TAKING CHARGE in 2017 ORLANDO
13th International CHARGE Syndrome Conference

Friday, July 28, 2017

Breakout Session #1: 10:45-11:45am
Panzacola F-3/F-4

Cochlear implants for CHARGE patients: sound present and better future

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

Presenter Information

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

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

Presentation Abstract

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

TAKING CHARGE in 2017
ORLANDO
13th International CHARGE Syndrome Conference

Friday, July 28, 2017

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

Assessment and treatment of problematic behavior in students with CHARGE Syndrome

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

Presenter Information

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

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

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

Presentation Abstract

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

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Breakout Session #1: 10:45-11:45am
Panzacola G-2

CHARGE 101: Diagnostic and other features of CHARGE and their effects on early development

Meg Hefner, MS, Kate Beals, OTR/L, and
Danielle Bushey, PT, DPT, NCS

Presenter Information

Meg is a genetic counselor with 35 years of experience with CHARGE syndrome. She was a founding Board member of the CHARGE Syndrome Foundation and remains active as an Advisor to the Board. She has written extensively on CHARGE for families (Management Manual for Parents), geneticists (American Journal of Medical Genetics special issue on CHARGE syndrome), and professionals working with children with CHARGE (CHARGE Syndrome, Plural Publishing). Awards for CHARGE syndrome work include the first Stars in CHARGE award and the Diane Baker Alumni Award from the University of Michigan. She has presented at every CHARGE Syndrome Conference and actively answers genetic and medical questions by email and on several CHARGE Facebook pages. Meg's most recent endeavor is the CHARGE syndrome database (CSCDP), created to facilitate research by providing baseline information on individuals with CHARGE to researchers around the world.

Kate Beals, OTR/L, is a pediatric occupational therapist. She has worked with children who have CHARGE Syndrome at the South Carolina School for the Deaf and the Blind, in the South Carolina Inter-agency Deafblind Project, and in the Deafblind Program at Perkins School for the Blind. She is presently employed at McCarthy Teszler School in Spartanburg, SC. Kate has served as a Consultant for Perkins International in China, and has provided training for international participants in Perkins' Educational Leadership Program.

Danielle Bushey, PT, DPT, NCS is a physical therapist specializing in working with children and adults with neurological impairments. She has worked at Perkins School for the Blind with children with CHARGE Syndrome for 7 years. She works at Perkins School for the Blind and Spaulding Rehabilitation Hospital in Boston, MA. Danielle has served as a consultant for Perkins International in China and has lectured on Motor Control at Northeastern University as adjunct faculty.

Presentation Abstract

CHARGE 101, 102 & 103 are for anyone who would like a comprehensive overview of CHARGE: from diagnosis to development to outcomes. 101 will start with Meg reviewing how the clinical diagnosis is made and other features seen in children with CHARGE. Kate and Danielle will describe how the sensory deficits (hearing, vision, balance) affect early childhood development. See the descriptions for CHARGE 102 and CHARGE 103.

CHARGE Syndrome 101 Series for New Families

Meg Hefner, M.S.
Genetic Counselor
Adjunct Associate Professor of Pediatrics
Saint Louis University School of Medicine
meg@chargesyndrome.org

Where does the name come from?

**1981 Pagon, et al.

- **C** = Coloboma of the eye
- **H** = Heart anomalies
- **A** = Atresia of the choanae
- **R** = Retardation of growth or development
- **G** = Genitourinary anomalies
- **E** = Ear anomalies and/or deafness

Name features should NOT be used for diagnosis

Epidemiology of CHARGE Syndrome

- ~1 in 10,000 births worldwide
- Most often a new dominant variant (mutation)
  - Copy error in sperm (or egg) production
  - Increased but low (1-2%) recurrence risk
  - Major gene identified in 2004 (*CHD7*)
- Mild end of spectrum is still being investigated

Major CHARGE gene: *CHD7* on chromosome 8q12

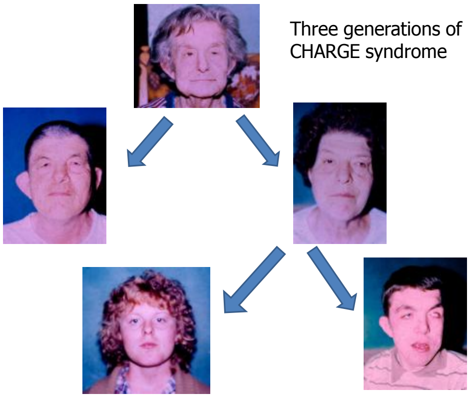
- Very large gene with many unique variants
  - Gene sequencing required to detect
  - What the gene does is being worked out
- If *CHD7* pathogenic variant (mutation) is identified
  - It confirms diagnosis in questionable cases
    - Help define the mild end of the spectrum
    - *Not finding a mutation does NOT rule out CHARGE*
  - Possible to test other people in the family
- Prenatal diagnosis /Pre-implantation genetic diagnosis
  - First identify a *CHD7* variant in the person with CHARGE
  - Possible to detect the presence or absence of a mutation but *not the severity of the features*
- *See presentations on Genetics of CHARGE*

Chance of Recurrence

- Parents who have one child with CHARGE:
  1-2%
- Children of individuals with CHARGE:
  50%
- Extended family members:
- <<1%

Two children who have CHARGE, three (two pictured) without

Three generations of CHARGE syndrome



2017 Diagnostic Criteria and Medical Features

- Which features help us know it is CHARGE
  - Major features
  - Supporting features
- What are some of the other features
  - Not as important for diagnosis, but often medically important
- Clinical diagnosis is still the gold standard

Major diagnostic features

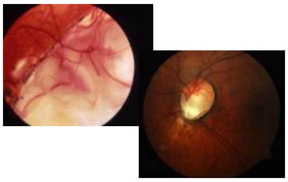
- Common in CHARGE but rare in other syndromes
  - Coloboma of the eye
  - Cranial nerve anomalies
  - Choanal atresia/stenosis
  - Characteristic CHARGE ears
    - Outer
    - Middle
    - Inner
  - *CHD7* pathogenic variants

Need at least 2 Major features + supporting features

Coloboma – cleft of the eye

Iris Coloboma

Increased sensitivity to light



Retinal Coloboma

Increased risk of retinal detachment with retinal coloboma

Retinal coloboma causes visual field defects

Retinal coloboma:
upper visual field defects

Children will position themselves to be able to see

Macular coloboma:
central vision loss

- The child will look *above* the point of interest and *not appear to be making eye contact*
- Note also facial palsy in this child
- This combination can make child appear inattentive

Cranial nerves 9 & 10: *Swallowing problems*

- Many require G-tube feeding
- May last for years
- Some adults avoid certain textures and continue to have choking episodes

Swallowing complication: Aspiration

- Aspiration is the most common reason for hospitalization in first 2 yr. of life
- GE reflux is common
  - Surgery (Nissen fundoplication) may help
- Gastrostomy may be needed to reduce aspiration

Cranial Nerve # 7
Facial palsy


Unilateral – lopsided face


Bilateral – no facial expression

Cranial Nerve #1
Sense of smell

Most have decreased or absent sense of smell
- Difficult to evaluate, but EXTREMELY common (>90%)
- Changes "taste"
- Implications for feeding
- Social implications
  - smelly feet
  - body odor
  - passing gas

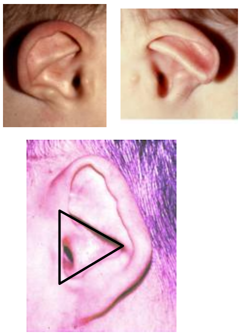
Choanal atresia/stenosis

- Two sides (BL) or one side (UL)
- Bony or membranous
- Blockage (atresia) or narrowing (stenosis)
- UL stenosis may be difficult to diagnose:
  - goopy nose all the time
  - lots of infections, fluctuating hearing loss
- Often requires several surgeries to remain open

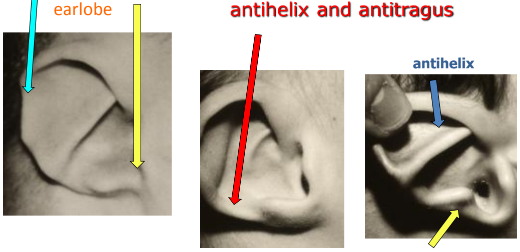

Baby with stents

Characteristic CHARGE Ear: **OUTER EAR**

- Asymmetry between the two ears →
- Floppy ears (deficient cartilage)
- Small/absent earlobe
- Triangular concha →
- Clipped off helix (outer fold)



Characteristic CHARGE Ear


Snipped off helix with small or absent earlobe

Discontinuity between the antihelix and antitragus

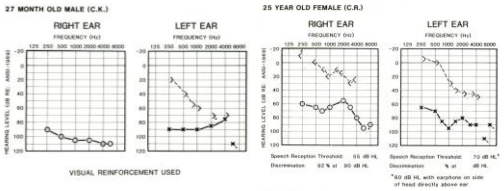
Characteristic CHARGE Ear:
MIDDLE AND INNER EAR

- Middle ear – ossicular (bony) malformations (stapes, incus) , others
  - Conductive hearing loss – not cured by tubes
- Inner ear *(by MRI or CT scan)*
  - Mondini defect: 1-1/2 turns to the cochlea
  - *Small or absent semicircular canals***
- Hearing Loss
  - Test early, test often
  - Know your child's hearing status

** most common feature of CHARGE

Hearing in CHARGE

- Mixed hearing loss (SN and conductive)
- Fluctuating with infections/fluid
- May respond to cochlear implant/BAHA
- May be progressive



Inner Ear **Balance** Problems

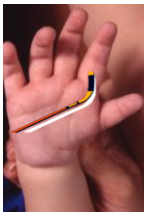
- Small or absent semicircular canals**
- Characteristic gross motor development
  - Stay close to the ground
  - Creep or combat crawl
  - 5-point crawl
  - "Bottom shuffle"
  - Cruise for very long time
- Age of independent walking
  - Walk at 24-32 months if no other problems
  - Walk at 3-4 years if hypotonia and visual impairment
- Vestibular system also important for
  - Processing visual information
  - Processing auditory information

CHARGE Syndrome **Supporting/minor** Diagnostic Features

- Some are very specific to CHARGE but difficult to evaluate consistently
- Some are very common in CHARGE but also very common in other syndromes
- Some are less common in CHARGE

CHARGE Syndrome Minor Features: Uncommon in other syndromes

- **Upper body (truncal) hypotonia**
  - Slumping posture
  - Crawl on back
  - Bottom shuffle
  - Delayed walking
  - Complicated by poor balance
- **Hockey stick palmar crease**
- **Characteristic CHARGE face**



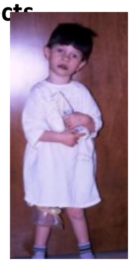
Characteristic CHARGE Face

- Square face
- Broad forehead
- Round eyes
- Nose
  - Prominent bridge
  - Square root
  - Prominent columella
- Small chin, gets bigger with age

CHARGE Syndrome Diagnosis Supporting features that are common in many syndromes: **Heart defects**

- Tetralogy of Fallot
- Aortic arch anomalies
- Complex heart defects
- Can be any heart defect

- Same spectrum of heart defects as in VCFS (aka 22q deletion syndrome, DiGeorge)



Heart surgery at four years old

CHARGE Syndrome Supporting Feature: **Facial Clefts**

- Cleft lip
- Cleft lip and palate
- Cleft palate
- Submucous cleft palate

Repaired cleft lip

CHARGE syndrome supporting feature: **Esophagus/Trachea**

- Esophageal atresia (EA)
  - esophagus not connected to stomach
- Tracheo-esophageal fistula (TEF)
  - connection between trachea and esophagus
- H-shaped TEF
  - can be hard to diagnose, but important
- Tracheomalacia
  - weak, collapsing trachea

CHARGE syndrome supporting feature: Renal (**kidney**) anomalies

- Hydronephrosis (retained fluid)
- Reflux
- Horseshoe kidney
- Small or absent kidney
- Cystic kidneys

40% have renal anomalies

CHARGE Syndrome Supporting Features

Short Stature

Due to:

