Indexed for MEDLINE]

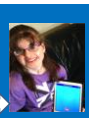
Hudson A, Macdonald M, Blake K. Packing and problematic feeding behaviors in CHARGE syndrome: A qualitative analysis. AJMG. 2016

Feeding Behaviours Identified from the Study

- Would not mix liquids and solid food
- Have to finish all food and have an empty plate
- Same routine needed at each mealtime
- Anger if food taken away in order to prevent pocketing/overstuffing

Hudson A, Macdonald M, Blake K. Packing and problematic feeding behaviors in CHARGE syndrome: A qualitative analysis. AJMG. 2016

Top 5 Parents' Tips & Tricks



An iPad timer that reminds to swallow ever 30 seconds

Intervention theme	Specific examples
Verbal prompts during eating	• Have a gestural prompt or cue (i.e., touch his hand) when starts over-stuffing • Tell or sign to chew and eat before give more food
Soft foods	• Cook to a soft consistency • Soft diet • Blending and pureeing the food • Give textures that they can handle easily
Include in the family dinner	• Sit at the dinner table with everyone • Eat similar foods as the family
Close supervision	• Be present during feeding • Have an occupational therapist watch him/her eat once a month
Distractions	• Use an iPad to distract while eating • Watch a favorite TV show during eating • Use favorite foods as incentives• Create a calm environment

Cranial Nerves

These guys direct the traffic & run the show

Name	What It Does
I Olfactory	Smell
II, III, IV, VI	Eye control
V Trigeminal	Chewing, sensory for facial regions; sensations in the sinuses, the palate and the upper lip, the jaw, mouth and tongue.
VII Facial	Facial movements, taste, salivation
IX Glossopharyngeal	Taste, salivation, swallow; some visceral
X Vagus	Phonation, swallow; important visceral
XI Spinal Accessory	Moves head & shoulders; laryngeal muscles
XII Hypoglossal	Movement of the tongue

11th International CHARGE Conference Kate Beals & Kim Blake

Experience with Feeding and Gastrointestinal Motility in Children with CHARGE Syndrome

Meghan & Kim at the Research in Medicine (RIM) Presentations at Dalhousie University 2015

Questionnaires

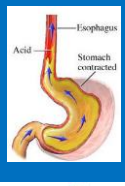
- Structural abnormalities
- Motor impairment
- Oral sensory impairment
- Delayed oral feeding
- Reflux
- Bloating
- constipation

Questionnaires + Short Answer Questions

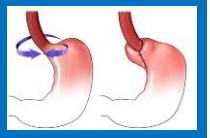
- Questionnaires include:
  - Demographic and CHARGE characteristics
  - Pediatric Assessment Scale for Severe Feeding Problems ©IWK
  - PedsQL™ Gastrointestinal Symptoms Scale
- Short Answer Question Topics:
  - Reflux and vomiting
  - Bloating
  - Constipation
  - Transition from tube feeding to oral feeding
  - Three major feeding/motility challenges

Treatments for Gastroesophageal Reflux (GER)

1. Behavioral treatment – raising the bed, small frequent meals, limiting foods that promote reflux such as tomatoes, meat, chocolate.



1. Medical management
   - Ranitidine 8mg/kg per day in 2-3 divided doses (for babies 3-4 divided doses)
   - Prevacid (lansoprazole)- 1-2 mg/kg per day at the beginning of the day (occasionally twice a day)
   - Domperidone (Motilium) – 4 times a day before meals (watch for side effects)
   - Cisapride (Propulsid) special authorization



Also consider cow's milk protein intolerance

Tube Feeding

- Over 90% need tube feeding (gastrostomy or jejunostomy)
- Tube feeders vs. oral feeders
  - More stomach pain
  - More stomach discomfort when eating
  - More food and drink limits
  - More trouble swallowing
  - More nausea and vomiting
  - More constipation

Macdonald M, Hudson A, Ratcliffe E, Bladon A, Blake K. Experiences with feeding and gastrointestinal motility in children with CHARGE syndrome. AJMG. 2016

Abdominal Pain

- Reflux
- Bloating
- Difficulty with digestion
- Abdominal migraine
- Constipation
- Non organic

Constipation – Big Issue

How are you dealing with it?

Prevention / Treatment for Constipation

Prevention:

- Fluids
- Exercise
- Behavioural therapy
- Diet
- Massage

Treatment:

- Polyethylene glycol / MiraLAX
- PEG
- Senocot
- Behavioural techniques

NCBI Resources How To

PubMed.gov US National Library of Medicine National Institutes of Health

PubMed | for poor bone health in adolescents and adults with CHARGE syndrom | Search

Create RSS Create alert Advanced

Format: Abstract Send to

Am J Med Genet A. 2007 Apr 15;143A(8):839-45.

Risk factors for poor bone health in adolescents and adults with CHARGE syndrome.

Forward KE, Cummings EA, Blake KD.

Author information

Abstract

CHARGE syndrome, is associated with genital hypoplasia, feeding difficulties and delayed puberty. In this study we examined the prevalence of risk factors for poor bone health in adolescents and adults with CHARGE. Questionnaires assessing fracture history, dietary intake of calcium and vitamin D, pubertal status and activity level using the Habitual Activity Estimation Scale (HAES) were completed by caregivers. Control data were collected for the HAES. When available, reports from dual-energy X-ray absorptiometry (DEXA) were obtained. Thirty individuals with CHARGE syndrome (n = 15 males; n = 15 females; age range 13 to 34 years; mean age 19.6 years) were recruited. Traumatic bony fractures were identified in 30% of the population. The recommended nutritional intake (RNI) for calcium and vitamin D were not met by 41% and 87% of the population, respectively, and 53% required past tube feeding. Delayed puberty was experienced by 87% with only 4 individuals (2 female, 2 males) having experienced normal puberty. Hormone replacement therapy (HRT) was taken by 33% of females and 60% of males. According to the HAES, adolescents with CHARGE syndrome (13-18 years) were significantly less active than controls. Individuals with CHARGE syndrome age 19 and older were also less active than controls, although this difference was not significant. DEXA scan data was obtained, however, due to small sample size (n = 10) and confounding variables (i.e., short stature, pubertal stage, height, weight), it was difficult to draw meaningful conclusions. Feeding difficulties, inactivity and hypogonadism are predisposing factors for the development of poor bone health among individuals with CHARGE syndrome. Education is necessary to raise awareness regarding the importance of HRT, proper nutrition and weight-bearing activity for healthy bone development and maintenance in individuals with CHARGE syndrome.

PMID: 17366585 DOI: 10.1002/ajmg.a.31679

[Indexed for MEDLINE]

Forward K, Cummings E, Blake K. Risk factors for poor bone health in adolescents and adults with CHARGE syndrome. AJMG. 2007

Bone Health

- 87% of individuals are not getting enough vitamin D
- 41% not getting enough calcium

- Treatment
  - Encourage intake of vitamin-D rich foods
  - Supplementation of 1000 IU Vit D

Forward K, Cummings E, Blake K. Risk factors for poor bone health in adolescents and adults with CHARGE syndrome. AJMG. 2007

Physical Activity

- CHARGE individuals have decreased activity compared to other teenagers, especially on weekends
- Weight-bearing exercises are important to increase:
  - Bone mineral density
  - Prevent osteoporosis
  - Help maintain normal weight

Forward K, Cummings E, Blake K. Risk factors for poor bone health in adolescents and adults with CHARGE syndrome. AJMG. 2007

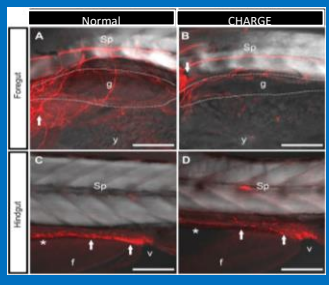
Adolescents and Adults

- Feeding difficulties found in 90% of adolescents and adults with CHARGE syndrome in Canada
- New issues that can arise after childhood
  - Abdominal colic
  - Pocketing/overstuffing
  - Gallstones

Modeling CHARGE Syndrome in Zebrafish: A Look at the Innervation and Function of the Gastrointestinal System

Kellie Cloney presenting at the Dalhousie Research in Medicine (RIM) 2015. Award for Outstanding Platform Presentation.

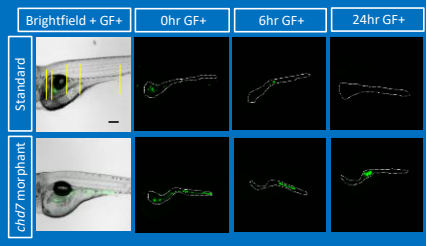
Innervation of the Gut



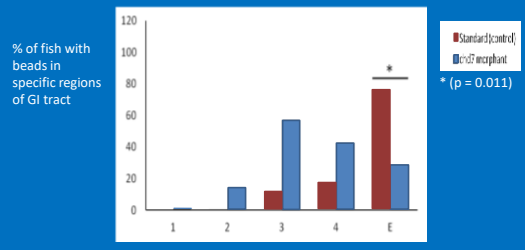
Using immunohistochemistry, we highlighted the enteric nervous system. Here we show that there was a decrease in the amount of enteric nerve branches around the foregut. Also, the gut is outlined in photos A and B – and you can appreciate that there is a difference in the morphology (size and shape) of the gut in the CHARGE fish as well.

Sp = spine, F = ventral fin, V = vent, G = gut (outlined in hashed line), arrow = vagal nerve plexus, y = yolk

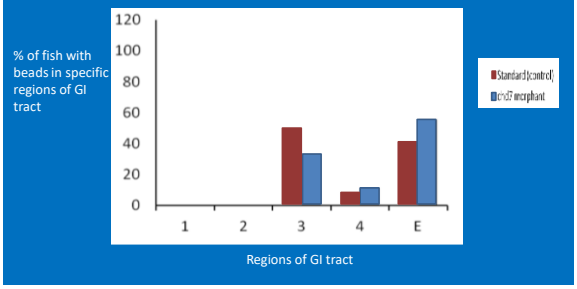
Decreased motility shown in CHARGE zebrafish by delayed emptying of GI tract



Significant difference in number of fish with empty gut at 24 hours when comparing CHARGE fish to normal zebrafish



Erythromycin corrects motility deficit in CHARGE zebrafish



"Hot off the press!"
A new feeding scale for CHARGE syndrome

Subsection of Feeding Scale

Circle one number on the scale:		Never	A Little	Sometimes	A lot	Always
16	He/she has difficulty moving food around with his/her tongue during eating.	0	1	2	3	4
17	He/she has a hard time feeling food or anything touching the inside of his/her mouth.	0	1	2	3	4
18	He/she dislikes oral eating.	0	1	2	3	4
19	He/she lets food sit in his/her **cheeks or palate** during eating (on purpose or not).	0	1	2	3	4
20	He/she will have food hidden in his/her **cheeks or palate** after the meal has ended (on purpose or not).	0	1	2	3	4

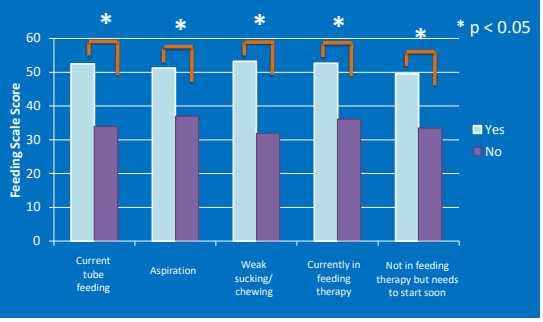
Scoring of feeding scale for CHARGE syndrome

29	Soft chewable foods (e.g. bread, crackers)	0	2
30	Tough chewable foods (e.g. meat)	0	1
31	Hard vegetables and fruit (e.g. raw apples)	0	1
	Total Score (sum of all items)		/100 total points

Out of 100 points

Higher score = worse feeding difficulties

Individuals with feeding difficulties had worse feeding scale scores



Three uses for the feeding scale for CHARGE Syndrome

1. As a structured tool to assess the severity of feeding difficulties
2. To track oral feeding progress before and after interventions
3. To warn the clinician and feeding therapist of new concerns

*Learn more at Alexandra Hudson's poster at the poster session

*Print off copies of the feeding scale on the CHARGE syndrome website

Ongoing research for parents at this conference!

GI and feeding difficulties in CHARGE syndrome:
Treatments tried and parents' perceptions of their effectiveness

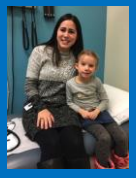
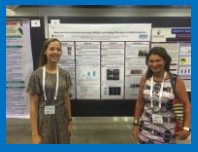
Visit us at the research booth!

IWK CHARGE Clinic Students & Residents Using the CHARGE Checklist





Questions and Answers



A new feeding scale for use in CHARGE syndrome: Potential for use in other genetic syndromes

Alexandra Hudson[1], Kasee Stratton[2], Jill Hatchette[3], Kim Blake[3,4]

[1]Dalhousie Medical School; [2]Mississippi State University; [3]IWK Health Centre; [4]Faculty of Medicine, Dalhousie University

Background

- CHARGE Syndrome is an autosomal dominant condition involving the *CHD7* gene on chromosome 8, affecting 1 in 15,000 live births.[1]

C: Coloboma of the eye
H: Heart defects
A: Atresia/stenosis of the choanae
R: Retardation of growth
G: Genitourinary abnormalities
E: Ear abnormalities and deafness.

Figure 2: Common 'cup' shaped outer ear.

Figure 1: Characteristic CHARGE facial features with facial palsy and square chin.

- Individuals experience a high prevalence of feeding difficulties, starting from birth.[1,2]
- Their feeding difficulties often differ from those of typically developing children, which may not be accurately captured using existing scales.[2]

Objective

To develop, and test the validity and reliability of, a user-friendly feeding scale for individuals with CHARGE syndrome of all ages.

Methods

Feeding scale questions were adapted from the Pediatric Assessment Scale for Severe Feeding Problems (PASSFP)[3] and the current literature

→ Experts on genetic syndromes, feeding therapy, and general pediatrics reviewed the new feeding questions

→ Ten parents of individuals with CHARGE syndrome (all ages) piloted the new scale

→ Parents of individuals with CHARGE syndrome were contacted via the official Facebook pages of each International CHARGE syndrome foundation

→ Interested parents were sent an online link to:
1. The new feeding scale (see figure below)
2. The PASSFP
3. General feeding questions

→ A subset of parents completed the new feeding scale again 2-4 weeks later

Date: _____
Name of Individual: _____
Age:_____ Gender (Circle one): Male Female Not Disclosed
Completed By (Circle one): Mother Father Feeding Therapist Nurse/Physician Other:_____

What percentage of your child/adult's daily fluid/nutrition intake is by GJ tube feeding? (Circle one percentage):

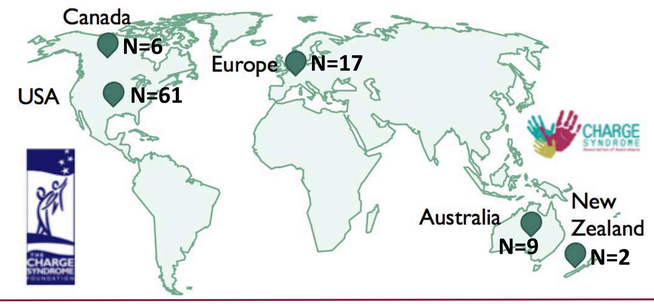
0%	25%	50%	75%	95%

Circle one number on the scale:		Never	A Little	Sometimes	A lot	Always
1	He/she will refuse food when eating orally.	0	1	2	3	4
2	He/she takes longer than 45 minutes to eat orally.	0	1	2	3	4
3	He/she takes less than 15 minutes to eat orally.	0	1	2	3	4
4	He/she needs **close supervision** when eating orally.	0	1	2	3	4
5	He/she needs **someone in the room** when eating orally.	0	1	2	3	4
6	He/she has problems cutting food when eating orally.	0	1	2	3	4
7	He/she has problems feeding him/herself when eating orally.	0	1	2	3	4
8	He/she chokes or coughs when eating orally.	0	1	2	3	4
9	He/she has **trouble** chewing food.	0	1	2	3	4
10	He/she has **trouble** swallowing food.	0	1	2	3	4
11	He/she has to be **told or reminded** to chew.	0	1	2	3	4
12	He/she has to be **told or reminded** to swallow.	0	1	2	3	4
13	He/she does not like to mix food textures when eating (e.g. mixing puree and solid food).	0	1	2	3	4
14	He/she accidentally loses food out of his/her mouth during eating.	0	1	2	3	4
15	He/she will over-stuff his/her mouth with food during eating.	0	1	2	3	4
16	He/she has difficulty moving food around with his/her tongue during eating.	0	1	2	3	4
17	He/she has a hard time fueling food or anything touching the inside of his/her mouth.	0	1	2	3	4
18	He/she dislikes oral eating.	0	1	2	3	4
19	He/she lets food sit in his/her **cheeks or palate** during eating (on purpose or not).	0	1	2	3	4
20	He/she will have food hidden in his/her **cheeks or palate** after the meal has ended (on purpose or not).	0	1	2	3	4
21	The **Parent/Caregiver** gets worried about their child/adult's ability to eat orally.	0	1	2	3	4
22	The **Parent/Caregiver** has difficulties feeding their child/adult. (e.g., preparing food the right way, getting enough information about helping them eat/drink)	0	1	2	3	4

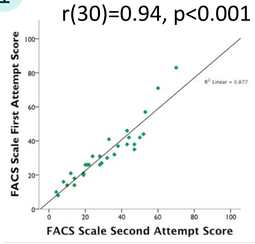
Does the child/adult have problems with:	No	Yes
23 Cold foods	0	1
24 Room temperature foods	0	1
25 Warm foods	0	1
26 Thin liquids (e.g. water)	0	1
27 Pureed foods (e.g. applesauce)	0	2
28 Mashed lumpy food (e.g. mashed potatoes or mashed vegetables)	0	2
29 Soft chewable foods (e.g. bread, crackers)	0	2
30 Tough chewable foods (e.g. meat)	0	1
31 Hard vegetables and fruit (e.g. raw apples)	0	1
Total Score (sum of all items)		/100 total points
Circle one:	**Feeding difficulties:** Mild (0-25 points) Moderate (26-50 points) Severe (51-100 points)	

Results

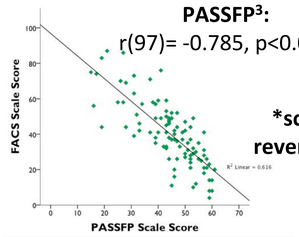
Participants: 100 parents of individuals with CHARGE syndrome (>1 year old) who ate at least 5% of their daily intake by mouth



1 **Test Re-Test Reliability:**
r(30)=0.94, p<0.001



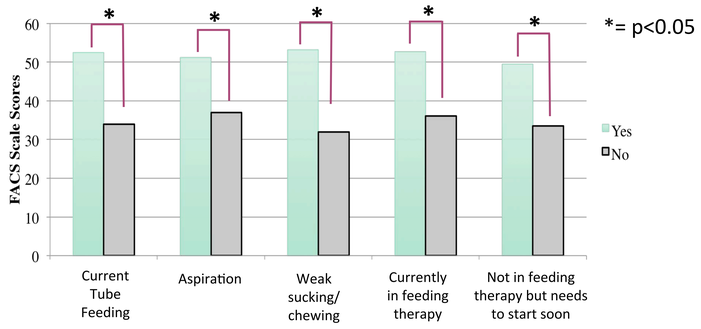
2 **Convergent Validity with the new feeding scale and the PASSFP[3]:**
r(97)= -0.785, p<0.001



***scales are reverse scored**

3 **Internal Validity**
Cronbach's alpha=0.909

Individuals with parent-reported feeding difficulties had significantly higher feeding scale scores



CHARGE syndrome characteristics associated with significantly worse feeding difficulties (higher feeding scale scores)

1. Cleft palate:
   - Mean feeding scale score 47 (SD 22) for those with vs. 38 (SD 16) for those without (p=0.03)
2. Cranial nerve IX, X, XI dysfunction (swallowing difficulties)
   - Mean feeding scale score 44 (SD 19) for those with vs. 29 (SD 14) for those without (p=0.002)

Conclusions

1. This new feeding scale is a valid and reliable tool in the CHARGE syndrome population.

2. The new feeding scale can be used:
   - ✓ As a structured tool to assess the current severity of feeding difficulties
   - ✓ To track oral feeding progress before and after feeding therapy, as well as over the entire lifespan
   - ✓ To alert to areas of concern requiring intervention

3. This feeding scale has the potential to be tested for validity and reliability in other genetic syndrome populations experiencing a high incidence of otolaryngological and feeding difficulties.

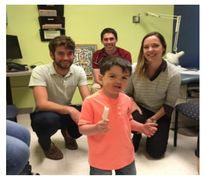


Figure 4: A young boy with CHARGE syndrome enjoying a popsicle snack.

Figure 3: From L to R (back): Alexandra , Kellie, Meghan. In front, Charley, a teenager with CHARGE syndrome from PEI, attending the 12th International CHARGE syndrome conference, Chicago, IL, 2015.

Easily added up to a score out of 100 points (higher scores = worse feeding difficulties)

29	Soft chewable foods (e.g. bread, crackers)	0	2
30	Tough chewable foods (e.g. meat)	0	1
31	Hard vegetables and fruit (e.g. raw apples)	0	1
	Total Score (sum of all items)		/100 total points
	Circle one:	**Feeding difficulties:** Mild (0-25 points) Moderate (26-50 points)	

Three categories of feeding difficulties:
1. **Mild (0-25)**
2. **Moderate (26-60)**
3. **Severe (51-100)**

References

1. Dobbelsteyn C, Peacocke SD, Blake KD, Crist W, Rashid M. (2008). Feeding difficulties in children with CHARGE syndrome: Prevalence, risk factors, and prognosis. *Dysphagia,* 23, 127-135.
2. Cooper-Brown, L, Copeland S, Dailey S, Downey D, Cesar Petersen M, Stimson C, Van Dyke DC. (2008). Feeding and swallowing dysfunction in genetic syndromes. *Developmental Disabilities*, 14, 147-157.
3. Crist W, Dobbelsteyn C, Brousseau AM, Napier-Phillips A. (2004). Pediatric assessment scale for severe feeding problems: Validity and reliability of a new scale for tube-fed children. *Nutrition in Clinical Practice,* 19, 403-408.

Acknowledgements

Thank you to Tracy Sainsbury for ongoing assistance and to the Dalhousie Medical School Research Foundation, Dalhousie medical research foundation music in medicine summer studentship, Murray McNeil Summer Studentship, Dalhousie Faculty of Medicine Webster Summer Studentship, and the International CHARGE Syndrome Foundation for funding.

Five Hints for new and seasoned Parents

Raising your child with CHARGE

Timothy S. Hartshorne

Communication, communication, communication

With oneself, with others, with the world

Communicate as you would with any other baby

- Facial expressions are important
- Cooing and laughing
- Motherese
- Touch
- Imagine being in a foreign country and not understanding the language

Learn the communication system that works best for your child

- Not the other way around
- Do not use just one system
- Feel free to combine communication approaches
  - Gestures and facial expressions
  - Oral
  - Sign
  - Picture

"My child has no communication"

- This is never the case.
  - All behavior has a purpose
  - All behavior is communication
- Once the child believes nobody is communicating, they will shut down
- Not all behavior is intentional communication – but it can be read
- Even if your child likes to withdraw, do not let them alone for too long

Routine

Find a routine as soon as possible

- Children with CHARGE thrive on routine and predictability
- A calendar system to communicate the schedule is essential
- While a certain amount of chaos is quite natural, particularly in some families, it will not be compatible for your child with CHARGE

Anxiety is related to uncertainty about what is going to happen next

- What will happen today?
- What do they want me to do?
- Where are we going?
- What will happen when we get there?
- Will I feel ***safe***?
- The world does not always make sense
- It can be unpredictable

We like to know what is going on.

- What are we doing right now?
- What are we going to do next?
- What did we just do?

When we are not sure…

- We become anxious
- We engage in behavior which expresses our feelings
- We engage in behavior or activities that help us feel more secure

Hitting mom

Supporting self-regulation

- Self-regulation allows us to organize and manage our thoughts, feelings, behavior, and body, so that we can manage our day and meet our goals
- Because self-regulation skills are hard for children with significant disabilities to develop
- We provide the external support for what will become an internal self-regulatory process
- A major component of this is routine

Discipline

"I can't say 'NO'."