- Medical problems
  - Heart
  - Feeding
- Growth hormone deficiency
- Short stature with unknown cause

Genital hypoplasia

- Males
  - Micropenis
  - Cryptorchidism (undescended testes)
  - Lack of normal puberty
- Females
  - Small labia
  - Absent uterus
  - Lack of normal puberty

Variability in CHARGE

- EVERY feature can vary from absent to severe in different children
- NO ONE FEATURE is seen in every person with CHARGE
- Definite CHARGE is 3 Majors or 2 Majors and 3 Minors
- Probable/Possible/CHARGE-like with fewer
- *CHD7* testing is especially helpful in less clear cases, but should always be done

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Other features of CHARGE

- Not necessarily helpful with diagnosis, but could be important medically or developmentally
- Differences have been noted in pretty much every organ system

Other features of CHARGE

- Brain anomalies seen on MRI or CT
- Seizures – can develop at any age
- Apnea
- Laryngomalacia
- Floppy cartilage
- Thymic or parathyroid abnormalities
- Immune system abnormalities
- Abdominal wall defects
  - Umbilical hernia
  - Omphalocele

Other features - continued

- Webbed neck
  - Sloping shoulders
  - Absent trapezius muscle
- Nipple anomalies
- Limb/skeletal anomalies
  - Limbs: missing or extra fingers or bones
  - Vertebral anomalies
  - Scoliosis
- Craniosynostosis
- Others (any organ system)

Additional CHARGE *management* issues

- Constipation - Autonomic nervous system?
- Potty training – nerve abnormalities?
- Sleep disturbances
  - abnormal circadian cycle?
- Cyclic vomiting/abdominal migraines
- Sensory integration
- Behavior – a separate topic in itself

Intelligence in CHARGE

- Assume normal intelligence until proven otherwise - long-term prognosis may be very good
- "Input impairment" due to combined vision & hearing loss – see CHARGE 102
- A few are "output impaired" due to bilateral facial palsy
- Delayed motor milestones due to vestibular dysfunction, upper body hypotonia and impaired vision.

How well do they do? The typical 2 year old with CHARGE:

- has spent 6 months in the hospital
- has had at least 6 surgeries
- is followed by 10 medical specialists
- is fed by G-tube
- is not walking or talking
- has some unusual behaviors

Delayed? Yes. But may have a lot of potential to catch up – you can't know yet.

Senses in CHARGE

- *Vision loss – field and acuity
- *Hearing loss – mixed, often severe
- Balance abnormalities
- Touch
  - Sensitive to certain textures
  - Light touch??
  - Altered pain sensation
- *Smell - absent or decreased
- Taste - possibly normal

* distance senses

Distance Senses and the Communication Bubble

- How far out and how well can the child *see*?
  - Coloboma (visual field)
  - Acuity
  - Other
- How far out and how well can the child *hear* ?
  - Sensorineural loss
  - Conductive loss
  - Fluid, infections
  - Amplification
- Can the child *smell*?
- Anything outside the bubble is "off the radar"

Communication Bubble

- The area *within which* the individual can
  - See
  - Hear
  - Smell
- Touch and taste do not give information at a distance
- Anything outside the bubble is "off the radar"

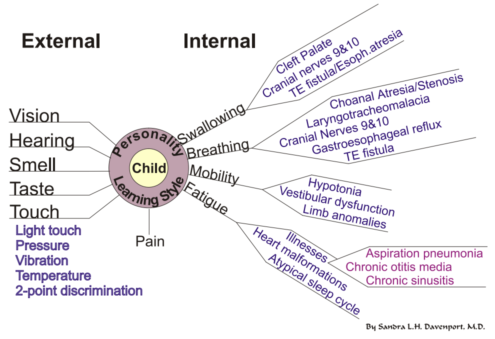
Sensory loss and development

- Early motor development – vision is important:
  - Head control
  - Sitting
  - Cruising, walking
- Communication: vision and hearing
  - Communication is learned by seeing and hearing – what if you don't see and hear?

Kids with CHARGE may be "Hard of" many things

- seeing
- hearing
- smelling
- feeling
- empathizing
- breathing
- balancing
- multitasking
- spacial awareness
- swallowing

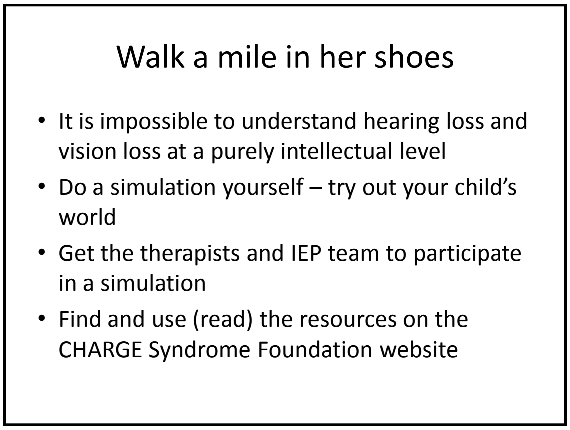
Physical Influences on Development in CHARGE



By Sandra L.H. Davenport, M.D.

Know your child

- Vision status (bubble)
- Hearing status (bubble)
- Balance
- Overall health, moods
- Observe carefully (learn from David Brown), communicate with caregivers
- Work on communication, communication, communication



Walk a mile in her shoes

- It is impossible to understand hearing loss and vision loss at a purely intellectual level
- Do a simulation yourself – try out your child’s world
- Get the therapists and IEP team to participate in a simulation
- Find and use (read) the resources on the CHARGE Syndrome Foundation website

The Sensory-Motor System in CHARGE Syndrome

Kate Beals, OTR/L and Danielle Bushey, DPT

13th International CHARGE Syndrome Conference (2017)

This part of CHARGE 101-102 will help you understand:

- How your child is moving and why it may look different from siblings or similar age peers
- Why there is variability in developing motor skills in kids with CHARGE Syndrome

The Motor System - What we see when the child moves.

The Sensory System – **What the child experiences** as he or she moves - what they see, feel, and sense.

Sensory IN – **Sensory information - from both external and internal sources - only goes INTO the brain. It cannot go out to the muscles.** It can only go **TOWARD the brain** because that's how the nerve fibers it travels on are made. Think of it like a one-way street, but with no option to go the wrong way. It is structurally impossible for sensory impulses to travel in the opposite direction from what they do. So sensory information only goes IN.

Motor OUT – **Motor impulses FROM the brain only travel AWAY from it – out to the muscles of the body.** Motor "messages" or "instructions" can only travel **AWAY from the brain** because that's where they originate. Just like sensory impulses, motor impulses travel on nerve fibers that are built like one-way streets. It is structurally impossible for motor impulses to travel in the opposite direction from what they do. So motor instructions only go OUT – to the muscles that respond by either lengthening or shortening to produce movement across joints.

Anatomy review -

- bones are connected together at joints
- joints are held together by muscles
- the brain tells the muscles when and how to move
- the brain receives information about the person's body and the environment
- the joints give the body information about the relative position of a person's body and the strength of effort being employed in the movement
- signals travel between the sensory receptors (the eyes, ears, semicircular canals, and joints) to the brain
- Sensory input -> Integrating in the brain -> Motor output

Sensory-Motor System – The seven sensory systems and the motor system are fully linked and interdependent. It is one, big, very **complex DYNAMIC system that is constantly in operation.** When the brain receives a piece of sensory input, it has to decide whether to: ignore it, pay attention, or do something about it. If it decides to do something, then the act of "doing" causes *new* sensory information to be generated, and so on.

What sensory systems have the most influence on movement (and balance)?

- Vision
- Vestibular
- Proprioception
- Hearing (a little bit)

Balance – Good balance (with help from muscle strength) means you can **keep your body upright against gravity without falling over.** This applies whether you are in a static posture (not moving) or dynamic (moving).
Balance is the ability to:

- stay upright against gravity without falling over
- transition from one position to another
- reach for something without falling over
- support and protect yourself when you do lose your balance

Sitting, crawling, and walking all require balance.

A *team* of sensory systems works together to create balance:

- The **VISUAL** System contributes information about the **environment** around you and *your body's relationship to it.* Vision provides vertical and horizontal markers for physical orientation, for example, the vertical lines of buildings and walls, horizontal lines of book shelves, baseboards, and intersecting streets.
- The **VESTIBULAR** System contributes information about the position of your **head**, and about how you head is moving through space.
- The **PROPRIOCEPTIVE** System contributes information about what your **body** is doing. It tells you what your joints and muscles are doing, as well as how much *force* your muscles are exerting as you move.
- The **AUDITORY** System – similar to the role of the visual system, though with less intensity – contributes information about the **environment** and *your body's relationship to it.*

If any ONE of the sensory systems on the "Balance Team" is absent or not functioning at full capacity, the brain is receiving insufficient, or distorted, information on which to make motor decisions. Since the brain is getting incomplete information, it may send incorrect messages to the muscles. In addition, it may *not send* a message that *should be* sent – a message that would help the body stay upright against gravity.

Balance in CHARGE Syndrome –

It is well documented that individuals with CHARGE Syndrome tend to have impairments in some – OR ALL – of the sensory systems that comprise the "Balance Team". They have to figure out how to stay upright against gravity without the complete, accurate, fully integrated information that their brains need to do it. Obviously, this has a dramatic effect on motor development, and causes significant delays in the development of the motor milestones of early childhood.

- **Vision in CHARGE** – **Usually an individual with CHARGE Syndrome has a visual field loss due to colobomas (missing tissue) of the eyes.** Most often it is an upper field loss, but the loss could be in any part of the visual field. An upper field loss is like wearing a baseball cap pulled low in the front – you can't see anything above a certain level.

- **Vestibular in CHARGE** – The vestibular system is a sensory system that tells you the position of your **head** in space, and how it is moving. It tells you if you are right-side up, upside down, leaning to one side or the other, what direction you are moving in (and how fast), if you are spinning and in which direction, and whether your speed is increasing or slowing down. The structures of the vestibular system are located inside the inner ear. Information from the vestibular system travels TO the brain on the same cranial nerve as hearing. **For many individuals with CHARGE Syndrome, the structures of the vestibular system are either malformed or altogether absent.** This makes it quite difficult for them to figure out what's going on as they move through space.

- **Proprioception in CHARGE** – Proprioception is a sensory system that tells you about the position of your **body**. The receptors for this system are located within your joints and muscles. These receptors respond to stretch (when a muscle lengthens) and compression (when a muscle shortens). You know whether your knees and elbows are bent or straight, even with your eyes closed. When you're driving, you don't have to look at your foot to know whether or not you've pressed the brake pedal at a stop sign. That's your proprioceptive system at work. **Individuals with CHARGE Syndrome often have reduced ability to process and use information from their proprioceptive systems.** It is hard for them to feel where their bodies are in space – so they might try to get more information about this by flapping hands, stomping feet, "squishing" themselves in beanbags or pillows, or even hitting their own bodies.

- **Hearing in CHARGE** – **Individuals with CHARGE Syndrome usually have some level of hearing loss.** You might not think that hearing loss has anything to do with motor skills, but it *can.* The structures of the auditory system (hearing) are literally *attached* to the structures of the vestibular system, and information from both systems *travels together* on the same cranial nerve, CN VIII, the Vestibulochochlear Nerve. **Research indicates that auditory input** (though not as significant a contributor as vision) ***does*** **play a role in postural stability, including auditory input through the use of cochlear implants.**

Typical motor compensations seen in kids with CHARGE –

- Laying on the ground, especially on their back
- Scooting on their back
- Loving being upside down
- Using their head for balance
- Crawling with their head on the ground
- Laying on surfaces for support

How do we use our brain and body?

- Play - Trial and Error
- Practice - Active Participation
- Problem solve

How can I help my child develop motor skills if they have these sensory challenges?

Why move? In order to move, you need to be MOTIVATED

- Moving has to be more rewarding than *staying still*
- Moving has to be more rewarding than it is *frightening*

1) Figure out what motivates them
2) Change the environment to set up movement, but don't make it too hard
3) Reward and celebrate even small progress
4) Have fun!

The brain and body

change, develop, and become stronger

with use!