No pass on discipline

- Because your child has CHARGE does not give them a break on learning to cooperate with family living.
- Behavior is communication

Jacob and the bath

Behavior also has consequences

- Natural consequences – if I did nothing what would happen
  - Doing nothing is surprisingly hard work for parents
    - Don't want to appear to be a bad parent
    - It can mean extra work
  - If you push your food off your plate, it falls to the floor and the dog eats it.
- Logical consequences – pre-established response
  - "Let the punishment fit the crime." Teaching cause and effect.
    - Must be related to the child's action
    - Must be revealed in advance
    - The child chooses the consequence
  - Splash in the tub and bath time is over

Destructive and Aggressive Behavior

- Consequences do not work very well
- First, stay calm
  - Of course it is not easy
  - But if you get aroused, it will increase the arousal of the child
- Know your child and their triggers
  - Changes in routine
  - Chaotic environment
  - Pain or illness
- Can the environment be modified to minimize risk?
- Watch out for responses to the child that increase the likelihood they will do this again

Getting Connected

Who understands what you are experiencing?

Get connected

- It is hard enough to raise a more typical child. For this one you need help.
- Join the CHARGE Syndrome Foundation
- Get together with other families who have a child with CHARGE
- Go to the conferences
- Join the Facebook pages
- Connect with parents of children with other disabilities
- Check out services for children who are deafblind

Acceptance and Advocacy

Acceptance and Advocacy

- Your child has CHARGE. It is tough on everyone. Move on.
- Learn to accept and love your child with no need for your child to be any different
- You are your child's primary and often sole advocate
- Your job is to fight like heck to make sure your child gets what he or she needs
- Find allies in the fight

TAMING THE WOLVES

AND THE PARENT FROM HELL

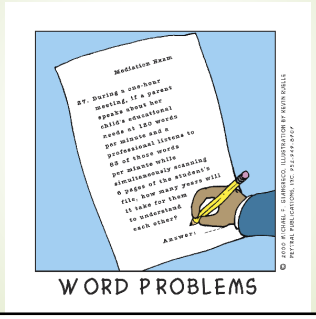
Diagnosis

DIAGNOSIS DU JOUR

Treatment

THE DISTRICT'S EXPERIMENTAL METHOD FOR DETERMINING RELATED SERVICES WORKS JUST AS WELL AS MAKING THOSE DECISIONS BEFORE KNOWING A STUDENT'S IEP GOALS AND OTHER LEARNING OUTCOMES.

Communication



Intimidation

Predictions

MARATHON SKILLS

Ann P. Turnbull

- Meet basic needs
- Know your self and your family
- Love unconditionally
- Establish relationships
- Experience and benefit from emotions
- Take charge
- Anticipate the future
- Establish balance

Saturday, July 29, 2017

Breakout Session #7: 2:15-3:15pm

Panzacola F-1/F-2

Incorporating Literacy into Daily Routines at School and at Home

Martha Veto and Christine Spratling, Ed.S.

Presenter Information

Martha Veto received her M.Ed from the University of Pittsburgh and worked as a teacher for the visually impaired/orientation and mobility specialist for 25 years before joining the South Carolina Interagency Deaf-Blind Project in 2005. She has worked as the GSAP Project Coordinator since moving to Georgia in 2008.

Christine is the Technical Assistance Specialist, Georgia Sensory Assistance Project.

Presentation Abstract

Children with combined vision and hearing loss have a hard time developing concepts about the world around them. Learning routines are an effective tool to help. In this session we will use materials from the Open Hands, Open Access (OHOA) learning modules to show the power of using routines to develop concepts, language and literacy skills. Participants will have an opportunity to use an OHOA tool for planning routines for individual students.

A Plan For My Routine Book

Who is it for? __Sidney_____

Age_13___ Vision: _blind Hearing: deaf (maybe some sounds, but minimal response to sound

Language development: tactile sign (<10 signs), object cues (<10)

What is the routine in which your book will be used? Daily hygiene routine

How will you use this book? What is its purpose? To build independence in moving from one step to another in a familiar routine (reduce physical prompts).

What concepts or skills are we working on with this routine book?

©Things happen in an order. I can do things for myself. Things are kept in a place where I can find them.

(S) get hygiene materials, turn on water, attempt to perform toothbrushing, face washing, deodorant, nails

How will the child participate in making this book?

Gather materials with teacher and help attach Velcro to symbols.

How will the child participate in reading and sharing this story?

Set up book by putting objects on each page at the beginning of the routine. Carry book to sink. Turn page when one step is over

What kinds of representational symbols will be used? (pictures, objects, textures, tactile symbols, sounds) Part of object used in the routine: piece of toothbrush, cap of deodorant, etc.

What kind of text will be used for this book? (braille, print, sound, sign language pictures, Spanish) Braille for her paired with tactile signs; pictures of signs and print for adults

College of Education
UNIVERSITY OF GEORGIA
Communication Sciences and Special Education
http://gsap.coe.uga.edu

GSAP Georgia Sensory Assistance Project
Supporting Children and Youth with Combined Vision and Hearing Loss

Communication Matrix Activity 1- What did we learn?

Student: Date: Who completed the form:

For the Matrix you just completed, respond to the following questions:

Which statement did you select for your child? (A, B, C or C symbols)

Briefly describe an example of the child's behavior that helped you choose that starting statement.

At what level (1-7) of communication do you feel this child is primarily functioning? 1 2 3 4 5 6 7

What leads to that conclusion? Describe the communicative forms and functions that point to that level.

What do you feel is the most important next step for this child in the development of expressive communication? What should be the focus of your intervention around communication? (e.g. develop intentional communication, initiate communication, use more conventional behaviors to communicate, begin using symbols, use more abstract symbols)

This activity was developed as a TA tool by the Georgia Sensory Assistance Project

Activity 2 - Choosing Goals

What do we know about the child's vision, hearing, and motor skills that could affect which communication modes at their Matrix level are appropriate to target? (visual or tactile sign/ pictures or tactual symbols/ point or eye gaze/movement of head or limbs)

What communication modes are most important to target now? (sign, speech, tangible symbols, use of device, gestures, body movement, facial expression, body tone) Note: children should have multiple modes available to them in different contexts and environments. The specific mode for each activity will be determined within each routine.

What messages are most important to target? (e.g., I want more ____, I don't like ____, I want (specific thing), labels, response to questions, comments, greetings)

Write 3 communication goals for the student: (X will touch a picture from 3 symbol array to request a toy, X will shake his head to indicate NO when asked a question, X will find and give me the object cue representing finished when he wants a break)

1.

2.

3.

Activity 3 - Embed goals into routines

Now think of some activities where you can practice these communication skills. Think about how you might alter the activity to build in opportunities for the student to have a communicative exchange, either with an adult or with a peer. (The Design to Learn Inventory is a great tool for this- www.designtolearn.com if you need help) Try to find 2-3 activities in the day to address each of your communication goals.

Activity	Communication goal(s) we can address	What will you do to create a communication opportunity in this step?

Develop a routine with steps that can be followed consistently. Think about the response you want the student to make (e.g.- speak, sign, touch a picture or object cue, use a device, gesture, smile, look toward….) and how you will let the student know it is his turn to do something without doing it hand-over-hand (e.g., verbal prompt, a signed prompt, an object or picture cue, or model the desired response). Finally, whether he responds correctly or incorrectly, what response will you make to confirm his response? (clap hands, "good job", sign "yes", / co-actively make the desired sign, reduce complexity of the array, model desired response and try again)

Activity:

Communication goals to address:

Step in the routine	What strategy or cue will you use to encourage / elicit the student's communicative behavior?	What specific communicative behavior do you want the student to exhibit?	How will you give the student specific feedback (praise or correction)?

Incorporating Literacy into Daily Routines at School and at Home- for Children with Multiple Disabilities

Christine Spratling & Martha Veto, Georgia Sensory Assistance Project

GSAP Georgia Sensory Assistance Project

An Expanded View of Literacy

Literacy is more than reading and writing.

- Literacy development is founded on experiences and concepts beginning very early in life
- Literacy instruction must include a strong emphasis on communication and socialization
- Literacy exists along a continuum from emergent to independent

http://literacy.nationaldb.org/index.php/welcome/

NCDB Literacy Website: http://literacy.nationaldb.org/index.php/welcome/

Social Functions of Literacy

Knowledge and/or information dissemination

Memory support/organization

Self-expression

Entering a fantasy world

Entertainment

Financial management

Instructions

Dealing with emotions

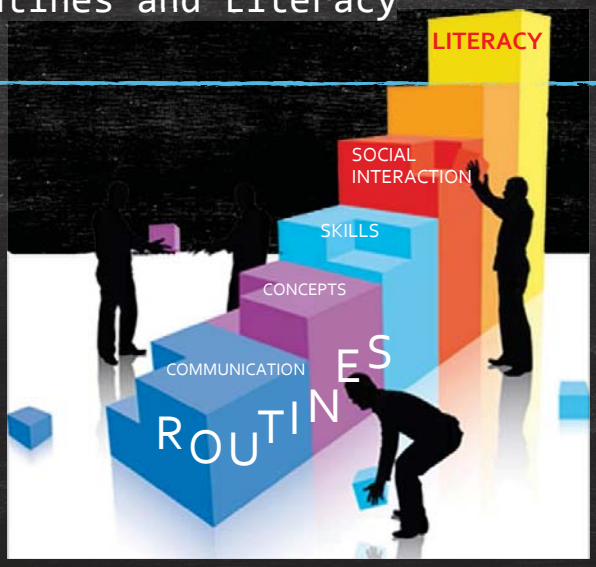
Identifying things or places

Creating and maintaining relationships

and more

Routines and Literacy

By building concepts, communication skills, and social interactions; routines are the building blocks of literacy

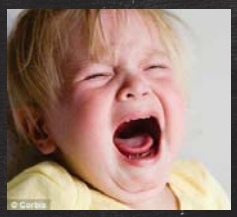


What is a routine?

- Has a clear beginning
- Happens in the same location each time
- Uses the same materials
- Uses a consistent sequence of steps
- Pacing dictated by the student's needs

OHOA Modules- Module 9: Routines for Participation and Learning

Why Routines? To reduce stress, build memory and skills through predictability and consistency



When children don't know what is about to happen- they are stressed. Routines can help with transitioning between activities

Because he walks this route every day, he remembers where his classroom is

When they practice a skill every day, children get better at it

Why Routines? To build concepts behind the skills we teach

Concept development is a critical issue for children with dual sensory loss

Skills vs Concepts and Schemas

Why Routines? To improve communication

Learning to interact with others, communicate with others in meaningful, daily activities

What activity makes a good routine?

- important skills are being worked on during the activity
- the activity can occur frequently—one or more times daily
- the learner enjoys the activity or, at least, some aspect of the activity
- a partner is available for interaction with the learner during the activity
- the activity can be structured so that it happens the same way each time

From Millie Smith- Sensory Learning Kit Guidebook

Developing a Routine

Student: Ray — Routine: Grooming with Chris

Routine Steps	Adaptation / Modification	Targeted Vocabulary	Skill	Concepts
Introduce the grooming routine to Ray. Start at the daily calendar. Show him the object symbol (toothbrush) for the routine. Say and sign "grooming."	Real (concrete) object symbols Daily calendar Hand-under-hand modeling Tactile sign and gestures Speech/ vocalizations	"Brush" "Wipe" "Shake-shake-shake" (mousse) "Hair" "Smack-smack" (aftershave) "And then" "Swing"	Using listening skills to help attach meaning to actions and objects. Tactile discrimination. Categorizing the items included in the grooming routine. Interacting with another person (turn-taking).	The grooming routine has a beginning. I can trust others. Other people are fun.
Move to the grooming station. Load the sequence box with objects for the routine.	Same as above	"Finished" "And then"	Listening skills. Using the sequencing box from left to right. Using a literacy system (sequencing box).	words/sounds are connected to objects and actions Steps in events can be organized in sequence I can read the sequence from left to right
Use the objects and sequence box and run the routine.	Same as above	"Good job" "Finished"	Turn taking Tooth brushing Listening Skills Identify body parts	Idea of "self." Idea of "mine" and "yours." There is a connection between a sign or word and a specific action (i.e., words have meanings).
Finish putting the grooming items in the finished box. Then empty the box into grooming drawer. End the routine.	Finished box Real (concrete) objects Grooming drawer	"Hug"	Putting things away where they are stored.	Building associations between objects, actions, and people.

This "Activity Routine Form" was developed by Kate Moss, Texas Deafblind Outreach, 2002 — August 2015

OHOA module 10- Learning Activity 4-"IUsing Routines to Enhance Concept Development"

Home Routines

Activity: Bedtime Routine

**Start – then PAUSE = Look for ANTICIPATION =Give Chance for PARTICIPATION

Object Cue	Key Signs	Key Words	Prompts Object, Sound, Smell, Taste, Touch, Proprioceptive, Vestibular
Blanket with baby safety pin with beads in the four corners	• Time to • Sleep • Blanket • Bed • Kiss	• Time to sleep • Lie down • Tuck Ivey in • Bedtime kisses • Night Night	• Touch: Blanket, Bed, cocoon of rolled blankets, Good night kisses • Sound: There was an old lady who swallowed a fly (classical) • Proprio: squeeze arms and legs

Where to Start with Literacy Instruction in Your Routines Begins with a Look at Communication

- The concepts, we can address through routines depend on the child's language development (Symbols and Meaning, Millie Smith, APH)

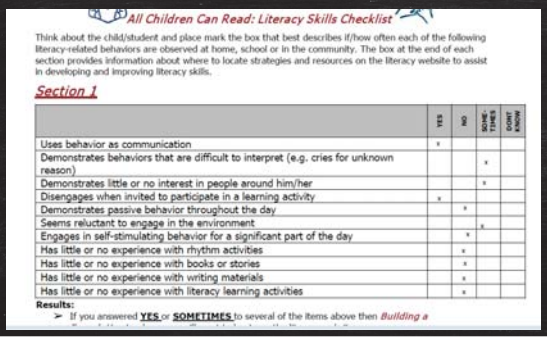
-The Communication Matrix: www.communicationmatrix.org

Communication-Based Routine Development

- Assess communication
- Develop communication goals
- Provide multiple opportunities daily to work on those goals (example)
- Develop routines with targeted vocabulary

Literacy Checklist from NCDB

- Knowing where your student is developmentally helps you provide appropriate literacy instruction
  - Literacy Checklist Literacy.nationaldb.org



All Children Can Read: Literacy Skills Checklist

Think about the child/student and place mark the box that best describes if/how often each of the following literacy-related behaviors are observed at home, school or in the community. The box at the end of each section provides information about where to locate strategies and resources on the literacy website to assist in developing and improving literacy skills.

Section 1

	YES	NO	SOME-TIMES	DON'T KNOW
Uses behavior as communication	x			
Demonstrates behaviors that are difficult to interpret (e.g. cries for unknown reason)			x	
Demonstrates little or no interest in people around him/her			x	
Disengages when invited to participate in a learning activity	x			
Demonstrates passive behavior throughout the day		x		
Seems reluctant to engage in the environment			x	
Engages in self-stimulating behavior for a significant part of the day		x		
Has little or no experience with rhythm activities		x		
Has little or no experience with books or stories		x		
Has little or no experience with writing materials		x		
Has little or no experience with literacy learning activities		x		

Results:

➢ If you answered **YES** or **SOMETIMES** to several of the items above then *Building a*

Linda Hagood's 3-levels of communication

Level 1 - Presymbolic with limited interactive skills

Level 2 - Early Symbolic with emerging dialoguing skills

Level 3 - Symbolic with developing conversational language

Communication - A Guide for Teaching Students with Visual and Multiple Impairments, Hagood, TSBVI 1997

Literacy routines for pre-symbolic communicators

Example 1: Taylor

- The first video example you will see is of Taylor and his teacher, Amy.
- Taylor is 6 years old and has hearing, but no vision. He is at a pre-symbolic level of language development.

Skills Taylor is working on:
Reaching out to Amy- finding her
Waiting while things get started
Moving left to right in sequence box
Transitioning from one routine to another

Concepts Taylor is working on:
A routine has beginning, end and steps
When I do this… Amy does this.
The things in the box mean what will happen
Things have names

What sort of communication and literacy activities is Taylor ready for?

Building a Foundation for Literacy

1. Embed opportunities for communication throughout the day. examples
1. Design learning experiences that are meaningful to the child. examples
1. Developing a trusting relationship with the child. examples

What would traditional literacy materials look like for Taylor?

Story Boxes: Cookie Time

- A collection of items in a box or bag that corresponds to the items mentioned in a story. It is a way for young children with visual impairments to experience a story.
- Children gather information through the experiences that they have. Literacy emerges from hands-on experiences for all children.

Routines for an emerging symbolic communicator

Ray: A Little Background

- Ray is 6 years old and has a moderate to severe hearing loss in both ears and no vision.
- He is at an emerging symbolic level of language development and is just beginning to understand that parts of objects can represent an action, place, person, or thing.
- He is still using many concrete objects to label these actions, places, and things.

What sort of literacy activities is Ray ready for?

Early Emergent Literacy

1. Embed the use of objects, symbols or words throughout the child's day.
2. Teach name, name sign and/or personal identifier of child and those the child interacts with on a regular basis .
3. Embed literacy learning activities into routines.

What would traditional literacy materials look like for Ray?

Story Boxes - Monica and the bag story

Routine book

- A book based on an experience the child knows and understands helps build symbol-action/object meaning
- A book based on a routine to help build anticipation and participation

WHAT MAKES A GOOD ROUTINE BOOK?

- USE EXPERIENCES THE CHILD DOES DAILY

USES CHILD'S LEVEL OF REPRESENTATION

- THE CHILD PARTICIPATES IN CREATION BY GATHERING ITEMS DURING THE ACTIVITY

Jarvis at the Drum Store

What sort of communication and literacy activities is Jarvis ready for?

Emergent Literacy

1. Expand awareness of books, print and writing
2. Connect real-life experiences to literacy activities
3. Create books adapted to individual child preferences, abilities and interests
4. Provide multiple opportunities to interact with text through shared storybook reading

What do traditional literacy materials look like for Jarvis

Experience books

- –Help the child understand that objects are symbols that can be "read"
- –Provide memory support and meaning since child chooses the objects
- –Enable the child to share memories with others

PLANNING A ROUTINE or EXPERIENCE BOOK

A Plan for My Routine Book

- Think about the purpose of the book
- Think about the accommodations for the individual student

Activity Routine Book Guide

- List steps of the routine
- List symbols used in the book
- List targeted vocabulary
- List skills/concepts addressed
- Write a "script" for using the book

Examples, tips for making Experience Books

- http://popdb.sd38.bc.ca/Experience_Books
- www.pathstoliteracy.org/tactile-experience-books
- http://www.wsdsonline.org/video-library/deaf-blind-videos/experience-books/

Project CORE- Center for Literacy and Disability Studies at UNC

- 5-year grant to develop an implementation model for building early symbolic communication for children with severe disabilities
- Focus on use by classroom teacher on daily basis instead of relying on SLPs
- 36 core vocabulary words available in different formats - including tactile 3-d reproducible
- Self-guided training modules with implementation strategies
- www.project-core.com

CORE Instructional Principles

- Plan ways to incorporate core vocabulary in existing routines
- Provide constant availability of core vocabulary in student's best format
- Model use of core vocabulary
- Attribute meaning to pre-symbolic student behaviors
- Repeat and expand any student use of core vocabulary
- Don't require response- encourage

Information for this presentation came from:

Symbols and Meaning from APH and the SAM videos at http://tech.aph.org/samvid/intro.html

The Sensory Learning Kit Guidebook from APH

Communication- A Guide for Teaching Students with Visual and Multiple IMpairments - Linda Hagood, TSBVI, 1997

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The modules were developed by the National Center on Deaf-Blindness. For more information on these modules please visit: http://moodle.nationaldb.org

NCDB Literacy Website http://Literacy.nahttp://www.project-core.com/tionaldb.org

Project CORE: Implementation Model for Building Early Symbolic Commuinicationhttp://www.project-core.com/

ROUTINES WORK!

AND THEY ARE FUN TOO

Develop a trusting relationship with the child.

What to do

- Always identify yourself when you interact with the child
  - Choose a name sign or personal identifier and use it consistently to let the child know who you are
  - Say "Hello" and "Good-bye" and expect the child to do the same
  - Learn how to have a conversation with a child in non-traditional ways
  - Provide opportunities with a partner for turn-taking
  - Expect, wait for and acknowledge child's responses
  - Identify the child's likes and dislikes
  - Allow the child to direct conversations about their topic (follow their agenda, not yours)
  - Have frequent conversations with the child (may or may not use spoken language)
  - Incorporate rhythm, music, finger plays and mime games into daily routines and activities

Embed opportunities for communication throughout the day

What to do:

- Work toward the child's understanding that a partner is needed in order to communicate
- Provide opportunities with a partner for turn-taking
- Expect, wait for and acknowledge any and all child responses
- Put meaning to the child's actions and provide vocabulary for it
- Use consistent repetitive language (may be spoken, signed or both)
- Provide opportunities for children to make choices
- Use communication for a variety of purposes (make comments, ask questions, express feelings, give instructions)

Design learning experiences that are meaningful to the child

What to do

- Identify the child's likes and dislikes
- Use the child's preferences to make learning more meaningful and fun
- Determine the child's preferred sensory learning channels and learning styles
- Use age appropriate activities and materials
- Establish routines around daily activities
- Decide ahead of time what words and concepts you want to focus on during each routine
- Use hand under hand techniques, especially when introducing new activities
- Promote active participation and/or partial participation.

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Routines and Literacy: By building concepts, communication skills, and social interactions; routines are the building blocks of literacy

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- the activity can be structured so that it happens the same way each time

From Millie Smith- Sensory Learning Kit Guidebook

Developing a Routine – copy of a form to create a routine (in handouts)

Home Routines (copy of a form to create home routines)

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Saturday, July 29, 2017

Breakout Session #5-7:
10:45-11:45am, 1:00-2:00pm, 2:15-3:15pm

Panzacola F-3/F-4

Adult Track

Kasee Stratton, Ph.D., NCSP, Daniel Gadke, Ph.D., NCSP, BCBA, and R. Matthew Coward, MD, FACS

Presenter Information

Dr. Kasee Stratton and Dr. Daniel Gakde are assistant professors of School Psychology at Mississippi State University. Both are also licensed psychologists and nationally certified school psychologists. Drs. Stratton and Gadke completed their doctoral internship and postdoctoral fellowship at Johns Hopkins School of Medicine and the Kennedy Krieger Institute. They specialize in treating challenging behavior and improving adaptive skills for children with developmental disabilities. Dr. Stratton has worked with individuals for CHARGE for over 12 years and Dr. Gadke primarily teaches behavioral assessment and intervention courses.

R. Matthew Coward, MD FACS is an Assistant Professor of Urology and Clinical Assistant Professor of Obstetrics and Gynecology at the UNC School of Medicine, and Director of Male Reproductive Medicine and Surgery at UNC Fertility in Raleigh, NC. He earned his MD with Distinction at UNC, followed by urology residency at UNC, and fellowship in Male Reproductive Medicine and Surgery at Baylor. Dr. Coward's clinical practice focuses in the areas of male reproduction and fertility as well as male sexual dysfunction. Dr. Coward's second of three children, Ryan, is a 4-year-old who has CHARGE syndrome.

Presentation Abstract

This three-session track will provide a series of presentations, discussions, and question and answer formats ***for adults with CHARGE syndrome ages 16+ only***. Sessions will include topics such as sex, sexual dysfunction, sustaining friendships, guidance on drinking, social media skills, advocating on the job and in the community, and question and answer time periods.

Saturday, July 29, 2017

Breakout Session #7: 2:15-3:15pm

Panzacola G-1

Five hints for new and seasoned parents: Raising your child with CHARGE syndrome

Tim Hartshorne

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

Parenting is always challenging, but particularly with a child who has challenges, such as one who has CHARGE. This presentation reviews five considerations for parenting a child with CHARGE.

Saturday, July 29, 2017

Breakout Session #7: 2:15-3:15pm

Panzacola G-2

Variables that Impact Walking in Individuals with CHARGE Syndrome

Dr. Elizabeth (Beth) Foster, CAPE

Presenter Information

Dr. Beth Foster is a Certified Adapted Physical Educator. She worked as an Elementary Adapted Physical Educator in Pennsylvania for 6 years then was an APE consultant in Texas for 4 years. During her time teaching in Pennsylvania, Beth was named the 2012 adapted physical education teacher of the year. Beth has been involved in Camp Abilities, a developmental sports camp for individuals who are blind, visually impaired, or deafblind for the past 12 years. She is currently the assistant director for Camp Abilities in Pennsylvania and Texas. From her experience at Camp Abilities, she developed a passion and determination to be knowledgeable within the field of deafblindness. Beth has presented on various topics about deafblindness across the U.S. She completed intervener training at the Minnesota Deafblind Project. Beth has been involved with the Texas Chargers for the past 3 years providing physical activities for individuals with CHARGE Syndrome at their annual retreat and has directed the Camp Abilities at the past two International CHARGE Conferences. Beth received her PhD in May 2016 by completing research related to children with CHARGE Syndrome and walking. Currently Dr. Foster is an assistant professor at Cal Poly Pomona in California in adapted physical education.

Presentation Abstract

Children with CHARGE syndrome are often delayed in the attainment of independently walking. The purpose of this session is to provide information about variables that impact walking and the benefits of walking in individuals with CHARGE syndrome. The session provides strategies to develop meaningful and accessible movement activities to enhance walking and provide children with movement confidence. Activities based on best practices and parent input will be presented. Participants leave with strategies that can be implemented when they get home.

Saturday, July 29, 2017

Breakout Session #8: 3:30-4:30pm

Panzacola F-1/F-2

Breakthroughs in Sensory Motor Processing & Feeding using Alternative Multi-Disciplinary Treatment Approaches

Whitney B. Pimentel MA, CCC-SLP, Isabel Lara & Carmen Romero

Presenter Information

Whitney Pimentel received her Master's degree in Speech and Language Pathology in 1997 from Louisiana Tech University. During her first two years in her new profession she quickly realized there was a need for understanding how the inability to eat was negatively impacting speech development. She spent 2005-2017 establishing her own practice that has led to creating a treatment base focused on feeding skills, oral placement development, motor skill development and speech. She has had the honor of presenting at the Charge Conference in 2013 and 2015.

Carmen Maria Romero received her BA in Physical Therapy from Florida International University Dec 1999. She worked for 12 years at Jackson Memorial Hospital/Ryder Trauma Burn Center/Miami Transplant Institute/Holtz Childrens Hospital in downtown Miami. As a therapist in a multicultural diverse medical center her patient population included pediatric, young adult, adult, and geriatric cases of multi level neurological, congenital, orthopedic, cognitive and systemic trauma and disability. From 2010-2017 she has developed her own private practice with an individualized holistic strength based approach to flourishing. Her practice utilizes the concepts of neuroplasticity, strength based resilience training, patient focused engagement, parasympathetic "calming" paired with physical challenge.

Isabel Lara has been a licensed pediatric physical therapist for 18 years who began her career working in the field of pediatric physical therapy at a PPEC (Prescribed Pediatric Extended Care) for 5 years treating children from birth to 16 years old with neurological disabilities. From January 2000-April of 2003 she furthered her education specifically in the field of sensory integration therapy by becoming certified in Sensory Integration Therapy (SIPT certified practitioner #7888). She has dedicated her career to creating innovative treatment strategies for neurological disorders that do not respond to traditional therapy models and opening the minds of professionals in the fields of education, psychology and therapy working with children with neurological disorders.

Presentation Abstract

Common deficits such as sensory, physical challenges, oral challenges, feeding, and speech difficulties associated with CHARGE syndrome will be discussed. They will teach a unique multi-disciplinarian approach of continually assessing the sensory system to determine a baseline at the beginning of each therapy session. Demonstrations of a variety of techniques will be taught to assist parents, therapists, and other educators in creating a therapeutic intervention program to address the needs of these individuals outside of traditional methods. An in-depth discussion will explain how and when to incorporate sensory motor developmental activities, core stability exercises, and cranial sacral therapy into a therapy program. The goal is that we provide the tools to assist these children with functioning in home, therapy, school, social situations, and work with the goals of improving physical stability, nutrition, motor processing, and speech clarity using unique multidisciplinary approach to increase their rate of progress towards meeting these goals.

Breakthroughs in sensory motor processing and feeding using alternative multidisciplinary treatment approaches

Topics of Discussion

- Most common structural and cranial nerve abnormalities in children with CHARGE syndrome and their connection to sensory motor processing systems.
- What is sensory integration
- What is cranial sacral therapy
- How to implement a treatment approach utilizing sensory integration and cranial sacral therapy to impact the progress rate of speech and feeding therapy and effectiveness of a treatment session .

Structural Abnormalities and their connection to sensory motor systems

1. Eyes
- Colombo-cleft of iris, retina, choroid, macula or disc
- Microphthalamos- small eye
- Anophthalamos- missing eye

Impact: vision perception impaired and or limited
Sensory System: Visual System

2. Ears
- Shape of ears short wide with little or no lobes, floppy
- Malformed middle ear bones(ossicles)
- Malformed cochlea
- Malformed semicircular canals-small or absent
- Impact: poor discrimination. localization and processing of sound and poor balance and equilibrium reactions
- Sensory System: Auditory and Vestibular System

Structural Abnormalities and their impact on sensory systems

3. Nose
- Choanal atresia or stenosis- passage from nose to throat narrow or blocked
- Impact: limits smell and respiration, note respiration directly linked to controlling heart rate to help modulate behavior during moments of frustration and anger.
- Sensory System: Olfaction

3. CN X- **Vagus-** motor to visceral organs and pharynx and larynx parasympathetic function of HR, RR stomach and esophagus
- Impact: coughing swallowing and speech, modulation of arousal level
- Sensory System: Oral Motor system

4. CN VII- **Facial** : muscles of facial expression, stapedius muscle of ear which dampens sound, motor for lacrimal gland, sensation of ant 2/3 of tongue and hard and soft palate
- Impact: poor affect, sound sensitivity, tearing, eating textures, and speech
- Sensory System: Auditory system. Tactile system, oral motor system

5. CN III- **oculomotor**-intrinsic movement of the eyes and eye lid and parasympathetic control of pupil
- impact- poor visual motor control
- Sensory system: visual system through its direct connections to the vestibular nuclei(affected by structural abnormality

6. CN IV-**trochlear**-superior oblique eye muscle, movement down and lateral
- Impact-poor visual motor control
- Sensory System: visual system through its direct connections to the vestibular nuclei

7. CN VI-**abducens**- lateral rectus , movement of eye lateral
- Impact-poor visual motor control.
- Sensory System: visual system through its direct connections to the vestibular nuclei

Sensory Integration

- Sensory integration is a neurological process that organizes sensations from one's own body and from the environment and makes it possible to use the body effectively within the environment.

- Sensory integration is centered on the ideas of an "adaptive response" and the "just right challenge."
- The "just right challenge" is a functional and meaningful activity for the child. (Ayers)
- An "adaptive response" is an appropriate action in which the child responds successfully to an environmental demand.(Ayers)

- Sensory Integration is rooted in the beliefs that: The environment has an impact on the maturation of the nervous system; and that the nervous system is a malleable, changeable structure. (Ayers)
- Neuroplasticity is the ability of the nervous system (brain) to change in response to the demands of the environment or as a result of an injury. The Innate plasticity of the nervous system is not fully realized until appropriate conditions exist.
  (Bach-Y-Rita 1992)

Cranial Sacral Therapy

According to John Upledger, "Cranial sacral therapy is a gentle hands on technique that enhances the functioning of the physiological cranial sacral system. The cranial sacral system is comprised of membranes and cerebral spinal fluid that surround and protect the brain and spinal cord. Using a soft touch CST is intended to release restrictions of cranial sacral system , thus improving the function of the central nervous system.

- When cranial sacral therapy is utilized prior to or during a therapy treatment session it optimizes arousal level, decrease stress, and facilitate body awareness and postural responses.(Sensory Integration theory and practice, 361-362.)
- CST can also be utilized to release restrictions and facilitate optimal functioning around the specific area of the brain that directly correlates with the area of sensory dysfunction caused by structural deformity or cranial nerve abnormalities.

Two foundation sensory systems that should be addressed to optimize full potential for therapeutic gains toward meeting developmental milestones :

- Somatosensory system-tactile and proprioceptive

1. Tactile-light and deep touch, vibration or stretch, temp, pain mechano receptors within the skin all over the body

- Signs of dysfunction: defensive to touch, textures on body and extremities and on tongue, doesn't respond to high temp or pain, clothing sensitivities, poor transitions, does not respond well to change etc…
- Cranial Sacral Implications: primary and secondary somatosensory cortex, parietal lobes and thalamus. Oral motor cavity if issue in mouth as well on gums and buccal cavity
- SI Treatment applications: incorporating deep touch activities , grounding weight bearing developmental positions, vibration to desensitize, Wilbarger brushing protocol

2. Proprioception-perception of joint and body movements as well position of the body and limbs in space., sensing the direction and velocity of movement and effort needed to move objects. Receptors are muscle spindles, mechano receptors and joint receptors.

- Signs of dysfunction: poor body awareness, difficulty avoiding environmental obstacles, clumsiness, heavy stomping, seeking high impact sensation, head banging, pinching, chin pushing ,finding tight small places to wedge in etc..
- Cranial Sacral Implications:
  primary and secondary somatosensory cortex, partietal lobe , thalamus and temporal lobes
- Treatment applications: Incorporating resistive movement activities in developmental WB positions, resistive oral motor tools, vibration for body awareness,

- Vestibular System: otiliths organs (utericle and saccule)processing linear movement and semicircular canals(horizontal, anterior and posterior) for processing rotational movement. Vestibular receptors are hair cells in otiliths and semicircular canals. Otoliths organs responsible for static function and semicirular canals responsible for dynamic angular motion.

  2 Sensory pathways: **vestibular –propioceptive(cochlear), vestibular visual pathway**

  Vestibular and proprioceptive input along with vision provide Awareness and coordination of movement of head in space, Postural tone and equilibrium Coordination of eye, head and body and stabilization of eyes in space during head movement(Sensory integration theory and practice p 58)

- Signs of dysfunction: Poor equilibrium reactions in all developmental positions, poor balance, poor disassociation of eyes from head movement, visual fixation statically and dynamically when head in motion poor, spatial orientation of body during gross motor and fine motor skills poor, gravitational insecurity and postural insecurity.
- Cranial Sacral Implications: temporal lobes, parital lobes, cerebellum, occipital lobes
- Treatment Applications: Incorporating development positions that challenge head position and visual gaze. Material used can be put in motion to connect eyes to task, sitting or standing position on dynamic equipment, incorporate body movement to task at hand, incorporate music and rhythm to organize timing and spatial concepts, vibration and music used as behavior modifier

Vestibular-Proprioceptive Pathway

- Both systems share a bony labyrinth, mechanical receptors operate in very similar fashion using common fluids (the perilymph and endolymph), they share cranial nerve VIII and some of its fibers.
- The only difference in movement and sound is the velocity of the vibrations
- The vestibular portion receives messages from the body about its position and orients the body in space at any given moment
- The auditory portion receives and processes the finer movements of air molecules, sound, which we cannot see or feel but which orient us to and help us locate objects and sound in our environment and navigate through it.

Vestibular Visual Pathway

- Signals from the three paired semicircular canals interact specifically with with the six paired extraocular eye muscles through pathways which project from the vestibular nuclei into the three bilateral cranial nerve nuclei (III, IV,VI)
- Cranial nerve III, IV, VI control the six extraocular muscles of the eyes
- Vestibular system impacts saccadic eye movement, smooth pursuits and convergence

Vestibular Visual Reflexes

- Rotational vestibular ocular reflex (VOR) allows the eyes to maintain fixation on the target when the head rotates
- Translational vestibular ocular reflex (VOR) allows the eyes to maintain fixation on a target when the head is moving in a linear direction
- Ocular Counter-Rolling Response compensates for the head tilt vertically.
- Pre and Post rotary nystagmus reflexes are elicited in an attempt to refocus on a stable point in space when there is prolonged rotation of the body.

Other areas of concern to observe and treat if necessary by qualified professionals and integrate into multidisciplinary treatment sessions

- Developmental reflex patterns
  - Primitive reflex
  - Postural Reflex
- Behavior modification and self regulation

QUESTIONS?

Breakthroughs in Sensory Motor Processing & Feeding using Alternative Multi-Disciplinary Treatment Approaches

Common Deficits of CHARGE Syndrome

Deficits which effect sensory, feeding and speech clarity: each of these deficits may range from non-existent to severe.

1. Hypotonicity

2. Visual Impairment

3. Hearing loss

4. Sensory deficits may range from minor to severe: smell, taste, touch, vision, hearing and interpretation of the environment

5. Oral and tactile sensitivity: hyposensitivity, hypersensitivity, mixed sensitivity, fluctuating sensitivity: The "feel" of feeding and the "feel" of speech

6. Tactile defensiveness

7. Cognitive deficits

Common Deficits of CHARGE Syndrome

8. Gap between expressive and receptive language skills

9. Weak jaw musculature: Symmetrical or Asymmetrical

10. Incomplete lip closure, decreased tongue mobility/grading results in limited retraction, lateralization, and tongue-tip pointing

11. Weakness in the muscles of the velum

12. Blocked nasal passages: /m, n, ng/

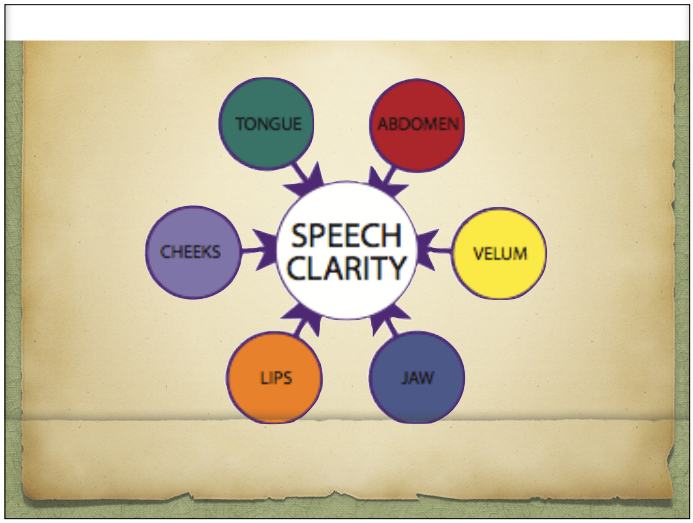
13. Motor planning deficits

14. Difficulty coordinating oral airflow with vocalizations to initiate speech sounds production

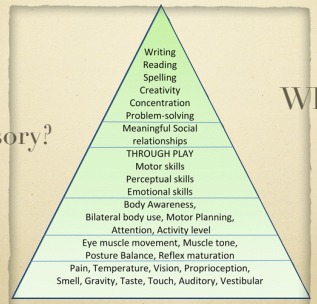
15. Anxiety/Trust

Goals of Oral Placement/Feeding Therapy

- To establish trust with client
- To improve feeding skills and nutritional intake
- To improve speech sound production and improve intelligibility/clarity



What is Sensory?



The basic building blocks of a child's learning and development need to be in place in order for them to engage in higher learning and reach their expected milestones.

Where do we start?

8 Sensory Systems

Far:

Visual
Auditory
Olfactory
Gustatory
Tactile

Near:

Vestibular
Proprioceptive
Interoception

Have to calm body before we go into mouth
Mouth has a high amount of receptors but message may be confused

Sensory Diagnosis/Tactile System

Tactile Hyposensitivity:
An under-reaction to tactile input.

Tactile Hypersensitivity:
An over-reaction to tactile input

Mixed Sensitivity:
Any combination of hyper, hypo or normal sensitivity.

Fluctuating Tactile Sensitivity:
Responses that change over time.

Before you begin to work on either feeding or speech:

1. Evaluate the Sensory System and make diagnosis
2. Eliminate tactile defensive behaviors by establishing trust.
3. Treating Sensory Deficits: Sensory Integration Deficits: Begin with a sensory warm-up as prescribed by an S.I. trained Therapist to collaborate

Muscle-Based Exercises(Oral-Motor)

Begin with a sensory program and a stable posture:

Work from whole body to mouth to achieve acceptance of touch and to develop trust.

1. Establish a supported feeding position:
Stability in the body allows for mobility within the oral cavity

Evaluate the Sensory System:

a. Toothette w/Vibrator
b. Sensory Bean Bags
c. Jigglers

Let's talk Sensory input

Why does my child bite and put everything in their mouth and avoid certain foods?

Why does my child suck their thumb, grind their teeth etc?

Why is feeding so important to an oral-motor (oral placement) therapy program?

**Nutritional Concerns
**The muscles that are used in feeding are the same muscles that are used in speech.

What is a Pre-Feeding Program

GOAL: to develop the motor skills to support safe, effective, nutritive feeding.

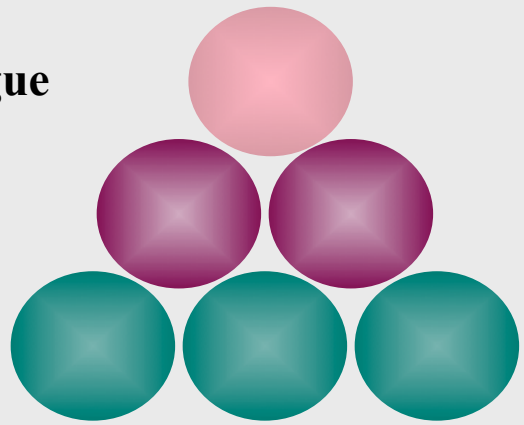
- Clients that do not have adequate nutrition
- Clients that have poor speech clarity
- Program should start with a motor goal

A Sensory Motor Approach to Feeding: Lori L. Overland MS, CCC-SLP, C/NDT; Robyn Merkel-Walsh, MA, CCC-SLP

⇧Tongue

⇧Lips

⇧Jaw



Techniques for Pre-Feeding

Motor Goal	Pre-Feeding/Therapy
Lip Closure	Spoon Feed
Tongue Retraction	Straws/Tongue hugs
Chewing Solids	Gloved Finger/Bite Tubes

Tyler

What is a Therapeutic Feeding Program

GOAL: to develop a set of techniques that support safe feeding and maximize a client's postural stability, muscle tone, sensory processing, and oral sensory-motor skills.

A Sensory Motor Approach to Feeding: Lori L. Overland MS, CCC-SLP, C/NDT; Robyn Merkel-Walsh, MA, CCC-SLP

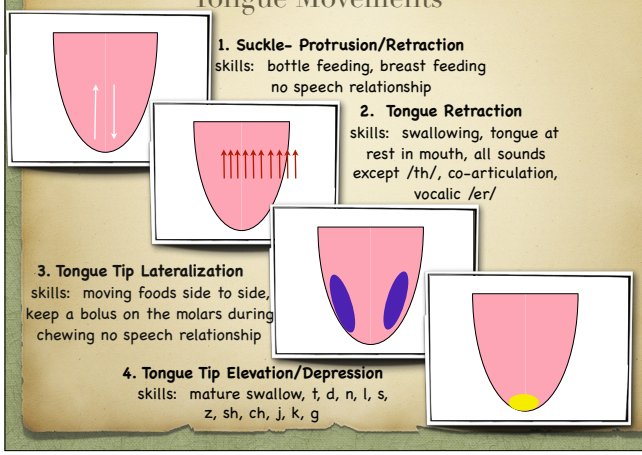
Lip Development

1. **Lip closure skills:** spoon feeding, cup drinking /m, p, b/

2. **Lip protrusion/retraction skills:** straw drinking, /oo, oh, w, ee, ih, eh, sh, ch, j

3. **Lower lip retraction/tension**
   Lower lip protrusion/tension
   skills: remove food from upper/lower lip /f, v, er/

Tongue Movements



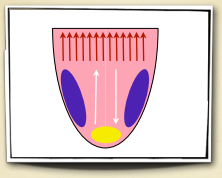
1. Suckle- Protrusion/Retraction
skills: bottle feeding, breast feeding
no speech relationship

2. Tongue Retraction
skills: swallowing, tongue at rest in mouth, all sounds except /th/, co-articulation, vocalic /er/

3. Tongue Tip Lateralization
skills: moving foods side to side, keep a bolus on the molars during chewing no speech relationship

4. Tongue Tip Elevation/Depression
skills: mature swallow, t, d, n, l, s, z, sh, ch, j, k, g

Tongue movements



In feeding and speech tongue does not move as one unit. Eac
part independently moves from the other

Therapeutic Feeding Techniques

- Spoon Feeding
  1. Lateral Placement
  2. Front Placement
  3. Pointed Spoon Slurp



Tools for Drinking

Liquids
1. Cup Drinking
2. Straw Drinking

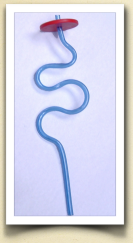
Goals: Lip closure (m,b,p)
Tongue retraction for all sounds except /th/



Why is Straw Drinking So important

- Straw Drinking
  1. Honey Bear
  2. TalkTools(R) Straw Hierarchy

TalkTools(R) Straw Hierarchy #1-#4

#1 #2 #3 #4

Goals: Lip Protrusion, Tongue Retraction, Jaw Stability. Repetitive suck. Last sip looks same as first. Able to drink 4 oz in less than 2 minutes. Use only thin liquids

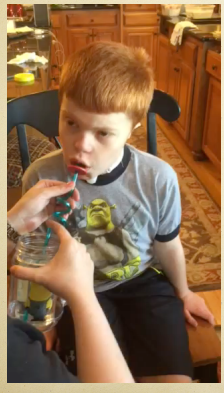
TalkTools(R) Straw Hierarchy #5-#8




#5 #6 #7 #8

Goals: Lip Protrusion, Tongue Retraction, Jaw Stability. Repetitive suck. Last sip looks same as first. Able to drink 4 oz in less than 2 minutes. Use only thin liquids

Andrew Straw Drinking



Overview of Optimal Feeding Positions and Techniques

Solids:Teach the motor plan for safe feeding of cubed solids, using non-food items.

Gloved Finger 

Infadent 

Ark Probe 

Overview of Optimal Feeding Techniques and Tools

Ark's Z-vibe 

Bite Tubes (Red & Yellow) 

Ark's Grabbers (Purple & Green) 

Jaw Grading Bite Bloc  

***Hierarchy as taken from *Assessment and Treatment of the Jaw*

Andrew

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Saturday, July 29, 2017

Breakout Session #8: 3:30-4:30pm

Panzacola G-1

Purposeful play, how wrestling and playing can benefit children with CHARGE

Michael M. Braga M.Ed

Presenter Information

In 1998, Mike and his wife Ruth were first introduced to the world of CHARGE syndrome when they adopted their oldest son Brandon. At the time, Mike was a high school drop out who was managing a fast food restaurant while Ruth attended college. Driven by a desire to help Brandon any way he could, Mike went back to school, earning his bachelor's degree in recreation therapy from the University of Utah. He later attended graduate school at Utah State University studying deaf/blind education.

As Brandon got older, Mike began looking at programs available for adults with deaf/blindess. Since there are no programs in Utah that specialize in this care, Mike and Ruth decided to open their own. They opened Bear-O Care in 2015 as a non profit care center. This center helps adults with multiple disabilities with a special emphasis on those with sensory intake dysfunction or deaf/blindness.

Presentation Abstract

During the day, we all receive input by walking, talking and even eating. Some with CHARGE may not receive all of this input that their brain's still need. By structured play, we can help them obtain this input. Come learn strategies that will help your children while you have fun with them and see how beneficial playing around can be.

Saturday, July 29, 2017

Breakout Session #8: 3:30-4:30pm

Panzacola G-2

Parents' Perspectives: Types and Purposes of Communication Used by Their Children Who Have 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.

Saturday, July 29, 2017

Breakout Session #8: 3:30-4:30pm

Panzacola H-1/H-2

Experiences of Families Raising a Child Who is DeafBlind and Teacher Response to those Shared Experiences

Donna Snyder, Ed.D & Kim Zeigler

Presenter Information

Donna is the State Coordinator for the Kentucky DeafBlind Project. She has been on the project for 11 years. Prior to joining the project, she worked as a classroom teacher for students who were deaf/hard of hearing and deafblind in public, private and state schools. She recently completed her dissertation examining the lives of families with children who are deafblind and teacher perception change when those experiences were shared through a short digital video. She was instrumental in the creation of a dual language (ASL/English) Montessori preschool and day care. Donna's parents had cerebral palsy which greatly influenced her choices to work with children, families, and professionals in the field of special education. She is very interested in how we present our children to other professionals and how that creates a negative mindset using a medical checklist.