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

Father’s Forum

Timothy Hartshorne, PhD.
Central Michigan University

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

CHARGE affects every member of the family. This meeting is only for fathers who have a son or daughter with CHARGE syndrome. It is their opportunity to have an open discussion and share experiences with other fathers.

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Panzacola H-3/H-4

Grandparent’s Forum

Pamela Ryan

Presenter Information

Pam became aware of the CHARGE Foundation in the '90s and has been "hooked" ever since. As the long-time School Psychologist in the Deafblind Program at Perkins (as well as in her other jobs at Perkins) she had the pleasure and privilege of working with and learning from countless students with CHARGE and their families. Through the CHARGE Foundation and the wonderful families, professionals, children, and young adults that Pam has had the good fortune to meet, work and play with, she now has this great opportunity to work with the Foundation as a Board member.

Presentation Abstract

CHARGE affects every member of the family. This meeting is only for grandparents who have a grandchild with CHARGE syndrome. It is their opportunity to have an open discussion and share experiences with other fathers.

TAKING CHARGE in 2017 ORLANDO

13th International CHARGE Syndrome Conference

Friday, July 28, 2017

Breakout Session #2: 1:00-2:00pm
Panzacola F-3/F-4

Promoting Recreation and Physical Activity in the Transition Process

Lauren J. Lieberman Ph.D., Pamela Haibach-Beach Ph.D., Beth Foster Ph.D.

Presenter Information

Dr. Lauren J. Lieberman is a Distinguished Service Professor in the kinesiology department of The College at Brockport, State University of New York (SUNY). She earned her undergraduate degree from West Chester University in Pennsylvania, her master's degree at the University of Wisconsin at LaCrosse, and her PhD in Movement Studies in Disability at Oregon State University. She taught in the deafblind program and coached three sports at the Perkins School for the Blind. She teaches undergraduate and graduate courses in adapted physical education. She codirects the Institute on Movement Studies for Individuals with Visual Impairments (IMSVI) at The College at Brockport and is the founder and director of Camp Abilities, an educational sports camp for children with visual impairments.

Dr. Beth Foster is an assistant professor at Cal Poly Pomona in California in the area of adapted physical education. She is also a nationally 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, Dr. Foster was named the 2012 Pennsylvania State Association for Health, Physical Education, Recreation and Dance 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 Camp Abilities Texas.

Dr. Pamela Haibach-Beach is an Associate Professor at the State University of New York, College at Brockport. She earned her Ph.D. at the Pennsylvania State University in kinesiology with a specialization in motor behavior and a minor in gerontology. Her two main areas of research are 1) postural control and balance and 2) motor development, more specifically, the influence of sensory modalities in human populations including healthy and special populations ranging from children to older adults.

Presentation Abstract

This presentation will share strategies for parents, teachers and specialists to ensure that every child has the basic fundamental skills provided in physical education, IEP meetings, transition meetings and beyond. The laws related to these educational requirements will be reviewed to provide tools and strategies to ensure every child is prepared to have a quality of life. Lastly, many resources will be provided to help support the teachers and families to ensure their children have a strong foundation to live their lives to their full potential.

Promoting Recreation and Physical Activity in the Transition Process CHARGE Conference 2017

Lauren J. Lieberman Ph.D.
Pamela Haibach-Beach Ph.D.
The College at Brockport
Beth Foster Ph.D.
California State University Polytechnical College at Pomona

Who are we?

- **Lauren J. Lieberman**
  - Distinguished Service Professor
  - Adapted Physical Education undergraduate and graduate courses
  - Founder Director Camp Abilities & Co-Founder of IMSVI
  - Research and writing in Inclusion & Children with visual impairments or deafblindness

Pamela Haibach-Beach

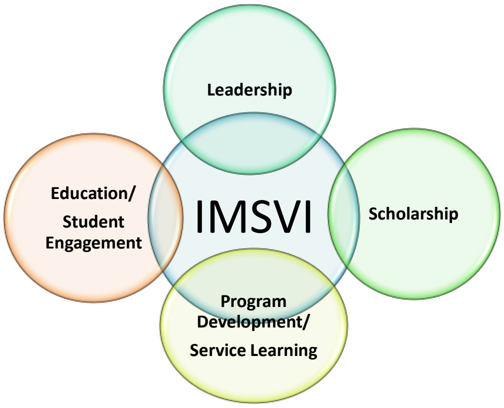
- Professor
- Motor Development, Motor Learning and Physical Activity in Aging courses
- Co-founder of IMSVI
- Researcher in areas of motor development and balance in individuals with visual impairments

Beth Foster

Institute of Movement Studies for
Individuals with Visual Impairments

- Programming
- Leadership
- Education
- Research

See www.brockport.edu/IMSVI



IMSVI

Leadership

Scholarship

Program Development/ Service Learning

Education/ Student Engagement

This presentation

- What is Transition?
- Overview of the research
- Foundational Skills-The need for Physical Education
- Physical Education in the IEP
- Transition meetings must include Recreation and discussion of Barriers

Transition defined

- The process of moving from a school based environment to the community.

What the law says about Recreation and Transition

- The Individuals with Disabilities Education Act (2004) states that every child be afforded transition planning beginning at age 16.

- This means that they need to be prepared for their future after school in the area of independent living, vocational pursuits and **recreational activities**.

Transition Specifically to Recreation

- The content of transition services can, and should, vary between children and is designed to reflect the child’s needs, “preferences, and interests”, and may include community-based physical activity and recreation (IDEA, 2004). These transition plans must be developed by the time a child reaches age 16, but can begin earlier.

Transition Experiences of Individuals who are Deafblind

- The purpose of this study was to find out what schools in the US are providing in regard to physical education services as well as transition services for students who are deafblind.
- In addition this study sought to determine if the current recreational experiences of individuals who are deafblind are satisfactory or if they would prefer to have more involvement in their lives.

Methods

<u>A questionnaire was developed to answer the questions of</u>

1) Demographics
2) Background in physical education and inclusion
3) Involvement in the IEP related to physical education
4) Background related to transition planning and involvement
5) Current recreation/physical activity involvement
6) Satisfaction related to recreation involvement
7) Preferred activities

Validity of the Questionnaire

The questionnaire was reviewed by:

- Three professors of higher education in adapted physical education
  - One was also a specialist in transition
- Two deafblind specialists
- Three people who were deafblind

The revisions were made and the questionnaire was sent out again for feedback. Once all parties agreed on all questions the questionnaire was complete

Participants

Participants had to be between the ages of 18-40, they also had to know they were deafblind in HS, they had to speak English as their primary language, and be from the US.

Demographic information of Participants

Males-13 Females-13

States: MN, IL, IN, NY, NJ, TX, WA, WI

Ages 23-36

Overall Results

1) Most participants were involved in their Individual Education Plan meetings yet physical education and the physical education teacher were not part of the process.

2) Most participants attended their transition meetings yet most never discussed recreation or physical activity let alone how to overcome barriers to their preferred activities.

3) The majority of participants revealed that they are currently not involved in the recreation activities that they want to do. They expressed a dissatisfaction with the support they received in the transition process that would have supported this in their lives.

Adult Recreation

No connection…..

"PE had too much group sports - I do better with solitary sports. Not much accommodations to make my experience with group sports better"

"Nothing was related between the two [transition and recreation], transition focused exclusively on academics.

"I don't recall transition planning having anything to do with recreational"

"I wasn't given any resources, buddy program, or guide on how I would continue to be active"

Results of Study on PE and Children with CHARGE

- Physical Education placement affects children's success and parental satisfaction
- Children with support staff such as a teachers aid, paraeducator or intervenor have a more successful experience
- Communication methods used in classes
- Successful units:
  - swimming, scooters, bowling, fencing, t-ball, dancing, rock climbing, floor hockey, field hocke and gymnastics
- Difficult units:
  - fundamental motor skills

(Lieberman, Haibach, & Schedlin, 2012)

What else do we know?

- Children with CHARGE Syndrome- benefit from appropriate placements and 1:1 instruction (Lieberman, Haibach, & Schedlin, 2012)
- Paraeducators need to be trained (Lieberman, & Conroy 2013)

What else do we know continued….

- Children with visual impairments and deadfblindness benefit from pre-teaching (Conroy, 2012)
- Children who are deadfblind must have specific communication strategies implemented into lessons (Arndt, Lieberman, & Pucci, 2004)

Benefits of adapted sports, physical education and participation

- Increased motor skills
- Improved physical activity
- Improved balance
- Increased socialization
- Self-determination
- Independence
- Orientation and Mobility
- Improved self-esteem
- Increased self-confidence
- Quality of Life

Physical Education as the foundation

- Physical Education is required by law for every child including children who are deafblind (IDEA, 2004)

Motor Skills are Foundation for Fitness

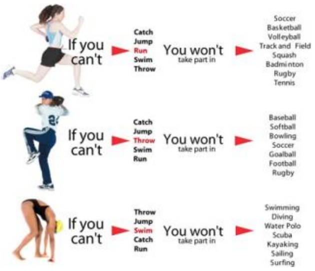
- The development of fundamental motor skills, and therefore motor skill competency, significantly influences an individual’s physical activity levels, fitness and health status (Cairney, Hay, Faught, & Hawes, 2005; Cantell, Crawford, Doyle-Baker, 2008; Cawley & Spiess, 2008; Hands & Larken, 2006; Hands, 2008).
- Physical activity levels at each life stage influences the physical activity levels of subsequent life stages, such that active children are more likely to become active adolescents (Barnett, Morgan, Beurden, & Beard, 2008) and active adults (Boreham & Riddoch, 2001; Cantell, Crawford, Doyle-Baker, 2008).

Balance in Children with CHARGE

- Over half (57%) are at medium to high fall risk
- Low self-efficacy of falls score - significantly correlated with balance.
- Balance did not improve with age
- Parents should emphasize activities which can improve balance in children with CHARGE Syndrome.

(Haibach & Lieberman, 2013)

Why is Motor Development Important?

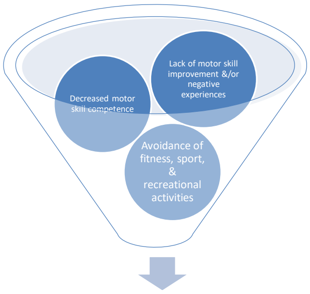


If you can't
Catch
Jump
Run
Swim
Throw
You won't take part in
Soccer
Basketball
Volleyball
Track and Field
Squash
Badminton
Rugby
Tennis

If you can't
Catch
Jump
Throw
Swim
Run
You won't take part in
Baseball
Softball
Bowling
Soccer
Goalball
Football
Rugby

If you can't
Throw
Jump
Swim
Catch
Run
You won't take part in
Swimming
Diving
Water Polo
Scuba
Kayaking
Sailing
Surfing

On the flip side…



Decreased motor skill competence

Lack of motor skill improvement &/or negative experiences

Avoidance of fitness, sport, & recreational activities

Reduced Health Status

Research Findings

- Children with Visual Impairments (CVIB) are behind in motor skill development (Wagner, Haibach, & Lieberman, 2013)
- The severity of the lag in motor development is correlated with the level of visual impairment (Wagner & Haibach, 2012).
- Parents, teachers, and support staff have limited knowledge about teaching children with visual impairments (Lieberman, Houston-Wilson, & Kozub, 2002; Stuart, Lieberman, & Hand, 2006; McKenzie, & Lewis, 2008; Perkins, Columna, Lieberman, Bailey, in press)

Physical Education

- Physical Education provides the foundational skills of balance, motor skills, sports, fitness and recreation that supports a lifetime of vitality
- Placement in an inclusive class, modified class, self-contained class or a combination depend on the needs of the individual child

Physical Education continued

- No matter the placement they need to learn the same curriculum as their sighted peers
- They will need pre-teaching
- They may need a 1:1 with an intervener, paraeducator, peer tutor or an interpreter (or a combination)

What should our children learn?

- The same curriculum that their aged peers learn.
- Need clear communication
- and modifications to the rules, equipment, environment and instruction.