Kim is the Family Specialist for the Kentucky DeafBlind Project. She has been on the project for over 12 years. She brings a wealth of personal experiences as a mother of twin boys with varying disabilities. Kim completes the team platform in bringing and keeping awareness to the families' perspectives. Her focus is to bring families together both face to face and on line to support one another. She has helped plan numerous family events and is able to locate resources for families. She works to support families understand their roles as part of the educational team.

Presentation Abstract

This presentation will explore the experiences of families raising a child who is deafblind and teacher response to those shared experiences using the photovoice method with short digital videos. Five families who all had a child on the Kentucky DeafBlind Project census and their lead teachers participated in individual interviews using photovoice. Family photovoice interviews uncovered five overarching themes: medical positive descriptors, family and community, likes/don't like, and parents' love. Teacher interviews identified a positive shift in teacher perception after viewing the short digital video created from the photos and experiences from the families. Teacher positive shifts included: "student can't do to student can do," "using medical descriptors to using human descriptors," "feeling disconnected with the family to feeling connected to the family," and "teacher self-examination of can't do to can do." Project staff will share their experiences that initiated this study and the impact of findings as well as the change in service delivery of how the project introduces a child on the census to their educational team.

Saturday, July 29, 2017

Breakout Session #5: 10:45-11:45am
Panzacola F-1/F-2

Sibling Panel

Nancy Salem-Hartshorne, PhD., Aaron Hartshorne, Mallory Beavers, Mindy Braga

Presenter Information

Nancy is a Professor of Psychology, School Psychologist, and mother of Jacob, age 28, who has CHARGE syndrome. Nancy will facilitate the panel composed of siblings of individuals who have CHARGE syndrome.

Additional panelists include: Hannah and Megan Troupe, Rachel Lobaugh, Matt stranger, Zach Chinicci, Seth Hartshorne, and Sarah Lent

Presentation Abstract

Siblings of individuals with disabilities have unique experiences. Siblings of individuals with CHARGE have even more unique experiences. Within these, there are still more variable experiences, depending on birth order, severity of disability, and parenting styles, among other things. This panel of young adults will describe their experiences, both rewarding and challenging, of being raised with a sibling with CHARGE syndrome. Moderators will then ask specific questions, after which audience questions will be welcomed.

Saturday, July 29, 2017

Breakout Session #5-7:
10:45-11:45am, 1:00-2:00pm, 2:15-3:15pm

Panzacola F-3/F-4

Adult Track

Kasee Stratton, Ph.D., NCSP, Daniel Gadke, Ph.D., NCSP, BCBA, and R. Matthew Coward, MD, FACS

Presenter Information

Dr. Kasee Stratton and Dr. Daniel Gakde are assistant professors of School Psychology at Mississippi State University. Both are also licensed psychologists and nationally certified school psychologists. Drs. Stratton and Gadke completed their doctoral internship and postdoctoral fellowship at Johns Hopkins School of Medicine and the Kennedy Krieger Institute. They specialize in treating challenging behavior and improving adaptive skills for children with developmental disabilities. Dr. Stratton has worked with individuals for CHARGE for over 12 years and Dr. Gadke primarily teaches behavioral assessment and intervention courses.

R. Matthew Coward, MD FACS is an Assistant Professor of Urology and Clinical Assistant Professor of Obstetrics and Gynecology at the UNC School of Medicine, and Director of Male Reproductive Medicine and Surgery at UNC Fertility in Raleigh, NC. He earned his MD with Distinction at UNC, followed by urology residency at UNC, and fellowship in Male Reproductive Medicine and Surgery at Baylor. Dr. Coward's clinical practice focuses in the areas of male reproduction and fertility as well as male sexual dysfunction. Dr. Coward's second of three children, Ryan, is a 4-year-old who has CHARGE syndrome.

Presentation Abstract

This three-session track will provide a series of presentations, discussions, and question and answer formats ***for adults with CHARGE syndrome ages 16+ only***. Sessions will include topics such as sex, sexual dysfunction, sustaining friendships, guidance on drinking, social media skills, advocating on the job and in the community, and question and answer time periods.

Saturday, July 29, 2017

Breakout Session #5: 10:45-11:45am
Panzacola G-1

CHARGE Syndrome and Behavior: Diagnoses and Intervention (Part I)

Tim Hartshorne, David Brown, Megan Schmittel, Shanti Madhavan-Brown, Shelby Muhn

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.

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.

Presentation Abstract

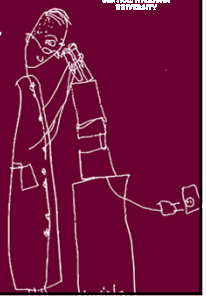
Part one: Diagnosis of behavior. Individuals with CHARGE are often diagnosed with a variety of psychiatric disorders such as autism, OCD, and ADHD. This session addresses the problem of psychiatric diagnoses in children with CHARGE: what are these diagnoses, why are they given to children with CHARGE, and what problems do they create, and are they appropriate?

CHARGE Research Lab

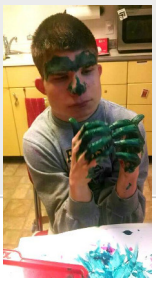
CMU

CHARGE Syndrome and Autism, ADHD, ODD, OCD, Et al.

Tim Hartshorne, David Brown, Megan Schmittel, and Shanti Brown



That's weird; must be autistic



CHARGE Research Lab

Diagnoses Piled On

- Autism
- ADHD
- OCD
- Tourette
- Etc.

CHARGE Research Lab

Problems with these Diagnoses

- Create a reality that may not exist
- Lack explanatory value
- Ignore the uniqueness of the behavior
- Lead to multiple drug treatments

CHARGE Research Lab

What are mental disorders?

- Nobody really knows
- There are no blood tests
- Symptom co-variation
  - If you have these behaviors you are likely to have this disorder
- There is no way to confirm
  - Except the agreement of professionals

CHARGE Research Lab

What is the cause of mental disorders?

- Probably not evil spirits
- Genetic
- Biological
- Psychological
- Environmental

CHARGE Research Lab

Epigenetics – the new direction

- "Certain genes are turned on or turned off, expressed or not expressed, depending on environmental inputs," Richard McNally, PhD, a clinical psychologist at Harvard University

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Diagnosis

- Behavior check lists
- If it looks like a duck, and quacks like a duck

CHARGE Research Lab

Diagnosis

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Why do we diagnose mental illness?

- As a guide to treatment

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Can people with CHARGE have mental illness?

- Yes
- So why not just diagnose it?
  - Does it lead to better treatment or outcomes?
  - And is the diagnosis accurate?
- Would we expect that the same behaviors which are co-variant in mental disorders for people ***without*** CHARGE to be co-variant in people ***with*** CHARGE?
- In other words, what would a disorder such as autism look like in a person with CHARGE?
- Or if a child with CHARGE is said to have autistic-like behaviors, does that mean they have autism?

CHARGE Research Lab

Autism

- Impairments in social communication
  - Social reciprocity
  - Nonverbal communication deficits
  - Lack of understanding of relationships
- Restricted, repetitive patterns of behavior, interests, or activities
  - Stereotyped or repetitive motor movements
  - Insistence on sameness
  - Fixated interests
  - Reactivity to sensory input

CHARGE Research Lab

Is it autism?

High rates of ASD have been reported in syndromes such as Cornelia de Lange and Fragile X. However, there is debate about whether the ASD profile of behavours that triggers a Diagnosis in these syndromes is the same as in individuals with idiopathic ASD.

Waite, J., Heald, M., Wilde, L. Woodcock, K., Welham, A., Adams, D., & Oliver, C. (2014). The importance of understanding the behavioural phenotypes of genetic syndromes associated with intellectual disability. Peediatrics and Child Health, 24, 468-472.

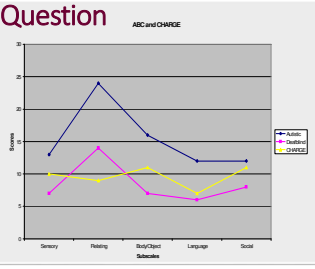
CHARGE Research Lab

Syndromes most often associated with autism

- Fragile X
  - social anxiety, extreme shyness and eye gaze avoidance – not central to autism
  - strong willingness to engage socially with others
- Cornelia de Lange
  - The nature of repetitive behaviors appears to be different compared to those with ASD
- Tuberous Sclerosis Complex
  - Repetitive behaviors are not as frequent as in ASD

CHARGE Research Lab

The Autism Question



Hartshorne, T. S., Grialou, T. L., & Parker, K. R. (2005). Autistic-Like Behavior in CHARGE Syndrome. *American Journal of Medical Genetics, 133A*, 257-261.

CHARGE Research Lab

Autism as an Additional Label

- An array of "symptoms" are seen in CHARGE and Autism, but they differ in function
  - Social: Uninterested vs. not able (Deafblind)
  - Physical: self-stim. vs. regulation
  - Sensory: over-stimulated vs. under-stimulated
  - Communication: immature/uninterested vs. functional
- Autism adds extra label, stops caregivers from finding function for communication

CHARGE Research Lab

Why Add the Label?

- Gives parents feeling that something can be done
- "…our goal has been to identify what is unique about the behavior of children with different genetic disorders, and not what is common. I have no doubt that there is a behavioral phenotype associated with CHARGE. My goal, and that of others, is to better specify that phenotype so that we can develop interventions as well as prevention strategies" –T. Hartshorne
- Does an extra label help? How do we treat them differently?

CHARGE Research Lab

Gain Access to Services?

- Add label to get ABA services
- Not always a bad thing – but the child with CHARGE could be misunderstood
- More physiological conditions with CHARGE that contribute to psychological behaviors
- ASD has fewer physical abnormalities
- Clinician needs to understand unique physical needs associated with CHARGE versus reluctance often associated with ASD
- ABA services good for FCT but not for everything
  - Walking on grass: irrational fear or painful experience?

CHARGE Research Lab

Obsessive Compulsive Disorder

- DSM-5 Diagnostic Criteria for Obsessive-Compulsive Disorder (300.3)

Obsessions

Recurrent and persistent thoughts, urges, or impulses that are intrusive and unwanted, and cause marked anxiety or distress. (Typically irrational fears.)

The individual attempts to ignore or suppress such thoughts, urges, or images, or to neutralize them with some other thought or action (i.e., by performing a compulsion).

Compulsions

Repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly.

The behaviors or mental acts are aimed at preventing or reducing anxiety or distress, however, these compulsions are not connected in a realistic way with what they are designed to neutralize or prevent.

CHARGE Research Lab

We believe……

- Most individuals with CHARGE syndrome don't have *true* OCD.
- Someone with true OCD has irrational thoughts leading to irrational anxiety.
- The treatment involves exposure to the irrational thought, and prevention of the compulsive response.

- Individuals with CHARGE have TRUE circumstances that lead to UNDERSTANDABLE anxiety!
- In other words, the EXPOSURE is happening all the time, and is unavoidable. The compulsive response is an understandable defense for dealing with the anxiety.

CHARGE Research Lab

OCD-like behaviors seen in CHARGE

- **"Everything must be just right."**
  - Ordering/lining up/making symmetrical
  - Placing/moving to correct place
  - Light switches
  - Doors closed/open
  - Handing cup to caregivers when he sees it
- **Other things reported or seen:**
  - Repetitive question-asking: "What color is your car?" "What color is your house?"
  - Stuffing things into slots—especially into places from which they are difficult to retrieve.
  - Repetitive, idiosyncratic behaviors: Hand movements, tics
  - Rigid inability to switch activities
  - All-consuming focus on one idea, activity, or item, to the point that it's not just a hobby/intense interest—keeping in mind that we ALL have hobbies/interests!
  - What else have you observed?

CHARGE Research Lab

"A lot of what looks like OCD in CHARGE is really just a reaction to having multi-sensory impairments"– D. Brown 2015

These are actually very creative responses to abnormal, anxiety-provoking circumstances.

Caveat: Someone with CHARGE syndrome could possibly also develop "actual" OCD, but this is not the norm.

CHARGE Research Lab

Attention-Deficit/Hyperactivity Disorder

- A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development
- Higher incidence among deaf children
  - Sensory integration issue?
  - Limited language exposure?
  - Social-emotional development issue?
  - Visual selective attention?
  - Boredom?
- Consider executive function impacted by sensory impairments

CHARGE Research Lab

Attention Deficit/Hyperactivity Disorder

- Diagnostic Criteria: Inattentive presentation
  - Lacks attention to detail
  - Lacks sustained attention
  - Does not seem to listen
  - Does not follow through on instructions and fails to finish work
  - Difficulty organizing tasks
  - Avoids tasks with sustained mental effort
  - Loses things
  - Easily distracted
  - Forgetful
- Diagnostic Criteria: Hyperactivity/Impulsivity presentation
  - Fidgets
  - Often out of seat
  - Runs or climbs in situations where inappropriate
  - Unable to play quietly
  - Often "on the go"
  - Talks excessively
  - Blurts out answers
  - Difficulty waiting turn
  - Often interrupts others

CHARGE Research Lab

Attention Deficit/Hyperactivity Disorder

- How can these behaviors be better explained by CHARGE syndrome?
  - Deafblindness
  - Difficulties with executive functioning
    - Attending
    - Organizing activities
    - Inhibition
  - Difficulties with self-regulation
  - Sensory needs

CHARGE Research Lab

Attention Deficit/Hyperactivity Disorder

- Example: Bradley, a third grade student with CHARGE syndrome, never seems to be paying attention during math. He spends math class staring up at the lights or inspecting his fingers close to his face.
- ADHD Perspective:
  - Bradley is unable to attend to what his teacher is saying. Bradley is also very fidgety with his fingers.
- CHARGE Perspective:
  - Bradley cannot see the board where his teacher is writing math equations.
  - Bradley cannot hear what the teacher is saying. He also cannot hear what questions his peers are asking.
  - When Bradley flicks his fingers in front of his face, he is getting sensory stimulation from the visual input.
  - Bradley has a hard time transitioning between activities and needs more time to get ready for math.

CHARGE Research Lab

Borderline Personality Disorder

- A pattern of instability in interpersonal relationships, self-image, and affects, and marked impulsivity
  - Fears of abandonment
  - Extremes of idealization and devaluation of others
  - Unstable self-image
  - Impulsivity
  - Recurrent suicidal behavior
  - Highly reactive emotions
  - Chronic feelings of emptiness
  - Anger difficulties
  - Stress related paranoia
- May be associated with the experience of severe abuse, neglect, parental conflict

CHARGE Research Lab

Tic disorders

- Two types of tics
  - Verbal
  - Motor
- Tourette's Disorder has both
- Worsened by anxiety, excitement, and exhaustion
- About 25% of children will have transient tics
- "Hearing parents and mental health clinicians unfamiliar with typical behaviors of deaf children may have difficulties differentiating the clinical presentation of symptoms of TD from the effects of deafness, as well as in implementing appropriate interventions." (Chovaz, 2013)
- Homemade utterances and gestures may be the result of
  - Language delays
  - Intentional personal entertainment

CHARGE Research Lab

Oppositional Defiant Disorder

- What are the diagnostic criteria?
  - Angry/irritable mood
  - Argumentative/Defiant Behavior
  - Vindictiveness

CHARGE Research Lab

Oppositional Defiant Disorder

- How can these behaviors be better explained by CHARGE?
  - Communication deficits
  - Sensory difficulties
  - Deafblindness
  - Executive Functioning Difficulties
  - Fatigue

CHARGE Research Lab

Opposition Defiant Disorder

- Example:
  - Julie was eating pureed peas for dinner, when all of a sudden, she scooted back her chair and threw the bowl of peas on the ground.
  - ODD Perspective:
    - Julie threw her peas on the ground to defy her caregiver.
  - CHARGE Perspective:
    - Julie was having some gas pain and needed to alert her caregiver that it hurt her stomach to eat.
    - Julie does not like peas and does not want to eat them.
    - Julie cannot stand the texture of pureed peas.

CHARGE Research Lab

Bipolar Disorder

People having a manic episode may:
•Feel very "up," "high," or elated
•Have a lot of energy
•Have increased activity levels
•Feel "jumpy" or "wired"
•Have trouble sleeping
•Become more active than usual
•Talk really fast about a lot of different things
•Be agitated, irritable, or "touchy"
•Feel like their thoughts are going very fast
•Think they can do a lot of things at once
•Do risky things, like spend a lot of money or have reckless sex

People having a depressive episode may:
•Feel very sad, down, empty, or hopeless
•Have very little energy
•Have decreased activity levels
•Have trouble sleeping, they may sleep too little or too much
•Feel like they can't enjoy anything
•Feel worried and empty
•Have trouble concentrating
•Forget things a lot
•Eat too much or too little
•Feel tired or "slowed down"
•Think about death or suicide

CHARGE Research Lab

Dunn Conceptual Model

Arousal of thoughts, behavior, feelings, sensations	PASSIVE Self-regulation Strategies	ACTIVE Self-regulation Strategies
Habituation	Non-reactive Tune it out	Sensation Seeking
Sensitization	Reactive to Stimuli	Sensation Avoiding

Psychotropic Medications

- Have generally not been researched with children
- No idea about impact on sensory systems
- Have numerous side effects – impact on brain?
- Are often prescribed off label
- Use is not often monitored closely with observation
- Side effects may lead to additional prescriptions
- There is a tendency to add drugs, rather than replace
- Goal should be to be weaned off of them
- May take away a form of communication
- Sometimes they are survival for the family

CHARGE Research Lab

The Trouble with Multiple Diagnoses

- Children's functional behaviors may present as symptoms of a mental health condition; however, given the child's multi-sensory impairment, the behaviors are often reasonable choices by the child.
- By classifying these behaviors as a mental health disorder, we may be dismissing the creative strategy the child has come up with to survive within his/her environment.
- Therefore, we need to see these accommodations the child has made as accomplishments for them in creating a world that makes sense to them.

CHARGE Research Lab

Puzzling Behaviors in CHARGE Syndrome

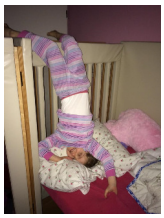
From the FaceBook post:

- Fascinated with fingers/hands (common)
- Laughs at hands
- Plays with hands instead of toys
- Stops what they're doing and touches ground repeatedly
- Knocks on walls/doors before entering a room
- Finger "twiddling" in front of face
- Grinds teeth
- Slaps knees
- Grunts
- Becomes angry when family laughs at jokes/cute things the child says (lunges/hits)
- Violent fits (pulling hair, kicking, punching)
- Constantly touches forehead
- Holds jumper away from stomach
- Leans over to the right
- Bangs elbows on things
- Sticks tongue out a lot
- Touches the inside of eyelids
- Spins in circles
- Bites fingertip with tip of it under tongue
- Obsessively collects things
- Skin picking (lips and fingers)
- Arms crossed
- Lies with one leg over knee
- Chews on things
- Sticks fingers in mouth to the point of gagging
- Spits/puts spit on their hair (or someone else's)
- Spins on floor
- Empties containers/drawers & put everything back
- Hands in fist with thumb tucked in
- Fingers in eyes
- Bangs head on things
- Tongue constantly sticking out
- Fascinated with lights
- Clears bed of anything on it
- Crawls on-top of people lying on the floor
- Flails body when happy
- Hits self in face
- Shakes head from side to side
- Arches back
- Turns on and off lights

CHARGE Research Lab

CHARGE
Research Lab

"CHARGE" is Enough



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Saturday, July 29, 2017

Breakout Session #5: 10:45-11:45am

Panzacola G-2

Creating and Using Nonconventional Signal Dictionaries and Communication Portfolios to Support Individuals who Communicate Primarily without the Use of Symbols

Susan M. Bashinski, Ed.D., Carol Darrah, M.S., Christine Spratling, Ed.S

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.

Carol Darrah is the Early Childhood Coordinator for the Georgia Sensory Assistance Project, which supports children and youth with combined vision and hearing loss. Carol focuses her efforts on early identification and referral, supporting families and early intervention providers, and assisting with transition from early intervention to school services. She earned her Bachelor's and Master's degrees in Child and Family Development from the University of Georgia and has worked in the field of Early Intervention for more than 18 years.

Christine is the Technical Assistance Specialist with the Georgia Sensory Assistance Project.

Presentation Abstract

For individuals at the earliest, non-symbolic stages of communication development, the implementation of consistent communication strategies enhances their participation in interactions and promotes their ongoing communication development. Learn how to build receptive and expressive Nonconventional Signal Dictionaries (written scripts and video clips) and to create Communication Portfolios (pictures and written descriptions) to support children as they enter new learning settings, participate in community activities, meet new service providers, and interact with family members and friends.

Saturday, July 29, 2017

Breakout Session #5: 10:45-11:45am

Panzacola H-1/H-2

Who Needs an Intervener? And A Day in the Life! A Case Study of 2 Adults with CHARGE and their Intervenor Services

Beth Kennedy, M.Ed., Leah Cameron, Cullen Drew

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.

Leah Cameron is Director of Services with the Canadian Deafblind Association Ontario Chapter leads a team of Managers and Intervenor Service Coordinators that support residential programs across the province of Ontario. Leah had the opportunity to attend a CHARGE Conference in California in 2007 and describes the experience as life changing! Leah is thrilled to have the opportunity to present at the 2017 conference and share what the Canadian Deafblind Association is doing to support individuals with CHARGE with their everyday life planning and accomplishing life goals both big and small!

Cullen Drew is an Intervenor Services Coordinator with the Canadian Deafblind Association Ontario Chapter and supports three individuals at CDBA's new apartment complex in Paris, Ontario. Two of the gentlemen he supports are deafblind due to CHARGE Syndrome; Jason and his roommate Nicholas. Cullen attended the CHARGE Conference in Chicago with Jason and it was an experience he will never forget.

Presentation Abstract

Beth will discuss students who have a combined vision and hearing loss and their 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. This will be followed by Leah and Cullen's presentation, which will feature a case study of 2 adults with CHARGE whom are currently supported by CDBA Ontario through Adult Intervenor Services. CDBA Ontario's vision is that all people who are deafblind will live rich meaningful lives.

Interveners Make a Difference

Overview and Real Life Examples

Beth Kennedy
Leah Cameron
Drew Cullen

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

References

- National Center on Deaf-Blindness. (2013). Intervener services and interveners in educational settings. Retrieved from https://nationaldb.org/library/page/2266.
- National Resource Center for Paraeducators. (n.d.). National Intervener Credential. Retrieved October 11, 2016, from http://www.nrcpara.org/intervener.
- Watkins, S., Clark, T., Strong, C., & Barringer, D. (1994). The effectiveness of and intervener model of services for young deafblind children. *American Annals of the Deaf*, *139*(4), 404-409.

A Day in the Life of Jason and Nicholas

Meet Jason Hotte

He has been with CDBA Ontario since 2003

I.A.M Jason Hotte

Appreciations

- Patience
- Clear communication
- Flexible and adaptable
- Handshakes
- Space and independence

How Best to Support Me

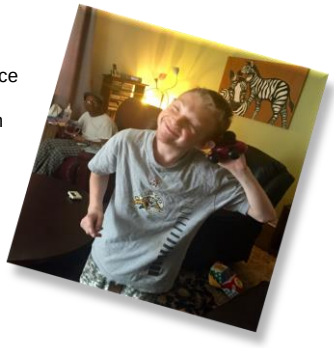
- Learn my language
- Proper sighted guide technique
- Give me choices
- Give me space to reflect

What Makes me Happy

- Visiting family – cottage
- Fishing
- Movies
- Historical deceased people
- The Simpsons
- Numbers on computer
- Friends
- Pudding
- Animals
- My calendar
- History

Meet Nicholas Fice

He has been with CDBA Ontario since 2016



I.A.M Nicholas Fice

Appreciations

- Physical contact when he initiates it
- Repeating information and signing slowly
- Positive feedback and attention
- Patience

How Best to Support Me

- Give me time to process information
- Communication in adapted ASL
- Positive reinforcement
- Approach me with a relaxed energy
- Use clear and precise communication
- Assist me in making independent choices: Do with me, not for me

What Makes me Happy

- Dogs
- Going for walks outside
- Spinning
- Playing musical instruments
- Vibrating handheld toys
- Attention
- Socks
- Visiting my family
- Colouring

CDBA Ontario's Apartment Complex

What

- It's About Me profile – snapshot of the individual
- Art of My Life – a visual/tactile representation of what's important to that person
- Individual goals – based on a person's needs, wants and dreams
- Everyday Life – incorporating goals into daily life

Why

- Improved quality of life
- Independence
- Empowerment & excitement
- Sense of achievement
- Enhanced community involvement

When

- Process begins with intake
- Goals reviewed every 3 months at minimum
- It's About Me reviewed annually

How

- Development of plan led by individual, families and Intervenor Services Coordinator

Who

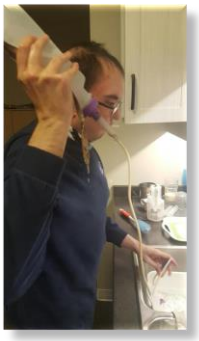
- Individual who is deafblind
- Family
- Friends
- Intervenor services team
- Significant others

It's My Life Planning Process

Jason's SMART Goal

What is your goal in one sentence?
- Jason will clean his food bag independently after his last meal of the day.

The benefits of achieving this goal will be…
- Improve daily living skills, increased responsibility and independence.



Specific
- What exactly will you accomplish?
  - A clean food bag.

Measurable
- How will you (and others) know when you have reached your goal?
  - When Jason cleans his food bag independently for a month.

Attainable
- Is attaining this goal realistic with effort and commitment? Do you have the resources to achieve this goal? If not, how will you get them?
  - Yes.

Relevant
- Why is this goal important to you? Hone in on why it matters
  - Health and independence.

Time-bound
- When will you achieve this goal?
  - 3 months.

Nicholas' SMART Goal

What is your goal in one sentence?
- To complete a load of laundry

The benefits of achieving this goal will be…
- Promote independence and life skills

Specific

- What exactly will you accomplish?
  - A clean load of laundry.

Measurable

- How will you (and others) know when you have reached your goal?
  - When Nicholas is able to put a load of laundry into the washing machine.

Attainable

- Is attaining this goal realistic with effort and commitment? Do you have the resources to achieve this goal? If not, how will you get them?
  - This goal is attainable with consistency and commitment. We have the resources and materials to achieve this goal.

Relevant

- Why is this goal important to you? Hone in on why it matters
  - This goal is promoting independence and teaching Nicholas a life skill.

Time-bound

- When will you achieve this goal?
  - September 2016.

Jason taking money out of the bank during the day and Line Dancing at night

Nicholas supply shopping during the day and Line Dancing at night

Saturday, July 29, 2017

Breakout Session #5: 10:45-11:45am

Panzacola H-3/H-4

Teaching Strategies: Building Bridges Between Home and School

Sharon Stelzer, M.Ed.

Presenter Information

Sharon Stelzer has been teaching students who are Deafblind and with CHARGE Syndrome for over thirty years at Perkins School for the Blind. Sharon has worked with students from the ages of six to twenty-one years old. She loves brainstorming and working with parents and other teachers/professionals in the areas of teaching strategies, communication strategies, literacy development and functional academics. Sharon has worked both nationally and internationally with professionals and families sharing ideas and techniques.

Presentation Abstract

For this presentation the presenter will share teaching strategies that work for children with CHARGE Syndrome. She will present how these strategies are used in school. With input from families of children with CHARGE Syndrome Sharon will link strategies that work at home to strategies that educators use in the classroom. She will discuss the importance of using similar vocabulary in the IEP process and methods to share strategies with the school team.

Saturday, July 29, 2017

Breakout Session #6: 1:00-2:00pm

Panzacola F-1/F-2

Personal Reflections on Transition Supporters in Baseball Parody Format: Take Me Out to The Ballgame

Christopher Sence, BFA
L. Kathleen Sheriff, Ed.D.

Presenter Information

Chris Sence is a 35-year-old man born with CHARGE syndrome. He has his Bachelor of Fine Arts degree from Sam Houston State University in Texas with a major in technical theatre. Mr. Sence is active in the Texas Chargers, volunteers at the Texas School for the Blind, and is an advisory board member for the Helen Keller National Center in New York. He is an avid baseball fan and had the opportunity to work as a baseball team manager in high school and in summer leagues leading to his love of the game. He dreams of watching a baseball game played in every major baseball stadium in the United States.

L. Kathleen Sheriff is the mother of Chris Sence and is a professional special educator. Her doctorate is in Special Education from Texas Tech University with certification in Dual Sensory Impairment. She has taught thousands of children in special education classrooms and currently is on the faculty at Stephen F Austin State University in Texas training pre-service special education teachers.

Presentation Abstract

Chris Sence, a 35-year-old man born with CHARGE syndrome, reflects on his personal transition support system in parody format emphasizing teaming together as a baseball team program to ultimately win at the game of life. He and his mother, Dr. Kathleen Sheriff, share his story of transition supporters matched with baseball program positions from little league to adulthood regarding the choices of majoring on the majors in life. Chris hopes this personal reflection adds to the lives of younger children with CHARGE syndrome and their supporting parents and transition teams.

Saturday, July 29, 2017

Breakout Session #5-7:
10:45-11:45am, 1:00-2:00pm, 2:15-3:15pm

Panzacola F-3/F-4

Adult Track

Kasee Stratton, Ph.D., NCSP, Daniel Gadke, Ph.D., NCSP, BCBA, and R. Matthew Coward, MD, FACS

Presenter Information

Dr. Kasee Stratton and Dr. Daniel Gakde are assistant professors of School Psychology at Mississippi State University. Both are also licensed psychologists and nationally certified school psychologists. Drs. Stratton and Gadke completed their doctoral internship and postdoctoral fellowship at Johns Hopkins School of Medicine and the Kennedy Krieger Institute. They specialize in treating challenging behavior and improving adaptive skills for children with developmental disabilities. Dr. Stratton has worked with individuals for CHARGE for over 12 years and Dr. Gadke primarily teaches behavioral assessment and intervention courses.

R. Matthew Coward, MD FACS is an Assistant Professor of Urology and Clinical Assistant Professor of Obstetrics and Gynecology at the UNC School of Medicine, and Director of Male Reproductive Medicine and Surgery at UNC Fertility in Raleigh, NC. He earned his MD with Distinction at UNC, followed by urology residency at UNC, and fellowship in Male Reproductive Medicine and Surgery at Baylor. Dr. Coward's clinical practice focuses in the areas of male reproduction and fertility as well as male sexual dysfunction. Dr. Coward's second of three children, Ryan, is a 4-year-old who has CHARGE syndrome.

Presentation Abstract

This three-session track will provide a series of presentations, discussions, and question and answer formats ***for adults with CHARGE syndrome ages 16+ only***. Sessions will include topics such as sex, sexual dysfunction, sustaining friendships, guidance on drinking, social media skills, advocating on the job and in the community, and question and answer time periods.

Saturday, July 29, 2017

Breakout Session #6: 1:00-2:00pm
Panzacola G-1

CHARGE Syndrome and Behavior: Diagnoses and Intervention (Part II)

Tim Hartshorne, David Brown, Megan Schmittel, Shanti Madhavan-Brown, Shelby Muhn

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.

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.

Presentation Abstract

Part two: Interventions for challenging behavior. This session describes interventions that can help to reduce the behaviors that often lead to psychiatric diagnoses. These interventions follow the principle that the behaviors are functional for the child given their various impairments. The interventions address issues of pain, sensory processing, and anxiety.

CHARGE Research Lab

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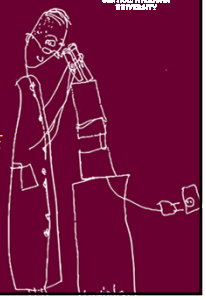
So what the h_ll are we supposed to do?

Coping with the behavior of people with CHARGE

Tim Hartshorne, David Brown, Megan Schmittel and Shanti Brown



One way of sorting and categorizing varied behaviors would be to list them in increasing order of urgency for intervention in the form of the following questions:

1.Is this a behavior that just bugs you personally, so that it can be accepted and ignored?
2.Is this a behavior that seems to help the child to function in a positive way, so that it can be accepted and ignored?
3.Is this a behavior that seems to help the child to function in a positive way, but should be reduced, or replaced by another, better behavior over time?
4.Is this a behavior that is undesirable and needs to be reduced or replaced fairly quickly?
5.Is this a behavior that needs to be prevented immediately?

CHARGE Research Lab

CHARGE Research Lab

Jane bangs her head against the side of the bathtub while taking a bath.
Alan flaps his arms and hands wildly when he is excited.
Megan sticks her hands in her food at some meals.
Bill refuses to get out of bed some mornings, but will just lie there and laugh.
April will sometimes press her fingers into her eyes.
John wants to pull the fire alarm whenever he sees one.
Amber interrupts the class with noisy outbursts.
Tim will drop to the ground sometimes when out on walks or excursions.
Hayley will often make clucking noises that go on and on.
Jason often rocks his body while sitting at the table.
Emily pushes people when they are in her way.
Trevor will sometimes hit and scratch people who are near him.
Heather will bite her fingers until they bleed.
Jared repeatedly checks where his cup and plate are at meals.
Nancy likes to hang upside down on her chair or couch.
TJ will put his hands behind him and grab feces and smear it over his face.
Toni likes to throw her toys after she has played with them.
Ray likes to look at lights and will hold a light close to his eyes.
Jacob will play with people's shows and likes to lick the bottoms of them.
Lauren will have a temper tantrum if anything in her schedule changes.

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Interventions

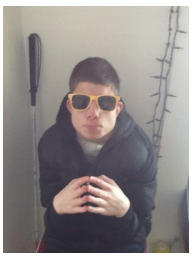
- Always consider pain first!
- Figure out why
- Co-regulation – what do you do to stay basically in control?
- Yoga or Tai Chi
- Sensory breaks
- Calendar systems
- Social stories
- Experience books
- Respect communication
- Managing transitions
- Adapt the environment

CHARGE Research Lab

PAIN?

CHARGE Research Lab

Understand behavior first



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This is normal viewing posture…

…when you have no vestibular sense, upper visual field loss, poor tactile & proprioceptive perception, & low muscle tone.

CHARGE Research Lab

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Co-Regulation

What works for you in managing

- Your thoughts and motivation
- Your feelings and emotions
- Your actions and behaviors
- Your physical state

How do we teach this to our children who do not learn passively?

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Supporting self-regulation

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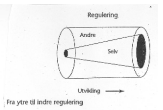
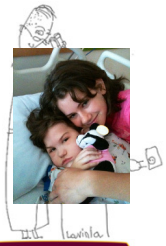
- Because self-regulation skills are hard for children with significant disabilities to develop
- We provide the external support for what will become an internal self-regulatory process





CHARGE Research Lab

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Fun Chi

Reduced stress
Reduced anxiety
Reduced depression
Increased self-esteem
Increased energy/focus/concentration
Increased positive mood
Better balance
Improved sleep
Improved immune system

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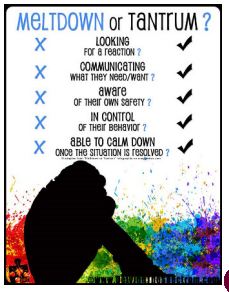
CHARGE Research Lab

Sensory breaks



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Calendar systems

- Anxiety due to a lack of predictability
- Utilize an informed calendar intervention
- Increase self-regulation and predictability
- Reduce anxiety and anxiety related behaviors

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Social Stories

Short, simple, to the point, easy to make, personalized

Conveys social situation and explains how someone would react or what to do

Repetition makes the message stronger

Can help teach a lesson visually

Potty training, sharing, handling anger, change in routine, etc.

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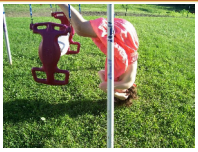
Respect communication



Communication vs. compliance: Jessica

Jessica will only sit in her chair for about 10 minutes at school before she wants to get down.

When she is told that she must stay in her chair longer she tantrums and has a meltdown.

One day she scratched her intervener and then flung herself from the chair and ran to a corner of the room where she lay down on the floor.

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Jacob and the bath

CHARGE Research Lab

CHARGE Research Lab

Managing Transitions

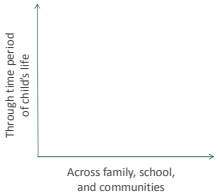
"Goal of a successful transition process is the child's success in the next environment." (Rouse, Hallam, Harbin, McCormick, & Jung, 2007)

Types of Transitions

Between daily activities

Life events

Changes in setting



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Managing Transitions

- Visual and auditory cues
- Visual and tactile daily and weekly schedules
- Explicit teaching on procedure for transitions
- Extra time for processing directions
- Reminders
- Social Stories
- Calendar systems
- Visit and explore new settings

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We know that external factors in the environment can have a profound impact on a child's behavior, so one way we can modify what the child is doing is to change features of the environment.

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Key Elements in Environment

- People
- Time
- Space

Tony Best (1998, July) Structuring the Environment. *Dbl Review*, 4-9

CHARGE Research Lab

People

- Limited in number
- Available
- Responsive
- Not overburdened with non-child tasks
- Consistent
- Engaged
- Skilled observers
- Familiar
- Identifiable (personal markers)

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Time

- Sequences
- Consistency
- Number
- Calendars/ schedules
- Survey past, and anticipate & plan future
- Repetitions (with concrete markers)
- Adapted timepieces

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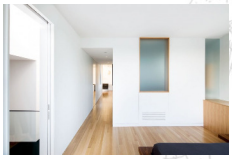
Space/Place

- Markers to identify areas by use/function
- Accessible
- Consistent
- Responsive
- Uncluttered
- Routes
- Landmarks



CHARGE Research Lab

Remember that a child's behaviors can indicate what is wrong/missing from their environment, and can also sometimes point you towards the solution to the problem.

CHARGE Research Lab

Minimize tactile distractions

CHARGE Research Lab

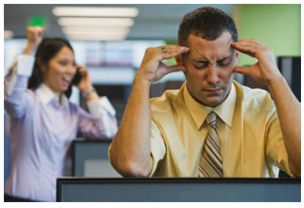
Provide the necessary physical supports for postural security

CHARGE Research Lab

Utilize and allow the most effective postures for attention and comfort

CHARGE Research Lab

Minimize ALL distractions!



CHARGE Research Lab

Keep smell & taste inputs pure and separate

CHARGE Research Lab

Position and support for optimum attention, comfort, and functioning

CHARGE Research Lab

Managing the environment to prevent behavior problems

Consider what you could do to make the environment of your child safe and secure to enable their optimal development, and to avoid challenging behaviors

- Familiar – how could you create an environment that feels safe and secure to the child?
- Regular – how could you create an environment that is predictable to the child?
- Responsive – how could you create an environment that anticipates and responds to the behavior of the child?
- Meets basic needs – how could you create an environment that anticipates and responds to the needs of the child?

For each question, consider the impact of people, time, and space, and sensory impairment.

CHARGE Research Lab

Resources

- Barrey-Grassick. S. (2011).Sign Chi: signing a way to relaxation and stress reduction. *DeafBlind International 47, 11-13.*
- Tony Best (1998, July) Structuring the Environment. DbI Review, 4-9
- Calendars: For Students With Multiple Impairments Including Deafblindness -- Blaha, Robbie. Austin: Texas School for the Blind and Visually Impaired. (2001)
- Lewis, S., & Tolla, J. (2003). Creating and using tactile experience books for young children with visual impairments. *Teaching Exceptional Children*, vol. 35, No. 3, pp. 22-28, Jan/Feb 2003
- Hartshorne, T. S. (2003). Positive behavioral supports and social relationships. *Deafblind International Review.* July-December, Number 32, 4-6.
- Ramirez, M. A., Hartshorne, T. S., & Nicholas, J. (2014, January). Self-regulation in individuals with CHARGE syndrome. *DbI Review, 52,* 43-47.

CHARGE Research Lab

Saturday, July 29, 2017

Breakout Session #6: 1:00-2:00pm

Panzacola G-2

Quality Adapted Physical Education and Recreation for Individuals with CHARGE Syndrome

Dr. Elizabeth (Beth) Foster, CAPE

Presenter Information

Dr. Beth Foster is a Certified Adapted Physical Educator. She worked as an Elementary Adapted Physical Educator in Pennsylvania for 6 years then was an APE consultant in Texas for 4 years. During her time teaching in Pennsylvania, Beth was named the 2012 adapted physical education teacher of the year. Beth has been involved in Camp Abilities, a developmental sports camp for individuals who are blind, visually impaired, or deafblind for the past 12 years. She is currently the assistant director for Camp Abilities in Pennsylvania and Texas. From her experience at Camp Abilities, she developed a passion and determination to be knowledgeable within the field of deafblindness. Beth has presented on various topics about deafblindness across the U.S. She completed intervener training at the Minnesota Deafblind Project. Beth has been involved with the Texas Chargers for the past 3 years providing physical activities for individuals with CHARGE Syndrome at their annual retreat and has directed the Camp Abilities at the past two International CHARGE Conferences. Beth received her PhD in May 2016 by completing research related to children with CHARGE Syndrome and walking. Currently Dr. Foster is an assistant professor at Cal Poly Pomona in California in adapted physical education.

Presentation Abstract

Many individuals with CHARGE Syndrome do not have the same movement opportunities in their schools and in their communities. Come to this session to learn about the federal laws and advocacy skills to obtain a quality physical education or an adapted physical education program for your child at their school. Learn about the motor assessment process and proper Individual Education Programs (IEPs) related to movement and motor skills. Participants will also leave with valuable information to assist in the inclusion of their child in recreation activities within their community.

Saturday, July 29, 2017

Breakout Session #6: 1:00-2:00pm

Panzacola H-3/H-4

Taking CHARGE of Your Gastrointestinal Issues

Dr. Kim Blake, Alexandra Hudson

Presenter Information

Dr. Kim Blake has researched CHARGE Syndrome for 30 years, with over 100 publications: including; post-operative airway events, sleep apnea, bone health, cranial nerve anomalies; gastrointestinal and feeding disorders. Recently her clinical understanding of CHARGE Syndrome has given her the ability to ask research questions that can be investigated with a Zebra Fish model. Dr. Blake's goal is to understand more about the cranial nerves associated with CHARGE Syndrome with respect to gastrointestinal and feeding issues. Dr. Blake has taught thousands of students and residents about CHARGE Syndrome and is involved in active research mentoring.

Presentation Abstract

Gastrointestinal (GI) symptoms and feeding difficulties are highly prevalent but are often a neglected area of diagnosis, treatment and research. In this presentation a young adult will report on her ongoing story with gastrointestinal problems, we will review what is known in the literature and treatment options; some of which have been gathered from you as parents, and from individuals with CHARGE syndrome.

Gastrointestinal (GI) and Feeding Issues in CHARGE Syndrome

Dr. Kim Blake, Professor Pediatrics
IWK Health Centre and Dalhousie University
kblake@dal.ca

Alexandra Hudson & MacKenzie Colp

Guess the Birds Names

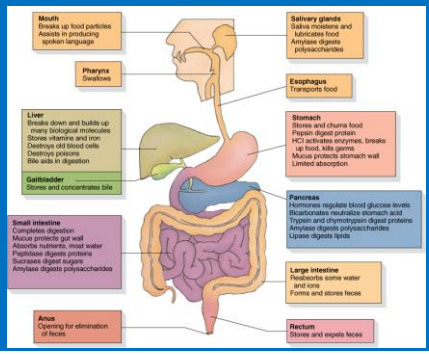
Objectives

After this presentation, you will have a greater understanding of:

1. A young adults struggle with gastrointestinal (GI) symptoms and eating challenges.
2. The breadth of gastrointestinal (GI) issues in CHARGE syndrome.
3. A new feeding scale for CHARGE syndrome.

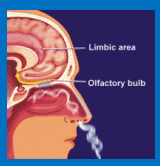
MacKenzie's Story

What We Know



Sense of Smell

- Olfactory bulb absence or hypoplasia has been reported as high as 100% in CHARGE syndrome.
- Reduced or complete absence of sense of smell.



https://www.sense.org.uk/sites/default/files/Puberty_and_smell_in_CHARGE.pdf

Craniofacial Abnormalities

- Cleft palate/lip can interfere with feeding, particularly in infancy
- Children with choanal atresia/stenosis have significantly more GI symptoms than those without this feature

Macdonald M, Hudson A, Ratcliffe E, Bladon A, Blake K. Experiences with feeding and gastrointestinal motility in children with CHARGE syndrome. 12th international CHARGE syndrome conference proceedings. 2016. AJMG.

Salivation

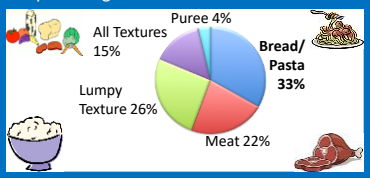
- Excessive salivation and secretions can be a problem
- Treatment options:
  - Botox injection into salivary gland every 3-5 months
  - Combine surgeries together if possible to reduce intra-operative risks (have to suction airway for excess saliva)
- Thin liquids can be a problem too

FIG. 1. Botox injections into the submandibular gland using ultrasound guidance.

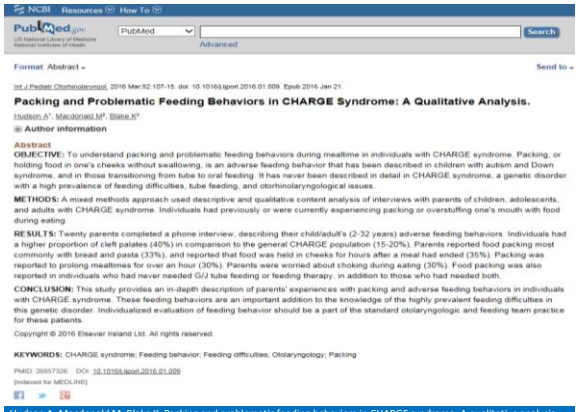
Mouth overstuffing and pocketing food into cheeks

- Can prolong mealtime for > 1 hour
- Parents are concerned about choking

Types of food pocketing occurs with:



Hudson A, Macdonald M, Blake K. Packing and problematic feeding behaviors in CHARGE syndrome: A qualitative analysis. AJMG. 2016



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Int J Pediatr Otorhinolaryngol. 2016 Mar;82:107-15. doi: 10.1016/j.ijporl.2016.01.009. Epub 2016 Jan 21.

Packing and Problematic Feeding Behaviors in CHARGE Syndrome: A Qualitative Analysis.

Hudson A[1], Macdonald M[2], Blake K[3].

Author information

Abstract

OBJECTIVE: To understand packing and problematic feeding behaviors during mealtime in individuals with CHARGE syndrome. Packing, or holding food in one's cheeks without swallowing, is an adverse feeding behavior that has been described in children with autism and Down syndrome, and in those transitioning from tube to oral feeding. It has never been described in detail in CHARGE syndrome, a genetic disorder with a high prevalence of feeding difficulties, tube feeding, and otorhinolaryngological issues.

METHODS: A mixed methods approach used descriptive and qualitative content analysis of interviews with parents of children, adolescents, and adults with CHARGE syndrome. Individuals had previously or were currently experiencing packing or overstuffing one's mouth with food during eating.

RESULTS: Twenty parents completed a phone interview, describing their child/adult's (2-32 years) adverse feeding behaviors. Individuals had a higher proportion of cleft palates (40%) in comparison to the general CHARGE population (15-20%). Parents reported food packing most commonly with bread and pasta (33%), and reported that food was held in cheeks for hours after a meal had ended (35%). Packing was reported to prolong mealtimes for over an hour (30%). Parents were worried about choking during eating (30%). Food packing was also reported in individuals who had never needed G/J tube feeding or feeding therapy, in addition to those who had needed both.

CONCLUSION: This study provides an in-depth description of parents' experiences with packing and adverse feeding behaviors in individuals with CHARGE syndrome. These feeding behaviors are an important addition to the knowledge of the highly prevalent feeding difficulties in this genetic disorder. Individualized evaluation of feeding behavior should be a part of the standard otolaryngologic and feeding team practice for these patients.