29

Communication during physical activity

- Determine communication mode
- Fully teach entire activity before the start of the program
- Continuous activity break down into component parts
- Discrete activity use clear communication
- Ensure comfort of intervener, SSP or interpreter
- Ensure safety
- Discuss adaptations and reflect on lessons

Modify Equipment

\

- Add sound
- Add texture
- Brighter balls
- Softer balls
- Balls on strings
- Larger balls
- Add tactile boundaries
- Add bright boundaries
- Lower baskets

Modify Rules

Allow Intervenor peer tutor or 1:1 aid for support and communication

Bat off a tee

Guide runner

No defenders in open sport games

Slow down the game such as scooters or carpet square games

Other?

Modify the Environment

- Ensure clear boundaries
- Modify lighting accordingly
- Decrease excessive sounds
- Increase tactile cues
- Use a multisensory teaching approach
- Other?

Transition and Recreation

- Recreation is one of the main components of the Expanded Core Curriculum for people who are visually impaired (Allman, Lewis, Lieberman, & Ross, 2014), this includes children who have CHARGE Syndrome.
- Students can learn skills through physical activity and recreation that can be transferred to their everyday life. For example, putting on a life jacket for kayaking can be transferred to putting on a jacket when a child is cold

Benefits of Recreation

- Experiences in recreation activities provide youth with typical experiences that they can share with siblings, friends, and neighbors._Participation in these opportunities can help to counteract the feelings of loneliness and isolation, while helping to increase engagement in community events and activities (Lieberman, et al., 2013, p.62)

Benefits of Recreation continued…

- By promoting physical activity and recreation, children who are deafblind can be active with their families, neighbors and friends.
- By giving children the tools to be active they are able to participate with those around them rather than sitting on the side. The variety of recreation experiences provides them with choices.

Transition meetings must include recreation planning

1) What does the student like to do?

2) What are some opportunities in the community where the student will live?

3) How can the student experience that activity?

4) How will the student learn the skills?

5) What are the barriers to accessing that activity and how can they be overcome?

6 What are some goals that can be set for this activity?

*Think of examples with the child(ren you work ith

Resource: Going PLACES through APH

Transition Planning

- Ensure the child learns every unit their peers learn
- Include the Physical Education Teacher in IEP meetings
- Ensure that Recreation, Sport and Physical Activity is a major component of the Transition meeting

Overcoming Barriers to Community Activities

- Community Programming may have multiple barriers
    - Transportation
    - Money
    - Communication
    - Systemic
    - Physical
    - Social
    - SSP’s
    - Other

- These must be discussed at the transition meeting

Role Models: Examples of what is possible

- Becca Meyers
- 3X Gold Medalist in the 2016 Paralympics
- Becca has Usher Syndrome and is Deaf

More examples of what is possible

- Andy Granda-1st man who is deafblind to complete and ironman
- Eddie Martinez-rides a unicycle and is deafblind
- https://www.youtube.com/watch?v=lLYp4b_p_wg
- Sarah Morrison-triathlete who has Usher Syndrome
- Megan Stanger is a skier and is deafblind from CHARGE Syndrome
- Great resource "Possibilities: Recreation Experiences of People who are Deafblind"

www.aph.org/stories

More Role Models

- Ryan Oler-Track and Field athlete competed in both paralympics and Deaflympics
- Rachel Weeks Triathlete with Usher Syndrome-the first woman with US to complete and Ironman competition
- http://www.greenvilleonline.com/story/sports/2014/05/11/rare-condition-impair-will-compete/8961295/

Role Models

- Cody Colchado-
  - Paralympic Power lifter
  - Deaf-blind

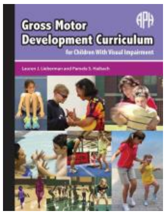
www.coachcody.org

Who is *YOUR* role model?

Examples Resources that Parents and Specialists Can Access

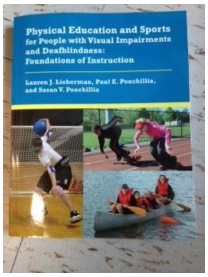
- www.aph.org/pe/stories Possibilities: Recreational Experiences of Individuals who are Deafblind
- www.aph.org/pe/products

New Resources



Books

Physical Education and Sports for Individuals with VI or DB: Foundations of Instruction



Celebrate Successes!

We need to celebrate the successes our children experience as it occurs and cherish what we accomplish!

TAKING CHARGE in 2017
ORLANDO
13th International CHARGE Syndrome Conference

Friday, July 28, 2017

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

What should we be looking for? Child-centered and capacity-building assessment approaches

Julie Maier, Educational Specialist
California Deafblind Services

Presenter Information

Julie Maier is an Educational Specialist for California Deafblind Services and provides technical assistance to families of children with deafblindness and their school teams. She has served many children and teens with CHARGE syndrome. Julie also serves as the Program Coordinator for an OSEP funded personnel preparation project "Specialization Program in the Education of Learners who are Deafblind" at San Francisco State University. Julie has been involved in the in the field of special education in the area of moderate-severe disabilities since 1987, including as a faculty member of SFSU Special Education Department since 1999. Julie has presented at numerous conferences on the topics of meaningful assessment for children with deafblindness and training providers in effective educational practices, including 2015 International TASH Conference, 2015 International CHARGE Syndrome Conference, and 2016 German CHARGE Syndrome Conference. She has written or co-authored several published articles on assessment, self-determination, social supports, collaborative partnerships between families and school teams during the transition process.

Presentation Abstract

Individuals with CHARGE syndrome who cannot effectively use formal language to communicate are difficult to accurately assess using norm-referenced assessment approaches and tools. This presentation will examine how one can use more authentic, effective and child-centered approaches to identify and learn about the abilities, intelligence, interests, and support needs of these individuals and use results from more authentic assessment approaches to develop and plan more effective adaptations, services and supports. Related authentic assessment resources will be shared.

What should we be looking for? Child-centered and capacity-building approaches to positive assessment

Julie Maier
California Deafblind Services
2017 International CHARGE Syndrome Conference
Orlando, FL

California Deafblind Services

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IDEAs that Work
Office of Special Education Programs

California Deafblind Services

In this presentation you will learn…

- the difference between *capacity-building* and *deficit-framing* perspectives and some of the assessment and educational outcomes associated with each perspective.
- about the behaviors and strategies associated with a capacity-building perspective and used with an individualized, child-centered, authentic assessment approach.
- about available resources related to authentic assessment for children and youth with CHARGE syndrome.

My mantra

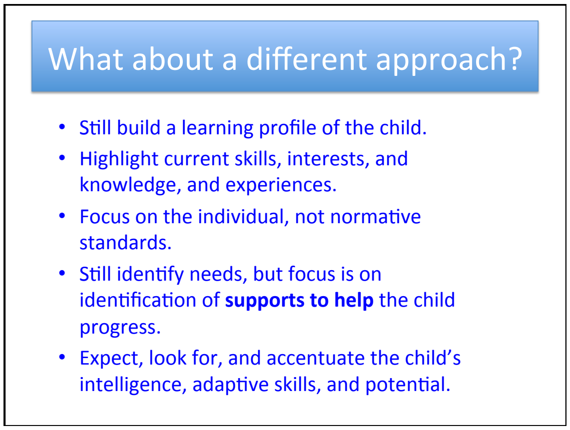
Student assessment is NOT a set of products; student assessment is a process.

My approach

- Positive
- Capacity-based, rather than deficit-framing
- Child-centered (or student-centered)
- Hold high expectations for child
- Assume child wants to and can learn
- Assume child can and wants to communicate and interact with others
- Child's motivation and interests are windows you should use
- Realize that parents are the real experts
- Learning and progress never stop when the right opportunities are provided

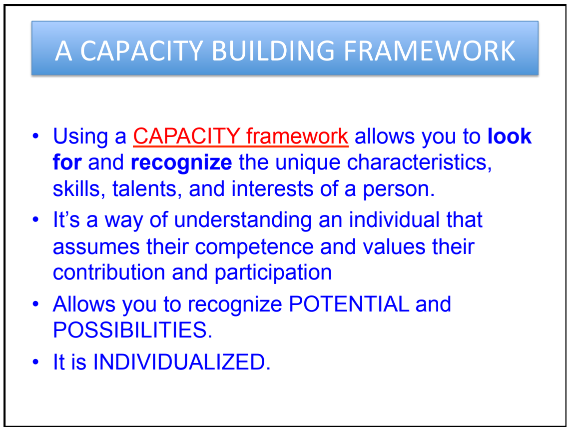
Typical purposes of assessment

- Provide a baseline of current skills, knowledge, and perhaps experiences.
- To determine need, or eligibility, for services.
- Identify supports & services needed by the child.
- Provide a roadmap for intervention and instructional techniques to help the child develop more skills and knowledge.
- Measuring child's growth and skills based upon normative standardized groups or results.



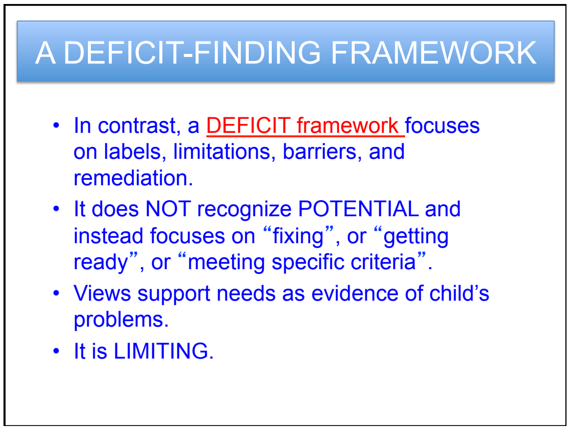
What about a different approach?

- Still build a learning profile of the child.
- Highlight current skills, interests, and knowledge, and experiences.
- Focus on the individual, not normative standards.
- Still identify needs, but focus is on identification of **supports to help** the child progress.
- Expect, look for, and accentuate the child's intelligence, adaptive skills, and potential.



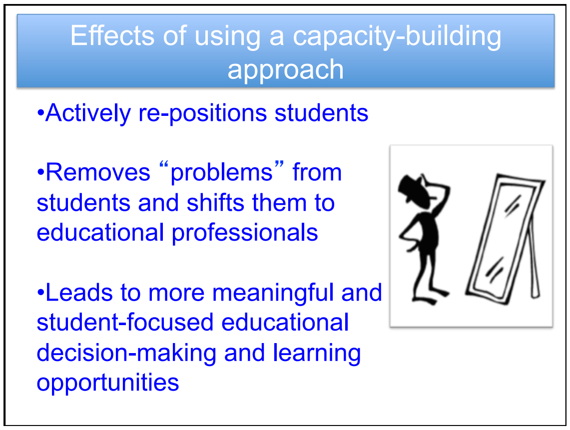
A CAPACITY BUILDING FRAMEWORK

- Using a CAPACITY framework allows you to **look for** and **recognize** the unique characteristics, skills, talents, and interests of a person.
- It's a way of understanding an individual that assumes their competence and values their contribution and participation
- Allows you to recognize POTENTIAL and POSSIBILITIES.
- It is INDIVIDUALIZED.



A DEFICIT-FINDING FRAMEWORK

- In contrast, a DEFICIT framework focuses on labels, limitations, barriers, and remediation.
- It does NOT recognize POTENTIAL and instead focuses on "fixing", or "getting ready", or "meeting specific criteria".
- Views support needs as evidence of child's problems.
- It is LIMITING.



Effects of using a capacity-building approach

- Actively re-positions students
- Removes "problems" from students and shifts them to educational professionals
- Leads to more meaningful and student-focused educational decision-making and learning opportunities

"When a flower doesn't bloom you fix the environment in which it grows, not the flower."

~Alexander Den Heijer

Presuming competence

"Presuming competence is the underlying assumption that even those individuals who behave, move, communicate, learn, and interact with others in different ways share the same human desires we all have for personal growth, community membership, and fulfilling relationships and work. Often these differences disguise the competencies of these individuals due to our society's narrow view of competency which does not allow us to recognize the atypical or unusual skills, abilities, behaviors, and contributions demonstrated by individuals with disabilities as competent or valuable."