KEYWORDS: CHARGE syndrome; Feeding behavior; Feeding difficulties; Otolaryngology; Packing

PMID: 26857326 DOI: 10.1016/j.ijporl.2016.01.009

[Indexed for MEDLINE]

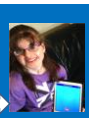
Hudson A, Macdonald M, Blake K. Packing and problematic feeding behaviors in CHARGE syndrome: A qualitative analysis. AJMG. 2016

Feeding Behaviours Identified from the Study

- Would not mix liquids and solid food
- Have to finish all food and have an empty plate
- Same routine needed at each mealtime
- Anger if food taken away in order to prevent pocketing/overstuffing

Hudson A, Macdonald M, Blake K. Packing and problematic feeding behaviors in CHARGE syndrome: A qualitative analysis. AJMG. 2016

Top 5 Parents' Tips & Tricks



An iPad timer that reminds to swallow ever 30 seconds

Intervention theme	Specific examples
Verbal prompts during eating	• Have a gestural prompt or cue (i.e., touch his hand) when starts over-stuffing • Tell or sign to chew and eat before give more food
Soft foods	• Cook to a soft consistency • Soft diet • Blending and pureeing the food • Give textures that they can handle easily
Include in the family dinner	• Sit at the dinner table with everyone • Eat similar foods as the family
Close supervision	• Be present during feeding • Have an occupational therapist watch him/her eat once a month
Distractions	• Use an iPad to distract while eating • Watch a favorite TV show during eating • Use favorite foods as incentives• Create a calm environment

Cranial Nerves

These guys direct the traffic & run the show

Name	What It Does
I Olfactory	Smell
II, III, IV, VI	Eye control
V Trigeminal	Chewing, sensory for facial regions; sensations in the sinuses, the palate and the upper lip, the jaw, mouth and tongue.
VII Facial	Facial movements, taste, salivation
IX Glossopharyngeal	Taste, salivation, swallow; some visceral
X Vagus	Phonation, swallow; important visceral
XI Spinal Accessory	Moves head & shoulders; laryngeal muscles
XII Hypoglossal	Movement of the tongue

11th International CHARGE Conference Kate Beals & Kim Blake

Experience with Feeding and Gastrointestinal Motility in Children with CHARGE Syndrome

Meghan & Kim at the Research in Medicine (RIM) Presentations at Dalhousie University 2015

Questionnaires

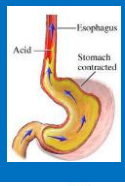
- Structural abnormalities
- Motor impairment
- Oral sensory impairment
- Delayed oral feeding
- Reflux
- Bloating
- constipation

Questionnaires + Short Answer Questions

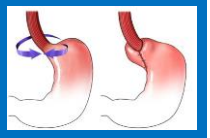
- Questionnaires include:
  - Demographic and CHARGE characteristics
  - Pediatric Assessment Scale for Severe Feeding Problems ©IWK
  - PedsQL™ Gastrointestinal Symptoms Scale
- Short Answer Question Topics:
  - Reflux and vomiting
  - Bloating
  - Constipation
  - Transition from tube feeding to oral feeding
  - Three major feeding/motility challenges

Treatments for Gastroesophageal Reflux (GER)

1. Behavioral treatment – raising the bed, small frequent meals, limiting foods that promote reflux such as tomatoes, meat, chocolate.



1. Medical management
   - Ranitidine 8mg/kg per day in 2-3 divided doses (for babies 3-4 divided doses)
   - Prevacid (lansoprazole)- 1-2 mg/kg per day at the beginning of the day (occasionally twice a day)
   - Domperidone (Motilium) – 4 times a day before meals (watch for side effects)
   - Cisapride (Propulsid) special authorization



Also consider cow's milk protein intolerance

Tube Feeding

- Over 90% need tube feeding (gastrostomy or jejunostomy)
- Tube feeders vs. oral feeders
  - More stomach pain
  - More stomach discomfort when eating
  - More food and drink limits
  - More trouble swallowing
  - More nausea and vomiting
  - More constipation

Macdonald M, Hudson A, Ratcliffe E, Bladon A, Blake K. Experiences with feeding and gastrointestinal motility in children with CHARGE syndrome. AJMG. 2016

Abdominal Pain

- Reflux
- Bloating
- Difficulty with digestion
- Abdominal migraine
- Constipation
- Non organic

Constipation – Big Issue

How are you dealing with it?

Prevention / Treatment for Constipation

Prevention:

- Fluids
- Exercise
- Behavioural therapy
- Diet
- Massage

Treatment:

- Polyethylene glycol / MiraLAX
- PEG
- Senocot
- Behavioural techniques

NCBI Resources How To

PubMed.gov US National Library of Medicine National Institutes of Health

PubMed | for poor bone health in adolescents and adults with CHARGE syndrom | Search

Create RSS Create alert Advanced

Format: Abstract Send to

Am J Med Genet A. 2007 Apr 15;143A(8):839-45.

Risk factors for poor bone health in adolescents and adults with CHARGE syndrome.

Forward KE, Cummings EA, Blake KD.

Author information

Abstract

CHARGE syndrome, is associated with genital hypoplasia, feeding difficulties and delayed puberty. In this study we examined the prevalence of risk factors for poor bone health in adolescents and adults with CHARGE. Questionnaires assessing fracture history, dietary intake of calcium and vitamin D, pubertal status and activity level using the Habitual Activity Estimation Scale (HAES) were completed by caregivers. Control data were collected for the HAES. When available, reports from dual-energy X-ray absorptiometry (DEXA) were obtained. Thirty individuals with CHARGE syndrome (n = 15 males; n = 15 females; age range 13 to 34 years; mean age 19.6 years) were recruited. Traumatic bony fractures were identified in 30% of the population. The recommended nutritional intake (RNI) for calcium and vitamin D were not met by 41% and 87% of the population, respectively, and 53% required past tube feeding. Delayed puberty was experienced by 87% with only 4 individuals (2 female, 2 males) having experienced normal puberty. Hormone replacement therapy (HRT) was taken by 33% of females and 60% of males. According to the HAES, adolescents with CHARGE syndrome (13-18 years) were significantly less active than controls. Individuals with CHARGE syndrome age 19 and older were also less active than controls, although this difference was not significant. DEXA scan data was obtained, however, due to small sample size (n = 10) and confounding variables (i.e., short stature, pubertal stage, height, weight), it was difficult to draw meaningful conclusions. Feeding difficulties, inactivity and hypogonadism are predisposing factors for the development of poor bone health among individuals with CHARGE syndrome. Education is necessary to raise awareness regarding the importance of HRT, proper nutrition and weight-bearing activity for healthy bone development and maintenance in individuals with CHARGE syndrome.

PMID: 17366585 DOI: 10.1002/ajmg.a.31679

[Indexed for MEDLINE]

Forward K, Cummings E, Blake K. Risk factors for poor bone health in adolescents and adults with CHARGE syndrome. AJMG. 2007

Bone Health

- 87% of individuals are not getting enough vitamin D
- 41% not getting enough calcium

- Treatment
  - Encourage intake of vitamin-D rich foods
  - Supplementation of 1000 IU Vit D

Forward K, Cummings E, Blake K. Risk factors for poor bone health in adolescents and adults with CHARGE syndrome. AJMG. 2007

Physical Activity

- CHARGE individuals have decreased activity compared to other teenagers, especially on weekends
- Weight-bearing exercises are important to increase:
  - Bone mineral density
  - Prevent osteoporosis
  - Help maintain normal weight

Forward K, Cummings E, Blake K. Risk factors for poor bone health in adolescents and adults with CHARGE syndrome. AJMG. 2007

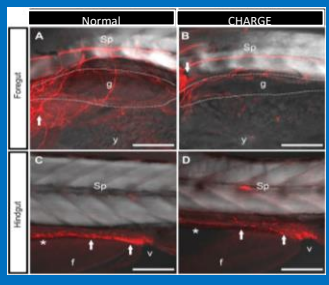
Adolescents and Adults

- Feeding difficulties found in 90% of adolescents and adults with CHARGE syndrome in Canada
- New issues that can arise after childhood
  - Abdominal colic
  - Pocketing/overstuffing
  - Gallstones

Modeling CHARGE Syndrome in Zebrafish: A Look at the Innervation and Function of the Gastrointestinal System

Kellie Cloney presenting at the Dalhousie Research in Medicine (RIM) 2015. Award for Outstanding Platform Presentation.

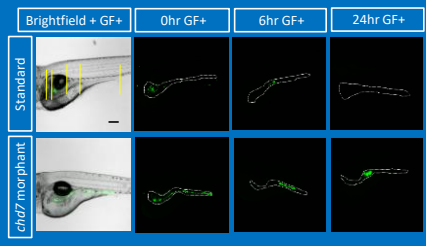
Innervation of the Gut



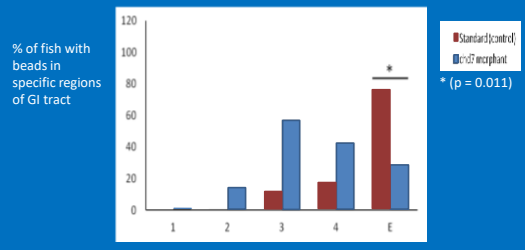
Using immunohistochemistry, we highlighted the enteric nervous system. Here we show that there was a decrease in the amount of enteric nerve branches around the foregut. Also, the gut is outlined in photos A and B – and you can appreciate that there is a difference in the morphology (size and shape) of the gut in the CHARGE fish as well.

Sp = spine, F = ventral fin, V = vent, G = gut (outlined in hashed line), arrow = vagal nerve plexus, y = yolk

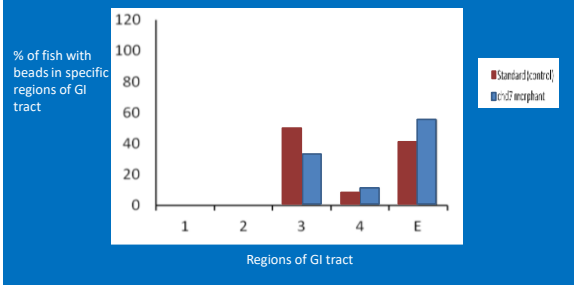
Decreased motility shown in CHARGE zebrafish by delayed emptying of GI tract



Significant difference in number of fish with empty gut at 24 hours when comparing CHARGE fish to normal zebrafish



Erythromycin corrects motility deficit in CHARGE zebrafish



"Hot off the press!"
A new feeding scale for CHARGE syndrome

Subsection of Feeding Scale

Circle one number on the scale:		Never	A Little	Sometimes	A lot	Always
16	He/she has difficulty moving food around with his/her tongue during eating.	0	1	2	3	4
17	He/she has a hard time feeling food or anything touching the inside of his/her mouth.	0	1	2	3	4
18	He/she dislikes oral eating.	0	1	2	3	4
19	He/she lets food sit in his/her **cheeks or palate** during eating (on purpose or not).	0	1	2	3	4
20	He/she will have food hidden in his/her **cheeks or palate** after the meal has ended (on purpose or not).	0	1	2	3	4

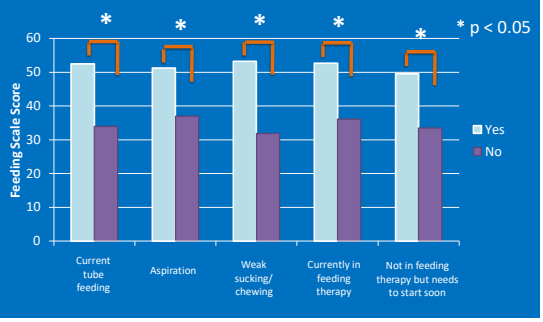
Scoring of feeding scale for CHARGE syndrome

29	Soft chewable foods (e.g. bread, crackers)	0	2
30	Tough chewable foods (e.g. meat)	0	1
31	Hard vegetables and fruit (e.g. raw apples)	0	1
	Total Score (sum of all items)		/100 total points

Out of 100 points

Higher score = worse feeding difficulties

Individuals with feeding difficulties had worse feeding scale scores



Three uses for the feeding scale for CHARGE Syndrome

1. As a structured tool to assess the severity of feeding difficulties
2. To track oral feeding progress before and after interventions
3. To warn the clinician and feeding therapist of new concerns

*Learn more at Alexandra Hudson's poster at the poster session

*Print off copies of the feeding scale on the CHARGE syndrome website

Ongoing research for parents at this conference!

GI and feeding difficulties in CHARGE syndrome:
Treatments tried and parents' perceptions of their effectiveness

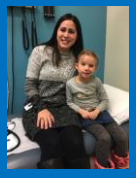
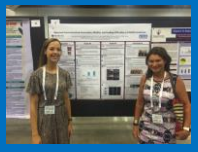
Visit us at the research booth!

IWK CHARGE Clinic Students & Residents Using the CHARGE Checklist





Questions and Answers



A new feeding scale for use in CHARGE syndrome: Potential for use in other genetic syndromes

Alexandra Hudson[1], Kasee Stratton[2], Jill Hatchette[3], Kim Blake[3,4]

[1]Dalhousie Medical School; [2]Mississippi State University; [3]IWK Health Centre; [4]Faculty of Medicine, Dalhousie University

Background

- CHARGE Syndrome is an autosomal dominant condition involving the *CHD7* gene on chromosome 8, affecting 1 in 15,000 live births.[1]

C: Coloboma of the eye
H: Heart defects
A: Atresia/stenosis of the choanae
R: Retardation of growth
G: Genitourinary abnormalities
E: Ear abnormalities and deafness.

Figure 2: Common 'cup' shaped outer ear.

Figure 1: Characteristic CHARGE facial features with facial palsy and square chin.

- Individuals experience a high prevalence of feeding difficulties, starting from birth.[1,2]
- Their feeding difficulties often differ from those of typically developing children, which may not be accurately captured using existing scales.[2]

Objective

To develop, and test the validity and reliability of, a user-friendly feeding scale for individuals with CHARGE syndrome of all ages.

Methods

Feeding scale questions were adapted from the Pediatric Assessment Scale for Severe Feeding Problems (PASSFP)[3] and the current literature

→ Experts on genetic syndromes, feeding therapy, and general pediatrics reviewed the new feeding questions

→ Ten parents of individuals with CHARGE syndrome (all ages) piloted the new scale

→ Parents of individuals with CHARGE syndrome were contacted via the official Facebook pages of each International CHARGE syndrome foundation

→ Interested parents were sent an online link to:
1. The new feeding scale (see figure below)
2. The PASSFP
3. General feeding questions

→ A subset of parents completed the new feeding scale again 2-4 weeks later

Date: _____
Name of Individual: _____
Age:_____ Gender (Circle one): Male Female Not Disclosed
Completed By (Circle one): Mother Father Feeding Therapist Nurse/Physician Other:_____

What percentage of your child/adult's daily fluid/nutrition intake is by GJ tube feeding? (Circle one percentage):

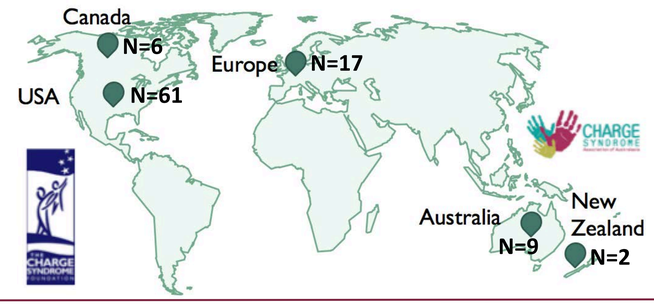
0%	25%	50%	75%	95%

Circle one number on the scale:		Never	A Little	Sometimes	A lot	Always
1	He/she will refuse food when eating orally.	0	1	2	3	4
2	He/she takes longer than 45 minutes to eat orally.	0	1	2	3	4
3	He/she takes less than 15 minutes to eat orally.	0	1	2	3	4
4	He/she needs **close supervision** when eating orally.	0	1	2	3	4
5	He/she needs **someone in the room** when eating orally.	0	1	2	3	4
6	He/she has problems cutting food when eating orally.	0	1	2	3	4
7	He/she has problems feeding him/herself when eating orally.	0	1	2	3	4
8	He/she chokes or coughs when eating orally.	0	1	2	3	4
9	He/she has **trouble** chewing food.	0	1	2	3	4
10	He/she has **trouble** swallowing food.	0	1	2	3	4
11	He/she has to be **told or reminded** to chew.	0	1	2	3	4
12	He/she has to be **told or reminded** to swallow.	0	1	2	3	4
13	He/she does not like to mix food textures when eating (e.g. mixing puree and solid food).	0	1	2	3	4
14	He/she accidentally loses food out of his/her mouth during eating.	0	1	2	3	4
15	He/she will over-stuff his/her mouth with food during eating.	0	1	2	3	4
16	He/she has difficulty moving food around with his/her tongue during eating.	0	1	2	3	4
17	He/she has a hard time fueling food or anything touching the inside of his/her mouth.	0	1	2	3	4
18	He/she dislikes oral eating.	0	1	2	3	4
19	He/she lets food sit in his/her **cheeks or palate** during eating (on purpose or not).	0	1	2	3	4
20	He/she will have food hidden in his/her **cheeks or palate** after the meal has ended (on purpose or not).	0	1	2	3	4
21	The **Parent/Caregiver** gets worried about their child/adult's ability to eat orally.	0	1	2	3	4
22	The **Parent/Caregiver** has difficulties feeding their child/adult. (e.g., preparing food the right way, getting enough information about helping them eat/drink)	0	1	2	3	4

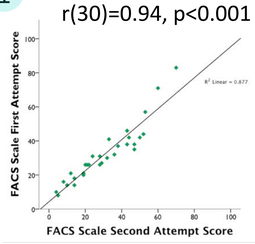
Does the child/adult have problems with:	No	Yes
23 Cold foods	0	1
24 Room temperature foods	0	1
25 Warm foods	0	1
26 Thin liquids (e.g. water)	0	1
27 Pureed foods (e.g. applesauce)	0	2
28 Mashed lumpy food (e.g. mashed potatoes or mashed vegetables)	0	2
29 Soft chewable foods (e.g. bread, crackers)	0	2
30 Tough chewable foods (e.g. meat)	0	1
31 Hard vegetables and fruit (e.g. raw apples)	0	1
Total Score (sum of all items)		/100 total points
Circle one:	**Feeding difficulties:** Mild (0-25 points) Moderate (26-50 points) Severe (51-100 points)	

Results

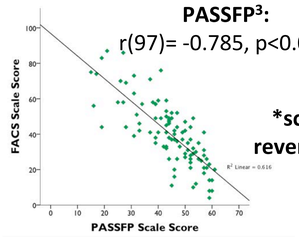
Participants: 100 parents of individuals with CHARGE syndrome (>1 year old) who ate at least 5% of their daily intake by mouth



1 **Test Re-Test Reliability:**
r(30)=0.94, p<0.001



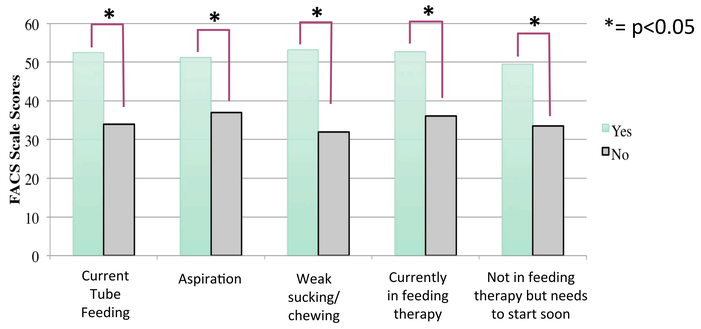
2 **Convergent Validity with the new feeding scale and the PASSFP[3]:**
r(97)= -0.785, p<0.001



***scales are reverse scored**

3 **Internal Validity**
Cronbach's alpha=0.909

Individuals with parent-reported feeding difficulties had significantly higher feeding scale scores



CHARGE syndrome characteristics associated with significantly worse feeding difficulties (higher feeding scale scores)

1. Cleft palate:
   - Mean feeding scale score 47 (SD 22) for those with vs. 38 (SD 16) for those without (p=0.03)
2. Cranial nerve IX, X, XI dysfunction (swallowing difficulties)
   - Mean feeding scale score 44 (SD 19) for those with vs. 29 (SD 14) for those without (p=0.002)

Conclusions

1. This new feeding scale is a valid and reliable tool in the CHARGE syndrome population.

2. The new feeding scale can be used:
   - ✓ As a structured tool to assess the current severity of feeding difficulties
   - ✓ To track oral feeding progress before and after feeding therapy, as well as over the entire lifespan
   - ✓ To alert to areas of concern requiring intervention

3. This feeding scale has the potential to be tested for validity and reliability in other genetic syndrome populations experiencing a high incidence of otolaryngological and feeding difficulties.

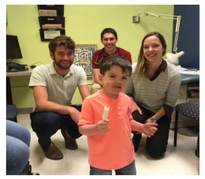


Figure 4: A young boy with CHARGE syndrome enjoying a popsicle snack.

Figure 3: From L to R (back): Alexandra , Kellie, Meghan. In front, Charley, a teenager with CHARGE syndrome from PEI, attending the 12th International CHARGE syndrome conference, Chicago, IL, 2015.

Easily added up to a score out of 100 points (higher scores = worse feeding difficulties)

29	Soft chewable foods (e.g. bread, crackers)	0	2
30	Tough chewable foods (e.g. meat)	0	1
31	Hard vegetables and fruit (e.g. raw apples)	0	1
	Total Score (sum of all items)		/100 total points
	Circle one:	**Feeding difficulties:** Mild (0-25 points) Moderate (26-50 points)	

Three categories of feeding difficulties:
1. **Mild (0-25)**
2. **Moderate (26-60)**
3. **Severe (51-100)**

References

1. Dobbelsteyn C, Peacocke SD, Blake KD, Crist W, Rashid M. (2008). Feeding difficulties in children with CHARGE syndrome: Prevalence, risk factors, and prognosis. *Dysphagia,* 23, 127-135.
2. Cooper-Brown, L, Copeland S, Dailey S, Downey D, Cesar Petersen M, Stimson C, Van Dyke DC. (2008). Feeding and swallowing dysfunction in genetic syndromes. *Developmental Disabilities*, 14, 147-157.
3. Crist W, Dobbelsteyn C, Brousseau AM, Napier-Phillips A. (2004). Pediatric assessment scale for severe feeding problems: Validity and reliability of a new scale for tube-fed children. *Nutrition in Clinical Practice,* 19, 403-408.

Acknowledgements

Thank you to Tracy Sainsbury for ongoing assistance and to the Dalhousie Medical School Research Foundation, Dalhousie medical research foundation music in medicine summer studentship, Murray McNeil Summer Studentship, Dalhousie Faculty of Medicine Webster Summer Studentship, and the International CHARGE Syndrome Foundation for funding.

Five Hints for new and seasoned Parents

Raising your child with CHARGE

Timothy S. Hartshorne

Communication, communication, communication

With oneself, with others, with the world

Communicate as you would with any other baby

- Facial expressions are important
- Cooing and laughing
- Motherese
- Touch
- Imagine being in a foreign country and not understanding the language

Learn the communication system that works best for your child

- Not the other way around
- Do not use just one system
- Feel free to combine communication approaches
  - Gestures and facial expressions
  - Oral
  - Sign
  - Picture

"My child has no communication"

- This is never the case.
  - All behavior has a purpose
  - All behavior is communication
- Once the child believes nobody is communicating, they will shut down
- Not all behavior is intentional communication – but it can be read
- Even if your child likes to withdraw, do not let them alone for too long

Routine

Find a routine as soon as possible

- Children with CHARGE thrive on routine and predictability
- A calendar system to communicate the schedule is essential
- While a certain amount of chaos is quite natural, particularly in some families, it will not be compatible for your child with CHARGE

Anxiety is related to uncertainty about what is going to happen next

- What will happen today?
- What do they want me to do?
- Where are we going?
- What will happen when we get there?
- Will I feel ***safe***?
- The world does not always make sense
- It can be unpredictable

We like to know what is going on.

- What are we doing right now?
- What are we going to do next?
- What did we just do?

When we are not sure…

- We become anxious
- We engage in behavior which expresses our feelings
- We engage in behavior or activities that help us feel more secure

Hitting mom

Supporting self-regulation

- Self-regulation allows us to organize and manage our thoughts, feelings, behavior, and body, so that we can manage our day and meet our goals
- Because self-regulation skills are hard for children with significant disabilities to develop
- We provide the external support for what will become an internal self-regulatory process
- A major component of this is routine

Discipline

"I can't say 'NO'."

No pass on discipline

- Because your child has CHARGE does not give them a break on learning to cooperate with family living.
- Behavior is communication

Jacob and the bath

Behavior also has consequences

- Natural consequences – if I did nothing what would happen
  - Doing nothing is surprisingly hard work for parents
    - Don't want to appear to be a bad parent
    - It can mean extra work
  - If you push your food off your plate, it falls to the floor and the dog eats it.
- Logical consequences – pre-established response
  - "Let the punishment fit the crime." Teaching cause and effect.
    - Must be related to the child's action
    - Must be revealed in advance
    - The child chooses the consequence
  - Splash in the tub and bath time is over

Destructive and Aggressive Behavior

- Consequences do not work very well
- First, stay calm
  - Of course it is not easy
  - But if you get aroused, it will increase the arousal of the child
- Know your child and their triggers
  - Changes in routine
  - Chaotic environment
  - Pain or illness
- Can the environment be modified to minimize risk?
- Watch out for responses to the child that increase the likelihood they will do this again

Getting Connected

Who understands what you are experiencing?

Get connected

- It is hard enough to raise a more typical child. For this one you need help.
- Join the CHARGE Syndrome Foundation
- Get together with other families who have a child with CHARGE
- Go to the conferences
- Join the Facebook pages
- Connect with parents of children with other disabilities
- Check out services for children who are deafblind

Acceptance and Advocacy

Acceptance and Advocacy

- Your child has CHARGE. It is tough on everyone. Move on.
- Learn to accept and love your child with no need for your child to be any different
- You are your child's primary and often sole advocate
- Your job is to fight like heck to make sure your child gets what he or she needs
- Find allies in the fight

TAMING THE WOLVES

AND THE PARENT FROM HELL

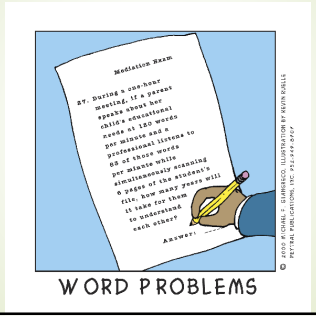
Diagnosis

DIAGNOSIS DU JOUR

Treatment

THE DISTRICT'S EXPERIMENTAL METHOD FOR DETERMINING RELATED SERVICES WORKS JUST AS WELL AS MAKING THOSE DECISIONS BEFORE KNOWING A STUDENT'S IEP GOALS AND OTHER LEARNING OUTCOMES.

Communication



Intimidation

Predictions

MARATHON SKILLS

Ann P. Turnbull

- Meet basic needs
- Know your self and your family
- Love unconditionally
- Establish relationships
- Experience and benefit from emotions
- Take charge
- Anticipate the future
- Establish balance

Saturday, July 29, 2017

Breakout Session #7: 2:15-3:15pm

Panzacola F-1/F-2

Incorporating Literacy into Daily Routines at School and at Home

Martha Veto and Christine Spratling, Ed.S.

Presenter Information

Martha Veto received her M.Ed from the University of Pittsburgh and worked as a teacher for the visually impaired/orientation and mobility specialist for 25 years before joining the South Carolina Interagency Deaf-Blind Project in 2005. She has worked as the GSAP Project Coordinator since moving to Georgia in 2008.

Christine is the Technical Assistance Specialist, Georgia Sensory Assistance Project.

Presentation Abstract

Children with combined vision and hearing loss have a hard time developing concepts about the world around them. Learning routines are an effective tool to help. In this session we will use materials from the Open Hands, Open Access (OHOA) learning modules to show the power of using routines to develop concepts, language and literacy skills. Participants will have an opportunity to use an OHOA tool for planning routines for individual students.

A Plan For My Routine Book

Who is it for? __Sidney_____

Age_13___ Vision: _blind Hearing: deaf (maybe some sounds, but minimal response to sound

Language development: tactile sign (<10 signs), object cues (<10)

What is the routine in which your book will be used? Daily hygiene routine

How will you use this book? What is its purpose? To build independence in moving from one step to another in a familiar routine (reduce physical prompts).

What concepts or skills are we working on with this routine book?

©Things happen in an order. I can do things for myself. Things are kept in a place where I can find them.

(S) get hygiene materials, turn on water, attempt to perform toothbrushing, face washing, deodorant, nails

How will the child participate in making this book?

Gather materials with teacher and help attach Velcro to symbols.

How will the child participate in reading and sharing this story?

Set up book by putting objects on each page at the beginning of the routine. Carry book to sink. Turn page when one step is over

What kinds of representational symbols will be used? (pictures, objects, textures, tactile symbols, sounds) Part of object used in the routine: piece of toothbrush, cap of deodorant, etc.

What kind of text will be used for this book? (braille, print, sound, sign language pictures, Spanish) Braille for her paired with tactile signs; pictures of signs and print for adults

College of Education
UNIVERSITY OF GEORGIA
Communication Sciences and Special Education
http://gsap.coe.uga.edu

GSAP Georgia Sensory Assistance Project
Supporting Children and Youth with Combined Vision and Hearing Loss

Communication Matrix Activity 1- What did we learn?

Student: Date: Who completed the form:

For the Matrix you just completed, respond to the following questions:

Which statement did you select for your child? (A, B, C or C symbols)

Briefly describe an example of the child's behavior that helped you choose that starting statement.

At what level (1-7) of communication do you feel this child is primarily functioning? 1 2 3 4 5 6 7

What leads to that conclusion? Describe the communicative forms and functions that point to that level.

What do you feel is the most important next step for this child in the development of expressive communication? What should be the focus of your intervention around communication? (e.g. develop intentional communication, initiate communication, use more conventional behaviors to communicate, begin using symbols, use more abstract symbols)

This activity was developed as a TA tool by the Georgia Sensory Assistance Project

Activity 2 - Choosing Goals

What do we know about the child's vision, hearing, and motor skills that could affect which communication modes at their Matrix level are appropriate to target? (visual or tactile sign/ pictures or tactual symbols/ point or eye gaze/movement of head or limbs)

What communication modes are most important to target now? (sign, speech, tangible symbols, use of device, gestures, body movement, facial expression, body tone) Note: children should have multiple modes available to them in different contexts and environments. The specific mode for each activity will be determined within each routine.

What messages are most important to target? (e.g., I want more ____, I don't like ____, I want (specific thing), labels, response to questions, comments, greetings)

Write 3 communication goals for the student: (X will touch a picture from 3 symbol array to request a toy, X will shake his head to indicate NO when asked a question, X will find and give me the object cue representing finished when he wants a break)

1.

2.

3.

Activity 3 - Embed goals into routines

Now think of some activities where you can practice these communication skills. Think about how you might alter the activity to build in opportunities for the student to have a communicative exchange, either with an adult or with a peer. (The Design to Learn Inventory is a great tool for this- www.designtolearn.com if you need help) Try to find 2-3 activities in the day to address each of your communication goals.

Activity	Communication goal(s) we can address	What will you do to create a communication opportunity in this step?

Develop a routine with steps that can be followed consistently. Think about the response you want the student to make (e.g.- speak, sign, touch a picture or object cue, use a device, gesture, smile, look toward….) and how you will let the student know it is his turn to do something without doing it hand-over-hand (e.g., verbal prompt, a signed prompt, an object or picture cue, or model the desired response). Finally, whether he responds correctly or incorrectly, what response will you make to confirm his response? (clap hands, "good job", sign "yes", / co-actively make the desired sign, reduce complexity of the array, model desired response and try again)

Activity:

Communication goals to address:

Step in the routine	What strategy or cue will you use to encourage / elicit the student's communicative behavior?	What specific communicative behavior do you want the student to exhibit?	How will you give the student specific feedback (praise or correction)?

Incorporating Literacy into Daily Routines at School and at Home- for Children with Multiple Disabilities

Christine Spratling & Martha Veto, Georgia Sensory Assistance Project

GSAP Georgia Sensory Assistance Project

An Expanded View of Literacy

Literacy is more than reading and writing.

- Literacy development is founded on experiences and concepts beginning very early in life
- Literacy instruction must include a strong emphasis on communication and socialization
- Literacy exists along a continuum from emergent to independent

http://literacy.nationaldb.org/index.php/welcome/

NCDB Literacy Website: http://literacy.nationaldb.org/index.php/welcome/

Social Functions of Literacy

Knowledge and/or information dissemination

Memory support/organization

Self-expression

Entering a fantasy world

Entertainment

Financial management

Instructions

Dealing with emotions

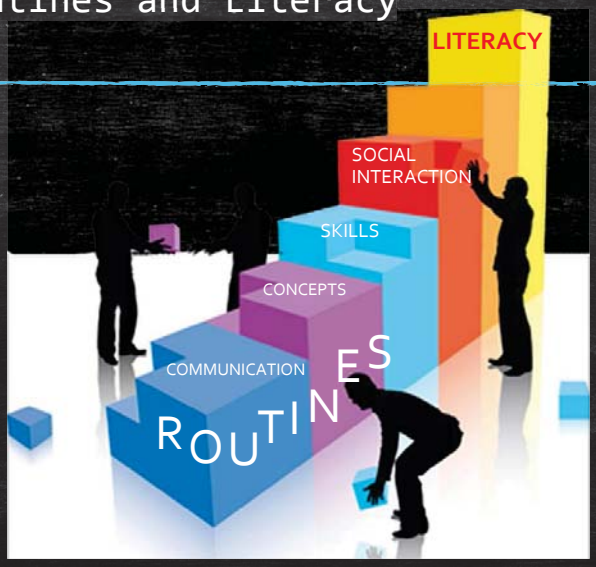
Identifying things or places

Creating and maintaining relationships

and more

Routines and Literacy

By building concepts, communication skills, and social interactions; routines are the building blocks of literacy

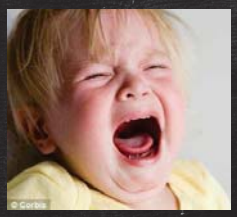


What is a routine?

- Has a clear beginning
- Happens in the same location each time
- Uses the same materials
- Uses a consistent sequence of steps
- Pacing dictated by the student's needs

OHOA Modules- Module 9: Routines for Participation and Learning

Why Routines? To reduce stress, build memory and skills through predictability and consistency



When children don't know what is about to happen- they are stressed. Routines can help with transitioning between activities

Because he walks this route every day, he remembers where his classroom is

When they practice a skill every day, children get better at it

Why Routines? To build concepts behind the skills we teach

Concept development is a critical issue for children with dual sensory loss

Skills vs Concepts and Schemas

Why Routines? To improve communication

Learning to interact with others, communicate with others in meaningful, daily activities

What activity makes a good routine?

- important skills are being worked on during the activity
- the activity can occur frequently—one or more times daily
- the learner enjoys the activity or, at least, some aspect of the activity
- a partner is available for interaction with the learner during the activity
- the activity can be structured so that it happens the same way each time

From Millie Smith- Sensory Learning Kit Guidebook

Developing a Routine

Student: Ray — Routine: Grooming with Chris

Routine Steps	Adaptation / Modification	Targeted Vocabulary	Skill	Concepts
Introduce the grooming routine to Ray. Start at the daily calendar. Show him the object symbol (toothbrush) for the routine. Say and sign "grooming."	Real (concrete) object symbols Daily calendar Hand-under-hand modeling Tactile sign and gestures Speech/ vocalizations	"Brush" "Wipe" "Shake-shake-shake" (mousse) "Hair" "Smack-smack" (aftershave) "And then" "Swing"	Using listening skills to help attach meaning to actions and objects. Tactile discrimination. Categorizing the items included in the grooming routine. Interacting with another person (turn-taking).	The grooming routine has a beginning. I can trust others. Other people are fun.
Move to the grooming station. Load the sequence box with objects for the routine.	Same as above	"Finished" "And then"	Listening skills. Using the sequencing box from left to right. Using a literacy system (sequencing box).	words/sounds are connected to objects and actions Steps in events can be organized in sequence I can read the sequence from left to right
Use the objects and sequence box and run the routine.	Same as above	"Good job" "Finished"	Turn taking Tooth brushing Listening Skills Identify body parts	Idea of "self." Idea of "mine" and "yours." There is a connection between a sign or word and a specific action (i.e., words have meanings).
Finish putting the grooming items in the finished box. Then empty the box into grooming drawer. End the routine.	Finished box Real (concrete) objects Grooming drawer	"Hug"	Putting things away where they are stored.	Building associations between objects, actions, and people.

This "Activity Routine Form" was developed by Kate Moss, Texas Deafblind Outreach, 2002 — August 2015

OHOA module 10- Learning Activity 4-"IUsing Routines to Enhance Concept Development"

Home Routines

Activity: Bedtime Routine

**Start – then PAUSE = Look for ANTICIPATION =Give Chance for PARTICIPATION

Object Cue	Key Signs	Key Words	Prompts Object, Sound, Smell, Taste, Touch, Proprioceptive, Vestibular
Blanket with baby safety pin with beads in the four corners	• Time to • Sleep • Blanket • Bed • Kiss	• Time to sleep • Lie down • Tuck Ivey in • Bedtime kisses • Night Night	• Touch: Blanket, Bed, cocoon of rolled blankets, Good night kisses • Sound: There was an old lady who swallowed a fly (classical) • Proprio: squeeze arms and legs

Where to Start with Literacy Instruction in Your Routines Begins with a Look at Communication

- The concepts, we can address through routines depend on the child's language development (Symbols and Meaning, Millie Smith, APH)

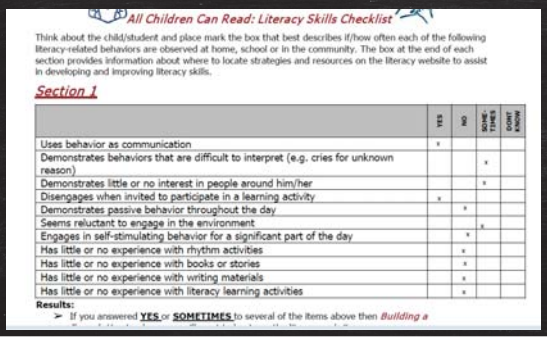
-The Communication Matrix: www.communicationmatrix.org

Communication-Based Routine Development

- Assess communication
- Develop communication goals
- Provide multiple opportunities daily to work on those goals (example)
- Develop routines with targeted vocabulary

Literacy Checklist from NCDB

- Knowing where your student is developmentally helps you provide appropriate literacy instruction
  - Literacy Checklist Literacy.nationaldb.org



All Children Can Read: Literacy Skills Checklist

Think about the child/student and place mark the box that best describes if/how often each of the following literacy-related behaviors are observed at home, school or in the community. The box at the end of each section provides information about where to locate strategies and resources on the literacy website to assist in developing and improving literacy skills.

Section 1

	YES	NO	SOME-TIMES	DON'T KNOW
Uses behavior as communication	x			
Demonstrates behaviors that are difficult to interpret (e.g. cries for unknown reason)			x	
Demonstrates little or no interest in people around him/her			x	
Disengages when invited to participate in a learning activity	x			
Demonstrates passive behavior throughout the day		x		
Seems reluctant to engage in the environment			x	
Engages in self-stimulating behavior for a significant part of the day		x		
Has little or no experience with rhythm activities		x		
Has little or no experience with books or stories		x		
Has little or no experience with writing materials		x		
Has little or no experience with literacy learning activities		x		

Results:

➢ If you answered **YES** or **SOMETIMES** to several of the items above then *Building a*

Linda Hagood's 3-levels of communication

Level 1 - Presymbolic with limited interactive skills

Level 2 - Early Symbolic with emerging dialoguing skills

Level 3 - Symbolic with developing conversational language

Communication - A Guide for Teaching Students with Visual and Multiple Impairments, Hagood, TSBVI 1997

Literacy routines for pre-symbolic communicators

Example 1: Taylor

- The first video example you will see is of Taylor and his teacher, Amy.
- Taylor is 6 years old and has hearing, but no vision. He is at a pre-symbolic level of language development.

Skills Taylor is working on:
Reaching out to Amy- finding her
Waiting while things get started
Moving left to right in sequence box
Transitioning from one routine to another

Concepts Taylor is working on:
A routine has beginning, end and steps
When I do this… Amy does this.
The things in the box mean what will happen
Things have names

What sort of communication and literacy activities is Taylor ready for?

Building a Foundation for Literacy

1. Embed opportunities for communication throughout the day. examples
1. Design learning experiences that are meaningful to the child. examples
1. Developing a trusting relationship with the child. examples

What would traditional literacy materials look like for Taylor?

Story Boxes: Cookie Time

- A collection of items in a box or bag that corresponds to the items mentioned in a story. It is a way for young children with visual impairments to experience a story.
- Children gather information through the experiences that they have. Literacy emerges from hands-on experiences for all children.

Routines for an emerging symbolic communicator

Ray: A Little Background

- Ray is 6 years old and has a moderate to severe hearing loss in both ears and no vision.
- He is at an emerging symbolic level of language development and is just beginning to understand that parts of objects can represent an action, place, person, or thing.
- He is still using many concrete objects to label these actions, places, and things.

What sort of literacy activities is Ray ready for?

Early Emergent Literacy

1. Embed the use of objects, symbols or words throughout the child's day.
2. Teach name, name sign and/or personal identifier of child and those the child interacts with on a regular basis .
3. Embed literacy learning activities into routines.

What would traditional literacy materials look like for Ray?

Story Boxes - Monica and the bag story

Routine book

- A book based on an experience the child knows and understands helps build symbol-action/object meaning
- A book based on a routine to help build anticipation and participation

WHAT MAKES A GOOD ROUTINE BOOK?

- USE EXPERIENCES THE CHILD DOES DAILY

USES CHILD'S LEVEL OF REPRESENTATION

- THE CHILD PARTICIPATES IN CREATION BY GATHERING ITEMS DURING THE ACTIVITY

Jarvis at the Drum Store

What sort of communication and literacy activities is Jarvis ready for?

Emergent Literacy

1. Expand awareness of books, print and writing
2. Connect real-life experiences to literacy activities
3. Create books adapted to individual child preferences, abilities and interests
4. Provide multiple opportunities to interact with text through shared storybook reading

What do traditional literacy materials look like for Jarvis

Experience books

- –Help the child understand that objects are symbols that can be "read"
- –Provide memory support and meaning since child chooses the objects
- –Enable the child to share memories with others

PLANNING A ROUTINE or EXPERIENCE BOOK

A Plan for My Routine Book

- Think about the purpose of the book
- Think about the accommodations for the individual student

Activity Routine Book Guide

- List steps of the routine
- List symbols used in the book
- List targeted vocabulary
- List skills/concepts addressed
- Write a "script" for using the book

Examples, tips for making Experience Books

- http://popdb.sd38.bc.ca/Experience_Books
- www.pathstoliteracy.org/tactile-experience-books
- http://www.wsdsonline.org/video-library/deaf-blind-videos/experience-books/

Project CORE- Center for Literacy and Disability Studies at UNC

- 5-year grant to develop an implementation model for building early symbolic communication for children with severe disabilities
- Focus on use by classroom teacher on daily basis instead of relying on SLPs
- 36 core vocabulary words available in different formats - including tactile 3-d reproducible
- Self-guided training modules with implementation strategies
- www.project-core.com

CORE Instructional Principles

- Plan ways to incorporate core vocabulary in existing routines
- Provide constant availability of core vocabulary in student's best format
- Model use of core vocabulary
- Attribute meaning to pre-symbolic student behaviors
- Repeat and expand any student use of core vocabulary
- Don't require response- encourage

Information for this presentation came from:

Symbols and Meaning from APH and the SAM videos at http://tech.aph.org/samvid/intro.html

The Sensory Learning Kit Guidebook from APH

Communication- A Guide for Teaching Students with Visual and Multiple IMpairments - Linda Hagood, TSBVI, 1997

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The modules were developed by the National Center on Deaf-Blindness. For more information on these modules please visit: http://moodle.nationaldb.org

NCDB Literacy Website http://Literacy.nahttp://www.project-core.com/tionaldb.org

Project CORE: Implementation Model for Building Early Symbolic Commuinicationhttp://www.project-core.com/

ROUTINES WORK!

AND THEY ARE FUN TOO

Develop a trusting relationship with the child.

What to do

- Always identify yourself when you interact with the child
  - Choose a name sign or personal identifier and use it consistently to let the child know who you are
  - Say "Hello" and "Good-bye" and expect the child to do the same
  - Learn how to have a conversation with a child in non-traditional ways
  - Provide opportunities with a partner for turn-taking
  - Expect, wait for and acknowledge child's responses
  - Identify the child's likes and dislikes
  - Allow the child to direct conversations about their topic (follow their agenda, not yours)
  - Have frequent conversations with the child (may or may not use spoken language)
  - Incorporate rhythm, music, finger plays and mime games into daily routines and activities

Embed opportunities for communication throughout the day

What to do:

- Work toward the child's understanding that a partner is needed in order to communicate
- Provide opportunities with a partner for turn-taking
- Expect, wait for and acknowledge any and all child responses
- Put meaning to the child's actions and provide vocabulary for it
- Use consistent repetitive language (may be spoken, signed or both)
- Provide opportunities for children to make choices
- Use communication for a variety of purposes (make comments, ask questions, express feelings, give instructions)

Design learning experiences that are meaningful to the child

What to do

- Identify the child's likes and dislikes
- Use the child's preferences to make learning more meaningful and fun
- Determine the child's preferred sensory learning channels and learning styles
- Use age appropriate activities and materials
- Establish routines around daily activities
- Decide ahead of time what words and concepts you want to focus on during each routine
- Use hand under hand techniques, especially when introducing new activities
- Promote active participation and/or partial participation.

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From Millie Smith- Sensory Learning Kit Guidebook

Developing a Routine – copy of a form to create a routine (in handouts)

Home Routines (copy of a form to create home routines)

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Saturday, July 29, 2017

Breakout Session #5-7:
10:45-11:45am, 1:00-2:00pm, 2:15-3:15pm

Panzacola F-3/F-4

Adult Track

Kasee Stratton, Ph.D., NCSP, Daniel Gadke, Ph.D., NCSP, BCBA, and R. Matthew Coward, MD, FACS

Presenter Information

Dr. Kasee Stratton and Dr. Daniel Gakde are assistant professors of School Psychology at Mississippi State University. Both are also licensed psychologists and nationally certified school psychologists. Drs. Stratton and Gadke completed their doctoral internship and postdoctoral fellowship at Johns Hopkins School of Medicine and the Kennedy Krieger Institute. They specialize in treating challenging behavior and improving adaptive skills for children with developmental disabilities. Dr. Stratton has worked with individuals for CHARGE for over 12 years and Dr. Gadke primarily teaches behavioral assessment and intervention courses.

R. Matthew Coward, MD FACS is an Assistant Professor of Urology and Clinical Assistant Professor of Obstetrics and Gynecology at the UNC School of Medicine, and Director of Male Reproductive Medicine and Surgery at UNC Fertility in Raleigh, NC. He earned his MD with Distinction at UNC, followed by urology residency at UNC, and fellowship in Male Reproductive Medicine and Surgery at Baylor. Dr. Coward's clinical practice focuses in the areas of male reproduction and fertility as well as male sexual dysfunction. Dr. Coward's second of three children, Ryan, is a 4-year-old who has CHARGE syndrome.

Presentation Abstract

This three-session track will provide a series of presentations, discussions, and question and answer formats ***for adults with CHARGE syndrome ages 16+ only***. Sessions will include topics such as sex, sexual dysfunction, sustaining friendships, guidance on drinking, social media skills, advocating on the job and in the community, and question and answer time periods.

Saturday, July 29, 2017

Breakout Session #7: 2:15-3:15pm

Panzacola G-1

Five hints for new and seasoned parents: Raising your child with CHARGE syndrome

Tim Hartshorne

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

Parenting is always challenging, but particularly with a child who has challenges, such as one who has CHARGE. This presentation reviews five considerations for parenting a child with CHARGE.

Saturday, July 29, 2017

Breakout Session #7: 2:15-3:15pm

Panzacola G-2

Variables that Impact Walking in Individuals with CHARGE Syndrome

Dr. Elizabeth (Beth) Foster, CAPE

Presenter Information

Dr. Beth Foster is a Certified Adapted Physical Educator. She worked as an Elementary Adapted Physical Educator in Pennsylvania for 6 years then was an APE consultant in Texas for 4 years. During her time teaching in Pennsylvania, Beth was named the 2012 adapted physical education teacher of the year. Beth has been involved in Camp Abilities, a developmental sports camp for individuals who are blind, visually impaired, or deafblind for the past 12 years. She is currently the assistant director for Camp Abilities in Pennsylvania and Texas. From her experience at Camp Abilities, she developed a passion and determination to be knowledgeable within the field of deafblindness. Beth has presented on various topics about deafblindness across the U.S. She completed intervener training at the Minnesota Deafblind Project. Beth has been involved with the Texas Chargers for the past 3 years providing physical activities for individuals with CHARGE Syndrome at their annual retreat and has directed the Camp Abilities at the past two International CHARGE Conferences. Beth received her PhD in May 2016 by completing research related to children with CHARGE Syndrome and walking. Currently Dr. Foster is an assistant professor at Cal Poly Pomona in California in adapted physical education.

Presentation Abstract

Children with CHARGE syndrome are often delayed in the attainment of independently walking. The purpose of this session is to provide information about variables that impact walking and the benefits of walking in individuals with CHARGE syndrome. The session provides strategies to develop meaningful and accessible movement activities to enhance walking and provide children with movement confidence. Activities based on best practices and parent input will be presented. Participants leave with strategies that can be implemented when they get home.