~J. Maier (2014)

The criterion of the *"least dangerous assumption"*…

"The criterion of the **least dangerous assumption** holds that in the absence of conclusive data, educational decisions ought to be based on assumptions, which, if incorrect, will have the least dangerous effect on the likelihood that students will be able to functional independently as adults."
~Anne Donnelan (1984)

Two different assumptions

Case #1	**Case #2**
A child with CHARGE syndrome who has significant visual impairments and profound hearing loss is provided with an object calendar and taught signed communication, basic literacy, functional math skills, and the use of a white cane early on in her school years. She is provided with daily integration opportunities with same age peers who receive modeling and support to communicate, interact, and play with her. She receives support from an intervener and her team regularly meets to discuss her progress and support needs.	Now consider that same child spending all day in a special education class and receiving primarily custodial care and no academic instruction or communication system because it was assumed that she is "not really aware of anything or anyone around her" and an academic curriculum will be too difficult for her due to her global delays. She must be led by hand to different activities in class and school by whichever staff is working with her at that time because she cannot see and hear and it isn't safe for her to use a cane yet. She plays alone by choice and because she is just not interested in her peers.

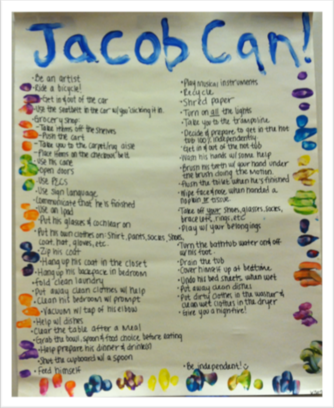
Which assumption is more dangerous to follow?

Support Needs

- A deficit-framing view judges the type and intensity of supports as another way to acknowledge the limitations and deficits of the individuals.
- What if supports were viewed as a means to expand the individual's participation and contribution and self-determination?
- Why is a visual or tactile checklist used to complete a job or task often viewed as, "This person cannot perform this job without help," instead of "Wow, with this checklist this person can independently complete this job."
- We all rely on supports in our lives, but when the need for supports is viewed as a deficit or limitation, then that colors a person's view and perspective of the capacity and contributions of another.

~J. Maier (2014)

From 2013 International CHARGE SYNDROME Conference Poster Session



Jacob Can!

- Be an artist
- Ride a bicycle!
- Get in & out of the car
- Use the seatbelt in the car w/ you clicking it in.
- Grocery shop:
  - Take items off the shelves
  - Push the cart
  - Take you to the carpet/rug aisle
  - Place items on the checkout belt
- Use his cane
- Open doors
- Use PECS
- Use sign language
- Communicate that he's finished
- Use an Ipad
- Put his glasses & cochlear on
- Put his own clothes on: Shirt, pants, socks, Shoes, coat, hat, gloves, etc.
- Zip his coat
- Hang up his coat in the closet
- Hang up his backpack in bedroom
- fold clean laundry
- Put away clean clothes w/ help
- Clean his bedroom w/ prompt
- Vacuum w/ tap of his elbow
- Help w/ dishes
- Clear the table after a Meal
- Grab the bowl, spoon & food choice before eating
- Help prepare his dinner & drink(s)
- Shut the cupboard w/ a spoon
- Feed himself
- Play musical instruments
- Recycle
- Shred paper
- Turn on all the lights
- Take you to the trampoline
- Decide & prepare to get in the hot tub 100% independently.
- Get in & out of the hot tub
- Wash his hands w/ some help
- Brush his teeth w/ your hand under the brush doing the motion.
- Flush the toilet when he's finished
- Wipe face & nose when handed a napkin or tissue.
- Take off your shoes, glasses, socks, brace lets, rings, etc
- Play w/ your belongings
- Turn the bathtub water on & off w/ his foot.
- Drain the tub
- Cover himself up at bedtime
- Undo his bed sheets when wet
- Put away clean dishes
- Put dirty clothes in the washer & clean wet clothes in the dryer
- Give you a high five!
- Be independent! :)

Two views of Jacob

What Jacob CAN do…	What Jacob CANNOT do…
• Ride a bike and can buckle seatbelt • Use sign language and picture symbols to communicate • Put his glasses and cochlear on • With some help can wash hands and brush teeth • Push a grocery cart & put items on the checkout conveyer belt • Shred paper • Put away clean dishes • Put dirty clothes in the washer and wet clothes in the dryer • Choose to use hot tub & get in and out independently	• Cannot drive a car • Cannot speak • Is deafblind • Cannot wash his hands or brush his teeth independently • Cannot read a recipe • Cannot cook a meal • Cannot grocery shop, wash dishes, or do laundry independently • Rips paper, so he he should not have paper • Cannot live alone

The IMPORTANT question here is…

Which list would be more helpful in helping Jacob live a life that will be fulfilling for him and bring him happiness?

A child-centered authentic assessment approach

Authentic Assessment

“Authentic assessment involves obtaining information about children in their everyday environments during normal activities. It provides a way to learn what children know and can do, as well as the types of situation and settings that encourage them to learn. It emphasizes identifying a child’s strengths, which serve as building blocks for further development and skill acquisition.”

~NCDB Practice Perspectives (2010)

Key Points of Authentic Assessment

- Assessment is the starting point of a child’s education.
- Family involvement in the assessment process is essential.
- Information should be gathered using a combination of techniques including interviews with people who know a child well, informal and structured observations, and evaluations by specialists.
- Assessment of children who are deafblind must go far beyond the use of assessment instruments.
- Standardized tests may be necessary to qualify a child for services but are inappropriate as tools to guide educational planning.

~Source: NCDB *“Authentic Assessment” (2010) Practice Perspectives, Vol. 6*

Jan van Dijk (1966)

> "In the educational atmosphere I describe, the child holds the central position, the teacher 'follows' the child and, when the child responds, the teacher is present to answer the child's request."

Van Dijk & Nelson "Principles of Assessment" (2001)

- Make the child at ease
- Determine the child's bio-behavioral state
- Determine the child's interest
- Follow the child's interest

The Van Dijk Approach to Assessment

- Child-guided
- Fluid
- Looks at the processes children with multiple disabilities, including sensory impairments, use to learn and develop
- Assessment is summarized in terms of strengths and next steps for intervention

David Brown's "Follow the Child" assessment approach

"The emotional needs of the children will exert a direct and powerful influence on their ability to function, so that serious consideration of questions like *"How do you feel?" "What do you like?" and "What do you want?"* will provide the best basis for successful assessment. People often think that *"What can you do?"* is the key question to pose to any child during an assessment, but with this group a better question to begin with would be *'What do you do?'* "

D. Brown "Follow the child" reSources Vol. 10 (9). Winter 2001

Assessment Questions
D Brown, "Follow the Child" (2001)

- How do you feel?
- What do you like?
- What do you want?
- What do you do?

D Brown 'Follow the Child' (2001)

- Consult those who know the child better than you do
- Identify the child's motivators
- It's okay to match different sensory inputs
- Relax/arouse the child
- Position the child to facilitate functional skills
- Allow the TIME necessary for the loop of sensory perception, interpretation, and response

Child-centered Approaches

Van Dijk & Nelson "Principles of Assessment" (2001)

- Make the child at ease
- Determine the child's bio-behavioral state
- Determine the child's interest
- Follow the child's interest

Assessment Questions
D Brown "Follow the Child" (2001 & 2014)

- How do you feel?
- What do you like?
- What do you want?
- What do you do?

David Brown, CDBS, 2014

STEPS IN A CHILD-CENTERED, AUTHENTIC ASSESSMENT PROCESS

Just 3 Steps

"We assess because there are things we don't know but we want to find out."
-David Brown (2014)

Step 1: Planning & Gathering Information
(before assessment begins)

- What do you want/need to know?
- What information do you already have?
- What information do you still want or need?
- Who else might have this information?
- Gather important medical and developmental information prior to assessment from family and current teacher(s).

Important areas for assessment

- All 7 senses (including vestibular and proprioceptive)
- Communication
- Concept development
- Self-care and daily living skills (e.g. expanded core curriculum)
- Orientation & mobility
- Personal-identity & self-image
- Assistive technology
- Behaviors
- Social/emotional needs

Step 2: Observation

- Observe child in natural contexts and familiar environments using familiar and/or interesting materials
- Look for functional use of vision during familiar & meaningful tasks *(consider quantity and quality)*
- Watch for changes in behavior or patterns of behaviors using any of the senses.
- What supports and accommodations does the child use?

Step 2: Observation

- Focus on current abilities, interests, strengths.
- Pay attention to posture, position, movement, and behaviors
- Observe across the day. Other specialists and team members can help collect the data.
- What other senses is the child using? How are they working together?
- Attend to how the child communicates (might be very subtle)
- What types of interactions does the child enjoy?

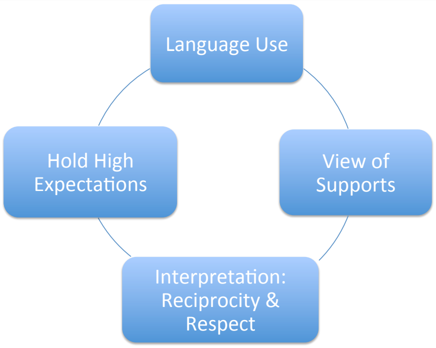
Step 2: Observation

- Attending to functional vision and hearing during your observations
  - Teller Acuity cards
  - Checking for visual fields (finger or motivating materials)
  - Preferred color contrasts
  - Interest in movements or light
  - Size of materials or text for comfortable use of vision
  - Distance and position and placement of materials
  - Types and volume of sound child responds to or avoids
  - Environmental sounds that cause a response or reaction

Step 3: Talk to others, ask questions

- Assessors are often unfamiliar to the child.
- People closer to the child (family members, teachers, support staff, other service providers) hold a lot of valuable information.
- Some good questions:
  - Why?
  - What do you think that means?
  - How often?
  - Does she do that when _____________?
  - When he does that how you usually respond?
  - Do you think she enjoys/prefers that toy/behavior?

Capacity-building Assessment Practices



Language Use

Hold High Expectations

View of Supports

Interpretation: Reciprocity & Respect

Language Use

- Language is very powerful. Both in spoken and written form.
- Your words can paint a **portrait of capacity** that highlights potential and abilities OR paint a **portrait of deficits** which extends view of person's disabilities, limitations.
- Use person-first language and strength-based descriptions.
- Focus on abilities, interests, and support needs.
- Avoid the "expert" voice. Use a voice that invites collaboration, discussion, and exploration of possibilities.

Example

Paul is a determined and resilient young boy who loves cars, playing music on the iPad, and movement. He is part of a tight knit family and spends a lot of time with cousins. Paul communicates with others through facial expressions, gestures and a few signs. He uses a walker or hangs onto furniture to move around his classroom and play yard and recently has begun to climb and slide by himself. At home he will walk short distances independently. Even with his vision loss and hearing loss, Paul is very observant and likes to watch others engage in activities and then sometimes decides to join the activity. Paul learns new routines and skills best when provided time to practice and often enjoys repeating the same routine, sequence or behavior multiple times. Paul is showing more interest in joining his peers in activities especially it involves his favorite songs, drumming, and drawing. Paul is very sensitive to touch, especially to certain textures, so be thoughtful and attentive with the materials and activities you present to him.

View of Supports

- First and foremost, we ALL rely on support from others in our lives.
- Need for support is accepted as natural and not indication of a problem with the child.
- Planned supports should enable the person to…
  - have control
  - make choices
  - participate as much as possible and as much as desired
  - contribute to class, group, family, or community

View of Supports

- Child and family are included in identification of supports that “fit” them well.
- Identify natural supports whenever possible, such as peers or siblings, regular routines, good seating arrangement, assistive technology like smart phone apps.
- Supports will change as child develops new skills and abilities (e.g. using a walker → assisted walking → O & M instruction → public transit).
- Planned supports enhance the child’s competency and dignity.

Reciprocity and Respect

- Others will learn more from what they see you do and say than any training you might provide.
- Your responses to the child in typical, as well as difficult, situations will provide others with information, strategies, and confidence to respond and engage with child during future opportunities.
- Point out child’s strengths, attempts, interests, and possible support needs.
- Remain calm, positive, respectful and supportive in your interactions and as you engage the child in activities during assessment.

Reciprocity & Respect (2)

- Critical role when assessing and supporting students who communicate and/or behave in an atypical manner.
- Your responses **acknowledges the message** of non-verbal communication or any challenging or less typical behavior.
- Ask “I wonder…?” questions.
- Point out how an child communicates and/or can participate and contribute to help others recognize the child’s strengths, interests, and contributions by commenting on what you’re observing in the child.
- Point out ways a person can participate, contribute, and/or meet an educational goal.

EXAMPLES
“Look, Sara is looking up at you and smiling. I think she is enjoying this art activity with you.”
Juan is excitedly jumping up and down in the cafeteria line: “I wonder if standing so close to all of the other students and waiting in line is making him anxious. What do you think?”
“Did you notice that Audrey laid down on her back and crossed her leg across her knee once you gave her the book? That’s really smart that she knows what she needs.”
“I imagine if Andres has his lines simplified and highlighted in the script and could practice with a peer partner, then he could easily participate in the reader’s theater group.”

Hold High Expectations

- Support student to identify their strengths, abilities, interests and support needs and share them with others.
- Identify ALL possibilities.
- Expect continual growth and progress.
- Develop educational goals that build upon student’s strengths, abilities, and interests.
- Stay focused on POTENTIAL & abilities and student’s/family’s goals for the future.
- Use person-centered planning approaches to develop a challenging vision for the future.

Questions? Comments?

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CDBS website: www.cadbs.org

Assessment Information Specific to Deafblindness

General Resources

Assessing Communication and Learning in Young Children Who are Deafblind or Who Have Multiple Disabilities
This guide is intended for all professionals who are responsible for assessing and developing interventions for young children who are deaf-blind. The contents should also be helpful for families of these children who seek to become actively involved in educational planning. The strategies and materials are applicable to many children who have multiple disabilities as well as to children who are deafblind. [From the guide's introduction.]
https://www.designtolearn.com/uploaded/pdf/DeafBlindAssessmentGuide.pdf

California Deafblind Services
The CDBS website features articles and resources categorized by subject matter. There are many resources specific to assessment.
http://www.cadbs.org/articles-by-subject/

Two articles that provide good general information to assessment:

- "Follow the Child – Approaches to Assessing the Functional Vision and Hearing of Young Children with Congenital Deaf-Blindness" by David Brown, CDBS Educational Specialist

- "What Does 'Follow the Child' Mean?" by David Brown, CDBS Educational Specialist

National Center on Deaf-Blindness
This page lists assessment tools that are sometimes used to conduct communication and educational assessments with children who are deaf-blind. For guidance about the appropriate use of assessment tools and instruments and how to select an instrument for a specific child, You might start with the manual linked under "Assessing Communication and Learning in Young Children Who Are Deafblind or Who Have Multiple Disabilities". Additional links go to the full text of assessment tools that are available online or to more information about how to purchase those that are not available online. [From National Center on Deaf-Blindness website.]
https://nationaldb.org/library/list/33

Anthony, T. (2004). A Functional Vision Assessment For Children Who Are Young and/or Multi-Disabled http://documents.nationaldb.org/products/conference/2004_topical_workshop/Partial-FVA-document.pdf

Blaha R. 1996. Thoughts on the Assessment of the Student with the Most Profound Disabilities. See/Hear Vol 1 No 4 Fall 1996, 13-25. http://www.tsbvi.edu/seehear/archive/thoughts.htm

Assessment Tools Listed Alphabetically

Analysis of Sensory Behavior Inventory
The *ASBI* helps teams determine if students are avoiding and/or seeking specific sensory information: vestibular, tactile, proprioceptive, auditory, visual, and gustatory-olfactory. [This is an “adapted” version but appears to be a verbatim copy. Please try to purchase an original version if possible.]
http://www.leics.gov.uk/analysis_of_sensory_behaviour_inventory.pdf

All Children Can Read: Literacy Skills Checklist.
http://literacy.nationaldb.org/files/7914/7672/3022/Literacy_Skills_Checklist_English.pdf
Developed by many different state partners around the country working together to collect information and resources for teaching and supporting literacy skills development for students with combined vision and hearing loss. This checklist can be used to identify what stage of literacy skills the child currently demonstrates (foundational, early emergent, emergent, developing, expanding, independent).

Communication Matrix
An easy to use assessment instrument designed for individuals of all ages who function at the earliest stages of **communication** and who use any form of communication. [From Communication Matrix website.]
https://www.communicationmatrix.org/

Home Inventory of Problem Solving Skills
This instrument is designed to assess the early cognitive development of children who have severe or multiple disabilities (including deafblindness) and who are not able to speak. The Problem Solving assessments are used to assess object interaction skills that reflect concept development. They include 33 items in three strands: Basic Skills with Objects, Ways to Gain Access to Objects, and Ways to Use Objects. This instrument contains the same items as the School Inventory of Problem Solving Skills, but it cites examples appropriate for the home setting and is designed for use by family members. [From Design to Learn website.]
https://www.designtolearn.com/content/home-inventory-problem-solving-skills-hipss

Home Talk
HomeTalk is an assessment tool designed for use by parents and care providers of children who are deafblind and who have other disabilities. Its purpose is to help you participate more actively in the planning of your child's educational program. HomeTalk is designed to provide a broad picture of your child's skills, special interests, and personality. [From National Center on Deaf-Blindness website.]
https://nationaldb.org/library/page/789

The INSITE Developmental Checklist
The INSITE is a comprehensive developmental checklist for infants and young children, birth to age six, who have sensory and multiple disabilities. The checklist is based on the development of typically developing children but adapted for use with children who are deaf-blind because of the often unique ways these children manifest development. [From the checklist’s description.]

https://hopepubl.com/proddetail.php?prod=404

Integrated Functional Behavior Assessment Protocol (IF-BAP): Holistic Behavioral Assessment of Students with Deafblindness and Severe Disabilities
The IF-BAP model and materials are based on more than ten years of validation developed primarily by Kevin Arnold and his colleagues, first at Ohio State University and later at the University of Dayton and the School Study Council of Ohio. The IF-BAP strategy is intended to create a comprehensive view of a student who is deaf-blind or has severe disabilities, in order to increase the teacher's understanding of the interactions among various behavioral and sensory systems. Once teachers understand those interactions, they can design a program that not only addresses each of those systems, but also the combined effects of each system's unique contribution to the whole student. IF-BAP relies on a transdisciplinary approach, in that the assessment strategies incorporate several specialized assessments, but do so through one individual. While various specialists conduct their assessments, the behavioral psychologist is charged with integrating their findings into one overall picture of the student. The material is presented as an instructional manual to be used by qualified professionals who are competent in psychological assessment, applied behavioral analysis, and instructional interventions. [From National Center on Deaf-Blindness website.]
http://www.slideshare.net/ccbtcolumbus/introduction-to-ifbap

PAIVI: Parents and their infants with visual impairments. (2nd edition). Louisville, KY : American Printing House for the Blind.
PAIVI, written by Deborah Chen, Gail Calvello, and Clare Taylor Friedman, is an updated version of the original Parents and Visually Impaired Infants (PAVII).
This set of materials is designed to help parents and teachers of infants who are visually impaired become involved as primary members of the intervention team.www.aph.org

School Inventory of Problem Solving Skills
This is a 20-page assessment of object interaction skills that reflect concept development. It includes 33 items in three strands: Basic Skills, Ways to Gain Access to Objects and Ways to Use Objects. It is designed to be administered in the school or childcare setting. It can be followed by the *Task-Based Assessment of Problem Solving Skills*. Additional information is available in *Hands-On Problem Solving for Children with Multiple Disabilities*. [Check with California Deaf-Blind Services for copies of the *Task-Based* and *Hands-On* documents.]
https://www.designtolearn.com/content/school-inventory-problem-solving-skills-sipss

Time to Learn
The *Time to Learn* environmental inventory is designed to help teachers identify and create opportunities for active participation and steady learning in typical classroom activities for children who are deafblind or who have other severe or multiple disabilities. The inventory contains 70 items in eight categories (Transitions, Activity, Adult's Interaction, Student's Communication System, Peer Interaction, Opportunities to Communicate, Opportunities to Use Objects, and Materials) that help a teacher assess the degree to which a specific activity encourages learning and independence for a specific student. *Time to Learn* is compatible with the *HIPSS* and *SIPSS* assessments and with the *Communication Matrix* in that it specifically addresses opportunities to demonstrate the skills included in both of those

instruments. [From *Time to Learn* materials. Check with CDBS for a copy of this tool if unavailable on web.]
https://www.designtolearn.com/

Resource List of Assessments

Resources for Vision and Hearing. Austin, TX: Texas School for the Blind and Visually Impaired Assessment.
Texas Deafblind Outreach has compiled a variety of assessment tools which we hope will help parents and educational staff gather functional information that may then be shared with these doctors to aid them in making a definitive determination of hearing or vision loss. These materials include those which will: guide observations and organize that information to share with medical staff; expand the range of questions to explore with the professionals to get good testing results; and help prepare the student for more formal testing procedures. Additionally, we have included materials which will aid the educational staff in determining modifications to improve programming for the child in the classroom. These materials are in no way meant to supplant formal testing done by ophthalmologists, optometrists, audiologists or otologists. Law and common sense dictates that formal testing must be done. Rather it is meant to aid in getting good testing results on hard to test children. [From Texas School for the Blind and Visually Impaired website]. http://www.tsbvi.edu/math/123-general-2/109-assessment-resources-for-vision-and-hearing. (Retrieved on 2/3/17).

Related Webcasts:

van Dijk, J. 2011. Child Guided Assessment. Perkins School for the Blind webcast
http://support.perkins.org/site/PageServer?pagename=Webcasts_Child_Guided_Assessment

van Dijk, J. 2011. The Role of the Emotional Brain. Perkins School for the Blind webcast
http://www.perkins.org/resources/webcasts/role-of-the-emotional-brain.html

Brown, D. 2012. Vision Issues for People with CHARGE Syndrome. Perkins School for the Blind webcast.
http://support.perkins.org/site/PageServer?pagename=Webcasts_Vision_Issues_For_People_With_CHARGE_Syndrome

Brown D. 2012. CHARGE Syndrome: Sensory Processing. Perkins School for the Blind webcast.
http://support.perkins.org/site/PageServer?pagename=Webcasts_CHARGE_Syndrome_Sensory_Processing

TAKING CHARGE in 2017 ORLANDO
13th International CHARGE Syndrome Conference

Friday, July 28, 2017

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

CHARGE 102 Effects of CHARGE features on development, behavior and outcomes

Kate Beals, OTR/L and
Nancy Salem-Hartshorne, PhD

Presenter Information

Kate Beals, OTR/L, is a pediatric occupational therapist. She has worked with children who have CHARGE Syndrome at the South Carolina School for the Deaf and the Blind, in the South Carolina Inter-agency Deafblind Project, and in the Deafblind Program at Perkins School for the Blind. She is presently employed at McCarthy Teszler School in Spartanburg, SC. Kate has served as a Consultant for Perkins International in China, and has provided training for international participants in Perkins' Educational Leadership Pr

Nancy is an Associate Professor of Psychology at Delta College in Bay City Michigan and a School. Psychologist. She has authored articles and book chapters about developmental outcomes for individuals with CHARGE syndrome. Her young adult son Jacob has CHARGE syndrome and lives in his own home. Nancy has been involved with language and education of children with CHARGE for 25years. She advocates for individuals with disabilities, teamwork, thorough planning, and forward thinking for quality life outcomes for all individuals.

Presentation Abstract

Kate Beals and Danielle Bushey will continue their presentation from 101 by presenting ideas on how to set up play and learning activities so the child derives optimum physical benefits from the experiences. Then Nancy Salem-Hartshorne will present an overview of what we know about behaviors and developmental outcomes in CHARGE based on 20 years of research and observations. Nancy will also introduce communication options appropriate for children with CHARGE – which will be continued in CHARGE 103.

COMMUNICATION

Communication, communication, communication!!!!!

Language: What's so hard? Isn't it a Natural Process?