Saturday, July 29, 2017

Breakout Session #8: 3:30-4:30pm

Panzacola F-1/F-2

Breakthroughs in Sensory Motor Processing & Feeding using Alternative Multi-Disciplinary Treatment Approaches

Whitney B. Pimentel MA, CCC-SLP, Isabel Lara & Carmen Romero

Presenter Information

Whitney Pimentel received her Master's degree in Speech and Language Pathology in 1997 from Louisiana Tech University. During her first two years in her new profession she quickly realized there was a need for understanding how the inability to eat was negatively impacting speech development. She spent 2005-2017 establishing her own practice that has led to creating a treatment base focused on feeding skills, oral placement development, motor skill development and speech. She has had the honor of presenting at the Charge Conference in 2013 and 2015.

Carmen Maria Romero received her BA in Physical Therapy from Florida International University Dec 1999. She worked for 12 years at Jackson Memorial Hospital/Ryder Trauma Burn Center/Miami Transplant Institute/Holtz Childrens Hospital in downtown Miami. As a therapist in a multicultural diverse medical center her patient population included pediatric, young adult, adult, and geriatric cases of multi level neurological, congenital, orthopedic, cognitive and systemic trauma and disability. From 2010-2017 she has developed her own private practice with an individualized holistic strength based approach to flourishing. Her practice utilizes the concepts of neuroplasticity, strength based resilience training, patient focused engagement, parasympathetic "calming" paired with physical challenge.

Isabel Lara has been a licensed pediatric physical therapist for 18 years who began her career working in the field of pediatric physical therapy at a PPEC (Prescribed Pediatric Extended Care) for 5 years treating children from birth to 16 years old with neurological disabilities. From January 2000-April of 2003 she furthered her education specifically in the field of sensory integration therapy by becoming certified in Sensory Integration Therapy (SIPT certified practitioner #7888). She has dedicated her career to creating innovative treatment strategies for neurological disorders that do not respond to traditional therapy models and opening the minds of professionals in the fields of education, psychology and therapy working with children with neurological disorders.

Presentation Abstract

Common deficits such as sensory, physical challenges, oral challenges, feeding, and speech difficulties associated with CHARGE syndrome will be discussed. They will teach a unique multi-disciplinarian approach of continually assessing the sensory system to determine a baseline at the beginning of each therapy session. Demonstrations of a variety of techniques will be taught to assist parents, therapists, and other educators in creating a therapeutic intervention program to address the needs of these individuals outside of traditional methods. An in-depth discussion will explain how and when to incorporate sensory motor developmental activities, core stability exercises, and cranial sacral therapy into a therapy program. The goal is that we provide the tools to assist these children with functioning in home, therapy, school, social situations, and work with the goals of improving physical stability, nutrition, motor processing, and speech clarity using unique multidisciplinary approach to increase their rate of progress towards meeting these goals.

Breakthroughs in sensory motor processing and feeding using alternative multidisciplinary treatment approaches

Topics of Discussion

- Most common structural and cranial nerve abnormalities in children with CHARGE syndrome and their connection to sensory motor processing systems.
- What is sensory integration
- What is cranial sacral therapy
- How to implement a treatment approach utilizing sensory integration and cranial sacral therapy to impact the progress rate of speech and feeding therapy and effectiveness of a treatment session .

Structural Abnormalities and their connection to sensory motor systems

1. Eyes
- Colombo-cleft of iris, retina, choroid, macula or disc
- Microphthalamos- small eye
- Anophthalamos- missing eye

Impact: vision perception impaired and or limited
Sensory System: Visual System

2. Ears
- Shape of ears short wide with little or no lobes, floppy
- Malformed middle ear bones(ossicles)
- Malformed cochlea
- Malformed semicircular canals-small or absent
- Impact: poor discrimination. localization and processing of sound and poor balance and equilibrium reactions
- Sensory System: Auditory and Vestibular System

Structural Abnormalities and their impact on sensory systems

3. Nose
- Choanal atresia or stenosis- passage from nose to throat narrow or blocked
- Impact: limits smell and respiration, note respiration directly linked to controlling heart rate to help modulate behavior during moments of frustration and anger.
- Sensory System: Olfaction

3. CN X- **Vagus-** motor to visceral organs and pharynx and larynx parasympathetic function of HR, RR stomach and esophagus
- Impact: coughing swallowing and speech, modulation of arousal level
- Sensory System: Oral Motor system

4. CN VII- **Facial** : muscles of facial expression, stapedius muscle of ear which dampens sound, motor for lacrimal gland, sensation of ant 2/3 of tongue and hard and soft palate
- Impact: poor affect, sound sensitivity, tearing, eating textures, and speech
- Sensory System: Auditory system. Tactile system, oral motor system

5. CN III- **oculomotor**-intrinsic movement of the eyes and eye lid and parasympathetic control of pupil
- impact- poor visual motor control
- Sensory system: visual system through its direct connections to the vestibular nuclei(affected by structural abnormality

6. CN IV-**trochlear**-superior oblique eye muscle, movement down and lateral
- Impact-poor visual motor control
- Sensory System: visual system through its direct connections to the vestibular nuclei

7. CN VI-**abducens**- lateral rectus , movement of eye lateral
- Impact-poor visual motor control.
- Sensory System: visual system through its direct connections to the vestibular nuclei

Sensory Integration

- Sensory integration is a neurological process that organizes sensations from one's own body and from the environment and makes it possible to use the body effectively within the environment.

- Sensory integration is centered on the ideas of an "adaptive response" and the "just right challenge."
- The "just right challenge" is a functional and meaningful activity for the child. (Ayers)
- An "adaptive response" is an appropriate action in which the child responds successfully to an environmental demand.(Ayers)

- Sensory Integration is rooted in the beliefs that: The environment has an impact on the maturation of the nervous system; and that the nervous system is a malleable, changeable structure. (Ayers)
- Neuroplasticity is the ability of the nervous system (brain) to change in response to the demands of the environment or as a result of an injury. The Innate plasticity of the nervous system is not fully realized until appropriate conditions exist.
  (Bach-Y-Rita 1992)

Cranial Sacral Therapy

According to John Upledger, "Cranial sacral therapy is a gentle hands on technique that enhances the functioning of the physiological cranial sacral system. The cranial sacral system is comprised of membranes and cerebral spinal fluid that surround and protect the brain and spinal cord. Using a soft touch CST is intended to release restrictions of cranial sacral system , thus improving the function of the central nervous system.

- When cranial sacral therapy is utilized prior to or during a therapy treatment session it optimizes arousal level, decrease stress, and facilitate body awareness and postural responses.(Sensory Integration theory and practice, 361-362.)
- CST can also be utilized to release restrictions and facilitate optimal functioning around the specific area of the brain that directly correlates with the area of sensory dysfunction caused by structural deformity or cranial nerve abnormalities.

Two foundation sensory systems that should be addressed to optimize full potential for therapeutic gains toward meeting developmental milestones :

- Somatosensory system-tactile and proprioceptive

1. Tactile-light and deep touch, vibration or stretch, temp, pain mechano receptors within the skin all over the body

- Signs of dysfunction: defensive to touch, textures on body and extremities and on tongue, doesn't respond to high temp or pain, clothing sensitivities, poor transitions, does not respond well to change etc…
- Cranial Sacral Implications: primary and secondary somatosensory cortex, parietal lobes and thalamus. Oral motor cavity if issue in mouth as well on gums and buccal cavity
- SI Treatment applications: incorporating deep touch activities , grounding weight bearing developmental positions, vibration to desensitize, Wilbarger brushing protocol

2. Proprioception-perception of joint and body movements as well position of the body and limbs in space., sensing the direction and velocity of movement and effort needed to move objects. Receptors are muscle spindles, mechano receptors and joint receptors.

- Signs of dysfunction: poor body awareness, difficulty avoiding environmental obstacles, clumsiness, heavy stomping, seeking high impact sensation, head banging, pinching, chin pushing ,finding tight small places to wedge in etc..
- Cranial Sacral Implications:
  primary and secondary somatosensory cortex, partietal lobe , thalamus and temporal lobes
- Treatment applications: Incorporating resistive movement activities in developmental WB positions, resistive oral motor tools, vibration for body awareness,

- Vestibular System: otiliths organs (utericle and saccule)processing linear movement and semicircular canals(horizontal, anterior and posterior) for processing rotational movement. Vestibular receptors are hair cells in otiliths and semicircular canals. Otoliths organs responsible for static function and semicirular canals responsible for dynamic angular motion.

  2 Sensory pathways: **vestibular –propioceptive(cochlear), vestibular visual pathway**

  Vestibular and proprioceptive input along with vision provide Awareness and coordination of movement of head in space, Postural tone and equilibrium Coordination of eye, head and body and stabilization of eyes in space during head movement(Sensory integration theory and practice p 58)

- Signs of dysfunction: Poor equilibrium reactions in all developmental positions, poor balance, poor disassociation of eyes from head movement, visual fixation statically and dynamically when head in motion poor, spatial orientation of body during gross motor and fine motor skills poor, gravitational insecurity and postural insecurity.
- Cranial Sacral Implications: temporal lobes, parital lobes, cerebellum, occipital lobes
- Treatment Applications: Incorporating development positions that challenge head position and visual gaze. Material used can be put in motion to connect eyes to task, sitting or standing position on dynamic equipment, incorporate body movement to task at hand, incorporate music and rhythm to organize timing and spatial concepts, vibration and music used as behavior modifier

Vestibular-Proprioceptive Pathway

- Both systems share a bony labyrinth, mechanical receptors operate in very similar fashion using common fluids (the perilymph and endolymph), they share cranial nerve VIII and some of its fibers.
- The only difference in movement and sound is the velocity of the vibrations
- The vestibular portion receives messages from the body about its position and orients the body in space at any given moment
- The auditory portion receives and processes the finer movements of air molecules, sound, which we cannot see or feel but which orient us to and help us locate objects and sound in our environment and navigate through it.

Vestibular Visual Pathway

- Signals from the three paired semicircular canals interact specifically with with the six paired extraocular eye muscles through pathways which project from the vestibular nuclei into the three bilateral cranial nerve nuclei (III, IV,VI)
- Cranial nerve III, IV, VI control the six extraocular muscles of the eyes
- Vestibular system impacts saccadic eye movement, smooth pursuits and convergence

Vestibular Visual Reflexes

- Rotational vestibular ocular reflex (VOR) allows the eyes to maintain fixation on the target when the head rotates
- Translational vestibular ocular reflex (VOR) allows the eyes to maintain fixation on a target when the head is moving in a linear direction
- Ocular Counter-Rolling Response compensates for the head tilt vertically.
- Pre and Post rotary nystagmus reflexes are elicited in an attempt to refocus on a stable point in space when there is prolonged rotation of the body.

Other areas of concern to observe and treat if necessary by qualified professionals and integrate into multidisciplinary treatment sessions

- Developmental reflex patterns
  - Primitive reflex
  - Postural Reflex
- Behavior modification and self regulation

QUESTIONS?

Breakthroughs in Sensory Motor Processing & Feeding using Alternative Multi-Disciplinary Treatment Approaches

Common Deficits of CHARGE Syndrome

Deficits which effect sensory, feeding and speech clarity: each of these deficits may range from non-existent to severe.

1. Hypotonicity

2. Visual Impairment

3. Hearing loss

4. Sensory deficits may range from minor to severe: smell, taste, touch, vision, hearing and interpretation of the environment

5. Oral and tactile sensitivity: hyposensitivity, hypersensitivity, mixed sensitivity, fluctuating sensitivity: The "feel" of feeding and the "feel" of speech

6. Tactile defensiveness

7. Cognitive deficits

Common Deficits of CHARGE Syndrome

8. Gap between expressive and receptive language skills

9. Weak jaw musculature: Symmetrical or Asymmetrical

10. Incomplete lip closure, decreased tongue mobility/grading results in limited retraction, lateralization, and tongue-tip pointing

11. Weakness in the muscles of the velum

12. Blocked nasal passages: /m, n, ng/

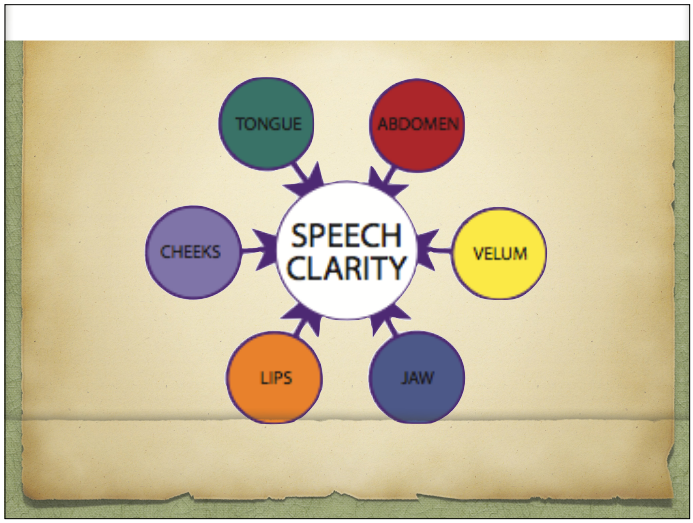
13. Motor planning deficits

14. Difficulty coordinating oral airflow with vocalizations to initiate speech sounds production

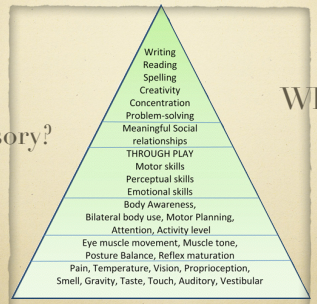
15. Anxiety/Trust

Goals of Oral Placement/Feeding Therapy

- To establish trust with client
- To improve feeding skills and nutritional intake
- To improve speech sound production and improve intelligibility/clarity



What is Sensory?



The basic building blocks of a child's learning and development need to be in place in order for them to engage in higher learning and reach their expected milestones.

Where do we start?

8 Sensory Systems

Far:

Visual
Auditory
Olfactory
Gustatory
Tactile

Near:

Vestibular
Proprioceptive
Interoception

Have to calm body before we go into mouth
Mouth has a high amount of receptors but message may be confused

Sensory Diagnosis/Tactile System

Tactile Hyposensitivity:
An under-reaction to tactile input.

Tactile Hypersensitivity:
An over-reaction to tactile input

Mixed Sensitivity:
Any combination of hyper, hypo or normal sensitivity.

Fluctuating Tactile Sensitivity:
Responses that change over time.

Before you begin to work on either feeding or speech:

1. Evaluate the Sensory System and make diagnosis
2. Eliminate tactile defensive behaviors by establishing trust.
3. Treating Sensory Deficits: Sensory Integration Deficits: Begin with a sensory warm-up as prescribed by an S.I. trained Therapist to collaborate

Muscle-Based Exercises(Oral-Motor)

Begin with a sensory program and a stable posture:

Work from whole body to mouth to achieve acceptance of touch and to develop trust.

1. Establish a supported feeding position:
Stability in the body allows for mobility within the oral cavity

Evaluate the Sensory System:

a. Toothette w/Vibrator
b. Sensory Bean Bags
c. Jigglers

Let's talk Sensory input

Why does my child bite and put everything in their mouth and avoid certain foods?

Why does my child suck their thumb, grind their teeth etc?

Why is feeding so important to an oral-motor (oral placement) therapy program?

**Nutritional Concerns
**The muscles that are used in feeding are the same muscles that are used in speech.

What is a Pre-Feeding Program

GOAL: to develop the motor skills to support safe, effective, nutritive feeding.

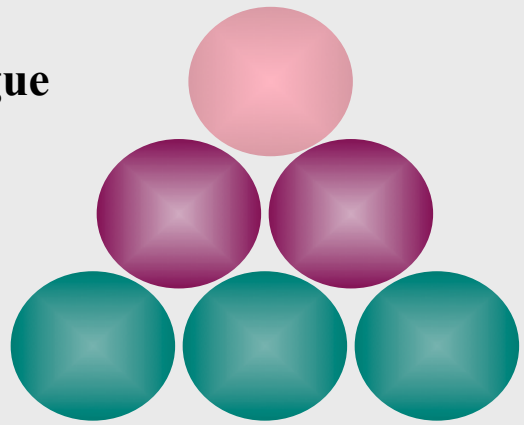
- Clients that do not have adequate nutrition
- Clients that have poor speech clarity
- Program should start with a motor goal

A Sensory Motor Approach to Feeding: Lori L. Overland MS, CCC-SLP, C/NDT; Robyn Merkel-Walsh, MA, CCC-SLP

⇧Tongue

⇧Lips

⇧Jaw



Techniques for Pre-Feeding

Motor Goal	Pre-Feeding/Therapy
Lip Closure	Spoon Feed
Tongue Retraction	Straws/Tongue hugs
Chewing Solids	Gloved Finger/Bite Tubes

Tyler

What is a Therapeutic Feeding Program

GOAL: to develop a set of techniques that support safe feeding and maximize a client's postural stability, muscle tone, sensory processing, and oral sensory-motor skills.

A Sensory Motor Approach to Feeding: Lori L. Overland MS, CCC-SLP, C/NDT; Robyn Merkel-Walsh, MA, CCC-SLP

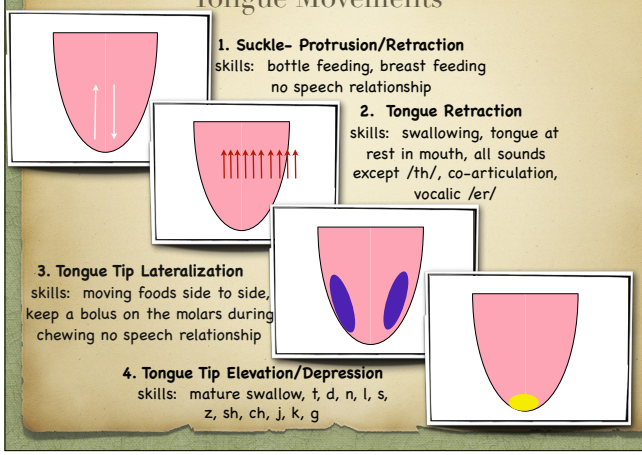
Lip Development

1. **Lip closure skills:** spoon feeding, cup drinking /m, p, b/

2. **Lip protrusion/retraction skills:** straw drinking, /oo, oh, w, ee, ih, eh, sh, ch, j

3. **Lower lip retraction/tension**
   Lower lip protrusion/tension
   skills: remove food from upper/lower lip /f, v, er/

Tongue Movements



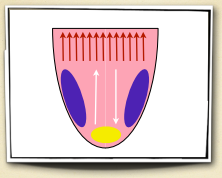
1. Suckle- Protrusion/Retraction
skills: bottle feeding, breast feeding
no speech relationship

2. Tongue Retraction
skills: swallowing, tongue at rest in mouth, all sounds except /th/, co-articulation, vocalic /er/

3. Tongue Tip Lateralization
skills: moving foods side to side, keep a bolus on the molars during chewing no speech relationship

4. Tongue Tip Elevation/Depression
skills: mature swallow, t, d, n, l, s, z, sh, ch, j, k, g

Tongue movements



In feeding and speech tongue does not move as one unit. Eac
part independently moves from the other

Therapeutic Feeding Techniques

- Spoon Feeding
  1. Lateral Placement
  2. Front Placement
  3. Pointed Spoon Slurp



Tools for Drinking

Liquids
1. Cup Drinking
2. Straw Drinking

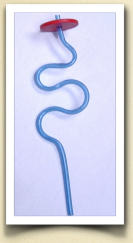
Goals: Lip closure (m,b,p)
Tongue retraction for all sounds except /th/



Why is Straw Drinking So important

- Straw Drinking
  1. Honey Bear
  2. TalkTools(R) Straw Hierarchy

TalkTools(R) Straw Hierarchy #1-#4

#1 #2 #3 #4

Goals: Lip Protrusion, Tongue Retraction, Jaw Stability. Repetitive suck. Last sip looks same as first. Able to drink 4 oz in less than 2 minutes. Use only thin liquids

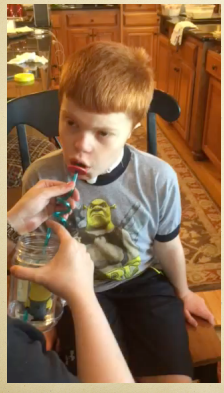
TalkTools(R) Straw Hierarchy #5-#8




#5 #6 #7 #8

Goals: Lip Protrusion, Tongue Retraction, Jaw Stability. Repetitive suck. Last sip looks same as first. Able to drink 4 oz in less than 2 minutes. Use only thin liquids

Andrew Straw Drinking



Overview of Optimal Feeding Positions and Techniques

Solids:Teach the motor plan for safe feeding of cubed solids, using non-food items.

Gloved Finger 

Infadent 

Ark Probe 

Overview of Optimal Feeding Techniques and Tools

Ark's Z-vibe 

Bite Tubes (Red & Yellow) 

Ark's Grabbers (Purple & Green) 

Jaw Grading Bite Bloc  

***Hierarchy as taken from *Assessment and Treatment of the Jaw*

Andrew

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Saturday, July 29, 2017

Breakout Session #8: 3:30-4:30pm

Panzacola G-1

Purposeful play, how wrestling and playing can benefit children with CHARGE

Michael M. Braga M.Ed

Presenter Information

In 1998, Mike and his wife Ruth were first introduced to the world of CHARGE syndrome when they adopted their oldest son Brandon. At the time, Mike was a high school drop out who was managing a fast food restaurant while Ruth attended college. Driven by a desire to help Brandon any way he could, Mike went back to school, earning his bachelor's degree in recreation therapy from the University of Utah. He later attended graduate school at Utah State University studying deaf/blind education.

As Brandon got older, Mike began looking at programs available for adults with deaf/blindess. Since there are no programs in Utah that specialize in this care, Mike and Ruth decided to open their own. They opened Bear-O Care in 2015 as a non profit care center. This center helps adults with multiple disabilities with a special emphasis on those with sensory intake dysfunction or deaf/blindness.

Presentation Abstract

During the day, we all receive input by walking, talking and even eating. Some with CHARGE may not receive all of this input that their brain's still need. By structured play, we can help them obtain this input. Come learn strategies that will help your children while you have fun with them and see how beneficial playing around can be.

Saturday, July 29, 2017

Breakout Session #8: 3:30-4:30pm

Panzacola G-2

Parents' Perspectives: Types and Purposes of Communication Used by Their Children Who Have 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.

Saturday, July 29, 2017

Breakout Session #8: 3:30-4:30pm

Panzacola H-1/H-2

Experiences of Families Raising a Child Who is DeafBlind and Teacher Response to those Shared Experiences

Donna Snyder, Ed.D & Kim Zeigler

Presenter Information

Donna is the State Coordinator for the Kentucky DeafBlind Project. She has been on the project for 11 years. Prior to joining the project, she worked as a classroom teacher for students who were deaf/hard of hearing and deafblind in public, private and state schools. She recently completed her dissertation examining the lives of families with children who are deafblind and teacher perception change when those experiences were shared through a short digital video. She was instrumental in the creation of a dual language (ASL/English) Montessori preschool and day care. Donna's parents had cerebral palsy which greatly influenced her choices to work with children, families, and professionals in the field of special education. She is very interested in how we present our children to other professionals and how that creates a negative mindset using a medical checklist.

Kim is the Family Specialist for the Kentucky DeafBlind Project. She has been on the project for over 12 years. She brings a wealth of personal experiences as a mother of twin boys with varying disabilities. Kim completes the team platform in bringing and keeping awareness to the families' perspectives. Her focus is to bring families together both face to face and on line to support one another. She has helped plan numerous family events and is able to locate resources for families. She works to support families understand their roles as part of the educational team.

Presentation Abstract

This presentation will explore the experiences of families raising a child who is deafblind and teacher response to those shared experiences using the photovoice method with short digital videos. Five families who all had a child on the Kentucky DeafBlind Project census and their lead teachers participated in individual interviews using photovoice. Family photovoice interviews uncovered five overarching themes: medical positive descriptors, family and community, likes/don't like, and parents' love. Teacher interviews identified a positive shift in teacher perception after viewing the short digital video created from the photos and experiences from the families. Teacher positive shifts included: "student can't do to student can do," "using medical descriptors to using human descriptors," "feeling disconnected with the family to feeling connected to the family," and "teacher self-examination of can't do to can do." Project staff will share their experiences that initiated this study and the impact of findings as well as the change in service delivery of how the project introduces a child on the census to their educational team.