Sure it was, for you and most of the people you know. But Imagine…

- you were just born into the world.
- you are hooked up to tubes, monitors, and pumps, some of which are painful.
- you have just been given a tracheostomy or gastrostomy.
- you have been in the hospital for weeks on end.
- you are recovering from surgeries, tests, and procedures, with pain and fatigue.
- your body isn't working right and you just plain don't feel good.

Now: How "ready" are you to learn?

After Medical/Health Issues…

- Enabling expressive and receptive communication for the individual with CHARGE syndrome is the most crucial goal. It underlies all other learning.

Let's add a few things: Imagine…

- your vision is limited: You can only see through one eye, or part of one.
- your hearing is limited: You can't hear much from one ear, and nothing from the other.
- you cannot move to what you want to explore: Your muscles are weak; you can't tolerate the feel of the carpet/floor on your hands or feet.
- your sense of balance is limited or nonexistent. What you see moves around and you can't get oriented. Being held and carried may even cause you distress.
- all of this doesn't allow for growthful parent/baby interaction.

Now: How "available" are you to learn?

Factors affecting language development in CHARGE syndrome

(Adapted from Swanson, L., in CHARGE Syndrome, 2011)

- Vision and mobility/balance
- Hearing loss
- Facial palsy may cause difficulty with speech
- Tracheostomy: problems vocalizing
- Difficult to stimulate language early because of medical issues
- Language delays may affect cognitive skills
- Parent-child interactions: difficult when the child is less available because of sensory/medical issues.
- Serious illness and hospitalizations

Distance Senses

- Hearing
  - Important for understanding oral language
  - Also gives environmental cues
  - How much hearing is available? From one ear or both? How much does an ear infection affect this? Do they wear hearing aids or cochlear implants?

Adapted from http://www.dbproject.mn.org/commbubble.html

Distance Senses

- Smell
  - Can identify a person
  - Can evoke strong memories
  - Is smell available? Not always, in CHARGE syndrome

Adapted from http://www.dbproject.mn.org/commbubble.html

Distance Senses

- Vision
  - Tells you what is in your environment
  - Tells you if things or people are moving toward you or away from you, or standing still
  - Tells you if people are trying to communicate with you through sign or gestures
  - How far up, down, and side to side can they see? Do they have blind spots? How far away can they see clearly? How does lighting affect their vision? What about contrast? These things may be able to be determined through a Functional Vision Assessment.

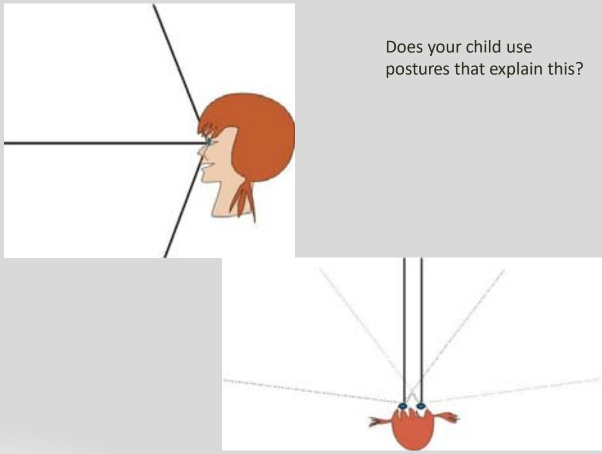
Adapted from http://www.dbproject.mn.org/commbubble.html

The Communication "Bubble"

"A child with CHARGE may not see you unless you are at a specific distance and in the individual child's visual field, or the child may see only parts of you and not as a person. These children also may not hear your natural voice, or they may not hear you at all. These same children may not smell properly in order to identify food, perfumes, or other common odors and may not have enough balance to attain normal motor milestones. These children are *input impaired*."

http://www.dbproject.mn.org/commbubble.html

What do you need to do to accommodate the individual person's communication bubble?



Does your child use postures that explain this?

http://www.dbproject.mn.org/commbubble.html

Communication/Language in Children with CHARGE Syndrome: Some data

Makes reactions or noises or behaviors which can be difficult to interpret	n =20	16.1%
Uses behaviors such as gestures, sounds, body movements	n = 12	9.7%
Uses single words, signs, picture symbols, or object symbols to represent basic needs	n =15	12.1%
Uses some 2- to 5-word phrases and sentences using speech, signs, picture symbols, etc.	n = 17	13.7%
Uses verbal or sign language in complete sentences	n = 59	47.6%

All children were 4 or older. Hartshorne, T.S., Unpublished Data

Communication Modes Used by Individuals with CHARGE Syndrome (Adapted from Swanson, L., CHARGE Syndrome, 2011.)

- Manual Sign
  - *Sign Language*: The "official" language used by Deaf culture in your country
  - *Signing Exact English*: Using English word order, instead of the "language" of sign
  - *Cued Speech*: Using gestures while speaking to enhance understanding of lip-reading
  - *Fingerspelling*: Spelling out words letter by letter using a signing alphabet
  - *Tadoma*: a method of touching a person's face and throat to feel what they are saying
  - *Home sign*: Signs used/invented by an individual that are specific to them

---

- Total Communication: recommended for ALL
  - The use of any form of communication available to the individual. Often, individuals choose to use more than one form.
  - For example, a person may use some sign language to answer questions, some picture symbols to ask for food, some push-pull to show you what he/she wants, and some idiosyncratic behaviors when in pain, because that is what works for them.
  - There is a growing consensus to allow for this to happen, as any communication helps the individual to be heard, no matter how it's done.
  - Limiting the individual to only one mode of communication may cause frustration as it blocks their ability to make themselves heard.

- Speech
  - Using verbal forms of language, both formal and informal
- Visual Symbols
  - Using objects, pictures, or textures to communicate
- Voice Output Communication Aids (VOCA)
  - Using electronic equipment to communicate a message
- Gestures and Vocalizations
  - Pointing, showing, push-pull, vocal noises to communicate, without the use of signs
- Idiosyncratic Behaviors
  - The individual's own form of communication when other forms are not adequate, available, or accessible. Examples: crying, smiling, pain behavior, or any other way of trying to get a message across.

Some General Guidelines

- Let the child take the lead in communication: follow them. Get into their world; don't force them into yours.

- Turn-taking is an important first skill in communication, even if there are no words involved. How? Respond to signals to get a conversation started, just like with a developmentally typical baby; mimic sounds and gestures, extend them, expand them. Don't ignore them. All behavior is communication!

- Validate the individual’s attempts at communication. Don’t assume you know what they are going to say. Let them say it before you respond.

- Make sure the individual has access to all of their communication tools at all times, (all pictures, all devices) even if the answer to their request is “no.” Never take away their ability to use their words, in whatever way they use them.

Behavior in CHARGE Syndrome

- Use total communication: Allow/encourage the individual to tell you what they need to tell you in any way they can.

- Ask for clarification if you are not sure what the individual is saying. Use a consistent signal/sign/word for “What?”

- Use calendar systems: help the individual to anticipate what will be happening during the time period. This helps to alleviate anxiety, to give them choices about their activities, and to understand time: before/during/after.

Common Deafblind Behavior

- **Eye pressing**
- **Finger flicking**
- **Rocking**
- **Tapping body/objects**
- **Self-injurious behavior**
- **Mouthing objects**
- **Tactile defensiveness**
- **Clinging**
- **Spinning**
- **Vocal tics**
- **Feces smearing**
- **Lining things up**
- **Extreme preferences**
- **Darting/running off**
- **Learned helplessness**
- **Submissive**
- **Stare at lights**
- **Inappropriate vocalize**

We see all of these in children with CHARGE

-Beth Kennedy, DeafBlind Central

Tim Hartshorne (CHARGE Syndrome, 2011) has studied behavior and found that “certain similarities and patterns are emerging.” These could possibly related to the genetic differences in CHARGE syndrome. Not all individuals with CHARGE will have all features. However, these seem to come up often.

1. Low-normal cognitive functioning: There is a wide range of abilities, but Salem-Hartshorne and Jacob (2003) found that about half have low-average to average abilities, which was surprising, given that medical reports had often said all had mental retardation.

2. Very goal-directed and persistent with a sense of humor: “Children with CHARGE syndrome seem to know what they want and persist in their intentions. This stubborn persistence helps them to learn to walk, to eat, and to achieve beyond all expectations.” However, sometimes they have trouble letting go of the idea of what they want, and this can be a problem. At other times, they may be unable to communicate what it is they want, causing frustration and escalation of behavior. Happily, they often have a great sense of humor as well.

3. Socially Interested but Immature: Children with CHARGE syndrome often have trouble making and keeping friendships. At the same time, they seem to be more interested in relating to others than others who are deafblind or have autism. However, they often “have difficulty understanding other children and often miss or misunderstand social cues.” Part of it may be because of their problems with vision and hearing, but they seem to have difficulty with taking turns, backing off when necessary, and playing nicely with others.

4. Repetitive Behaviors that Increase under Stress: Many children with CHARGE are diagnosed with Obsessive Compulsive Disorder because of these behaviors. OCD is an anxiety disorder, and behaviors will increase with stress. The behaviors tend to soothe the anxiety. Whether or not individuals with CHARGE syndrome have OCD is still in question. Still, they often engage in repetitive behaviors, lining things up, and keeping strict routines. It seems to make sense that with limited sensory input, the world can be a bit chaotic. Using these behaviors may simply help to keep anxiety levels down.

5. High Degree of Sensation Seeking: "Light flicking, hand flapping, body shaking, and rocking are among the self-stimulatory behaviors that are common in children with CHARGE." Although these behaviors can get in the way of learning at times, they seem to serve a function for individuals with CHARGE syndrome. Because they often lack sensory stimulation from vision and hearing, these behaviors may serve to make up for that lack, to keep the brain alert (just as you or I might tap a pencil, chew gum, or sway our calf back and forth to keep alert.) Some individuals with CHARGE may simply need a sensory break to pull themselves back together before working again. "A hard-working student might suddenly drop everything and shake his or her whole body for a moment, and then be able to go back to work."

6. Under Conditions of Stress and Sensory Overload, Find it Difficult to Self-Regulate and Easily Lose Behavioral Control: Most of us are able to self-regulate well. We can concentrate even though there's a little bit of noise in the background, or we know that when we are overwhelmed in a noisy environment we need to get someplace quiet. Everyone is different in what they can tolerate to their senses, and in how they deal with it. Individuals with CHARGE have difficulty regulating this. Sometimes they may want extra stimulation, such as rubbing their hands on a textured surface repeatedly. Then, suddenly, it becomes too much. The sensation "might send them over the sensory edge and cause loss of behavioral control." They may crave the sensation of staring at a colorful disco light toy, but then knock the light away when it becomes too much.

7. Difficulty with Shifting Attention and Transitioning to New Activities; Easily Lost in Own Thoughts.

Many individuals with CHARGE syndrome become very focused internally. This may in part be because of sensory impairments, but there seems to be more. They seem to have difficulty shifting their attention, and "moving freely from activity to activity."

Additionally some may have difficulty initiating new activity. They may want to, and may be ready, but might have difficulty getting started.

They may also have trouble with monitoring their own behavior and how it affects others.

These individuals will need assistance to learn to do these things.

Behavioral Threshold:

This is the point at which someone loses control. Consider anger in you or me. Most people may be able to control their behavior when they are angry, but then someone does or says something, and it's the "last straw," and they may lose control.

Likewise, an individual with CHARGE syndrome may hold it together as long as they are under the behavioral or sensory threshold. Once things become too much, they can have an abrupt change in behavior, seemingly coming out of the blue.

Three things can put an individual with CHARGE syndrome over the threshold for behavior:

1. Sensory stimulation: As stated before, what begins as a welcome need for stimulation can often escalate to be too much. It can change from "pleasant or bearable to painful and upsetting very quickly."

2. Buildup of stress in the environment to the point that they can no longer cope. Consider all of the medical interventions they must go through, for example. In addition, consider the mere exhaustion factor when trying to see, hear, stand, walk, and all of the other things these individuals must work hard at, all day.

3. Pain: This may be the most important thing to look at. Often, pain is subjective. We cannot see it. A child with CHARGE may not be able to tell us that their throat or ear hurts, or that they feel achy. There are many other types of pain that are specific to CHARGE syndrome (see next slide). A sudden change in behavior without explanation should always lead to an immediate investigation of what may be causing the person pain.

Why pain is so important

- **Can affect normal brain and nerve development**
- **Can affect sleep**
- **Can interfere with exploration of the environment and learning**
- **Can interfere with the development of attachment and trust**
- **If they begin to get used to it, it may affect their health if not taken care of.**

(Hartshorne, T.S. 2012)

Frequent Sources of Pain in CHARGE

- Otitis Media (middle ear infections)
- Sinus infections
- Migraines
- Abdominal Migraines (migraines felt in the belly)
- Gastroesophageal reflux disease (GERD)
- Gas
- Constipation
- Muscle pain
- Tactile defensiveness (too much sensation at the skin level)
- Stoma pain (inflammation around the skin at the entrance of the feeding tube in the stomach.)

When you are in pain, do you …

- **Whine?**
- **Complain?**
- **Seek attention?**
- **Make demands?**
- **Act out?**

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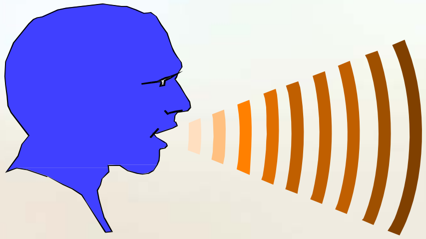
"He's complaining of chest pain, shortness of breath, cramps and dizziness. Do you sell earplugs?"

ALL BEHAVIOR IS COMMUNICATION



How can you help?

- Communication, communication, communication
- Always interpret behavior as communication.
- Develop a pain management plan.
- Figure out if the behavior serves a purpose for the individual. It doesn't always have to be changed or eliminated!
- If it is determined that the behavior should be changed or eliminated (maybe they are injuring themselves or others), we must teach them alternative ways to communicate their needs.
- Sensory diet: deep pressure/squeeze hugs, brushing and joint compression (ask your occupational therapist for help). These things can help regulate the sensory and behavioral thresholds by getting the nervous system reorganized.
- Break down larger tasks into smaller, more manageable chunks.
- Help the individual learn ways to self-soothe.
- Build sense of safety and trust
  - Consistency
  - Routine
  - Calendar System

Sometimes behaviors make perfect sense!

This is normal viewing posture…

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

(-David Brown)

EXAMPLES

David Brown (2005). CHARGE Syndrome "Behaviors": Challenges or Adaptations? *American Journal of Medical Genetics, 133A*, 268-272.

- A young child who was said to be self stimulating "all the time" was actually practicing and developing his mobility and orientation skills, and using vision and touch to explore objects, very creatively. While doing this he needed to get onto his back on the floor to reorganize his sensory system with brief episodes of limb shaking and hyper-ventilating every 10 to 20 minutes. (sensory break)

- People were concerned when a young boy began to insist on the unusual idea of wearing band-aids wound tightly around the tips of all his fingers and thumbs every day. He was expressing his need for more and stronger pressure and touch inputs as a part of his sensory diet. (Needed more pressure/stimulation)

- A kindergartener was often self- abusive when he got distracted and over- aroused by incidental touch and air movement caused by people repeatedly walking behind his chair. Once his chair was placed with its back securely against a wall he was less self-abusive and more amenable to social interaction. (Too much stimulation)

- Every morning in a pre-school program a student refused to sit on the floor with her class to watch the teacher sign a story. When an appropriate chair was provided the student sat and attended with great interest and a growing level of participation. (balance problems)

- A girl was described as very disruptive during sessions that required the class to sit still and participate in a signed conversation with the teacher for up to 30 minutes. When the teacher used a strategy of asking the student to move periodically to carry out small chores during these sessions (to fetch a pen, open a door, bring a book, take a paper to the school office) the disruptive behaviors largely ceased. (visual fatigue)

- During Orientation and Mobility sessions a teenager was refusing to stand still to receive spoken/signed instructions, but the problem was solved when the student was allowed to stabilize himself by leaning against a pole or a tree or a wall, or by placing one hand on the instructor's shoulder during these conversations.

(balance problem/stabilizing body/head)

- A teenager enjoyed, and was quite good at, soccer in the school gym, but was unwilling or unable to play it outdoors due to the absence of strong vertical visual markers to aid equilibrium. The ability to participate in such complex physical activities outdoors did not develop until significant adaptations were introduced. (need for visual "handles" in the environment to know where his body is in space)

Developmental Considerations

Three Developmental Domains

- In studying human development, we look at three domains:

- Physical Development
- Cognitive Development (Intelligence)
- Social/Emotional Development

Normal Gross Motor (Large Muscles)Milestones

- What's typical for a non-CHARGE baby?
  - Hold head up
  - Roll over
  - Sit up
  - Crawl on belly, then on all fours
  - Pull to stand
  - Cruise holding onto furniture
  - Walk independently (Average Age=12 months)
  - Stairs, hopping, running, skipping, etc.

Physical Development

- We've already discussed the physical differences in individuals with CHARGE syndrome. We have discussed senses, sensory systems, surgeries, medical problems, and many other aspects. What's left?
  - **Motor Milestones**

CHARGE Gross Motor Milestones

- Arching back
- Back scooting (rub hair off back of head)
- 5-point crawl (four limbs plus head)
- Sitting
- Bottom Shuffling
- Crawl
- Pull to Stand
- Cruise around furniture
- Walk independently (average age = 42 months)
  - (Age ranges from 30 to 84 months)
- May continue to have unsteady gait

With what you know…

- About sensory, vestibular, and other CHARGE systems, can you hypothesize why these milestones might occur differently?
  - Visual field reasons?
  - Vestibular reasons?
  - Keeping head stable reasons?
  - Tactile defensiveness reasons?

Normal Fine Motor (small muscles) milestones

- Suck, swallow
- Eat puree
- Chew, bite
- Grasp with whole fist
- Grasp with finger and thumb
- Manipulate/trade objects between hands
- Hold/draw with crayon, etc.

Vestibular

- We use eyes, joint pressure, and semi-circular canals to balance. Many children with CHARGE have little vision, and malformed or missing semi-circular canals. In order to walk, they must rely on joint pressure, primarily. Does this explain the wide, slow, toddling gait many have?

With what you know….

- About eating, tactile defensiveness, and low muscle tone, what might this mean about fine motor milestone achievement for children with CHARGE syndrome?

- Early tactile defensiveness (inability to tolerate some sensory input to skin) limits how much touch and object manipulation the child can handle without going over the "sensory threshold." This may delay fine motor milestones.
- Of course, eating/swallowing/breathing issues will delay eating milestones.

What does this mean?

- It means that **we can/should have high expectations** of these children from the beginning, because we absolutely cannot tell what the outcome might be, based alone on how sick they are as babies.
- It MAY mean that we can possibly predict how well a child will do based on when they start walking. (This is definitely not set in stone, but has been found in other studies as well.)

Cognitive Ability

- *We gave the Adaptive Behavior Evaluation Scale* to 100 Children with CHARGE
- They showed a higher range of ability than once thought: 54 had scores higher than 70 (Average score is 100. Below 70 is typically considered mental retardation)
- Those who walked earlier, had fewer medical problems, and had better hearing and vision scored higher. Age at walking had the strongest result.

Salem-Hartshorne N, Jacob S. 2004. Characteristics and development of children with CHARGE association/syndrome. *Journal of Early Intervention Vol 26*: 292-301.

Age at Walking? Why?

- The ability to walk depends a great deal on the vestibular system. Some children may have more severe problems there, and therefore walk later.
- It's not walking age that causes problems, though. The vestibular system can affect a LOT of things that have to do with learning. Walking is just one thing it delays.
- So, does having more problems with the vestibular system mean the child may have more developmental problems, overall?
- It's what we are beginning to think, and it makes sense, but there is no clear proof of this.

Social Skills Deficits

- Acquisition deficit - never learned the skills
- Performance deficit - prefers not to use the skills
- Fluency deficit – knows the skills but not very good at applying them

Most children with CHARGE appear to have a fluency deficit rather than the other two.

Social Skills they Need

- Getting along with peers
- Managing their behavior
- Classwork skills
- Cooperation
- Being assertive

- They will need practice, guidance, and support to do well at these things.

This means:

- They know what to do.
- They want to do well.
- They have trouble doing it well.

- Management of emotions can be difficult, because of that emotional threshold that is difficult to come back from. Melt-downs may be common.
- Need to teach them strategies for self-soothing, talking to themselves about what's going on, and recognizing when they are approaching the threshold.
- How much is emotional management associated with sensory overload? We do not know. But sensory breaks seem to help.

ATTACHMENT/BONDING

Infant Attachment Problems

- It's difficult to attach when there is little to no eye contact, and no hearing of one anothers' voices, between parent and baby. Add in tactile defensiveness (not wanting to be touched), and it can become very hard.
- Medical procedures, and just trying to stay alive can have a huge effect as well.
- The shock of having a baby with a disability can also play a part.
- Many parents report delayed bonding with their child with CHARGE syndrome.

Reda, N. M. & Hartshorne, T. S. (2008). Attachment, bonding, and parental stress in CHARGE syndrome. *Mental Health Aspects of Developmental Disabilities, 11*, 10-21.

Toileting

Salem-Hartshorne, Blake, and Hartshorne (CHARGE Syndrome, 2011) surveyed information for 44 children with CHARGE, ages 9-21.

Independence with urine 73%
The rest needed assistance, reminders, or did not use the toilet

Independence with bowel 65%
The rest needed assistance, reminders, or did not use the toilet

Independence with overnight 54%
The rest needed protective undergarments, reminders, or physical help.

WHY?

Prerequisites for Toilet Training

Denno, L. ~~CHARGE Syndrome~~, 2011

- Feel the need to eliminate
- Walk to bathroom
- Pull down pants and underpants
- Sit on toilet
- Eliminate in toilet
- Use toilet paper
- Put toilet paper in toilet
- Stand up
- Pull up underpants and pants
- Flush toilet
- Wash hands
- Dry hands
- Exit bathroom

For what reasons might these skills be difficult for an individual with CHARGE syndrome?

Balance/mobility (if you can't balance, it's difficult to undress standing up.

Can the individual button/snap/zip?

Inability to hear urine stream

Inability to smell feces

May not be socially motivated to try

There is some discussion of the possibility that they may have limited sensation because of problems with the nerves or muscles

Finally, they will likely get a late start because of all of the medical/physical problems (walking late, for example)

SLEEP……zzzzzzzzzzzzzzzzzz

Over half of children with CHARGE syndrome have sleep problems.
Why?

- Deaf-blindness: It is well-known that darkness cues the brain to release melatonin, a hormone that causes sleepiness. If you are blind or visually impaired, the darkness may not work as a cue. Therefore, is the melatonin released? Some parents have found over-the-counter melatonin to be helpful in inducing sleep, pointing to a possible deficit.
- Pain from ear infections/other problems keep child awake
- Behavioral difficulties and anxiety (think of that threshold!) leading to troubles settling at night
- Obstructive sleep apnea: Large tonsils/adenoids, choanal atresia, clefts, and other physical anomalies may get in the way of breathing while asleep. This can "fragment" sleep, so that good quality sleep is not obtained, night after night.

So….

Toilet training is likely to happen later with individuals with CHARGE.

Some may never be totally independent.

It is still a really important teaching opportunity, in terms of communication, turn-taking, and development of independence.

Effects of too-little sleep

Think about how you feel when you haven't had sleep.

Some of these children may be having that effect compounded by having fragmented sleep night after night.

Fragmented sleep means they may never enter the Rapid Eye Movement stage….this is when protein is synthesized, dreaming takes place, and the brain regenerates.

Do you think there are behavioral effects of exhaustion?

What to do?

(Heussler, H. S., ~~CHARGE Syndrome~~, 2011)

- First, take care of obstructions. Surgery to remove tonsils and adenoids, or other medical management may help.
- Teach good sleep hygiene. This includes using a regular bedtime and routines (bath, read a book, teddy). The child will begin to associate these things with getting sleepy.
- Pay attention to sensory preferences. Sometimes a heavy blanket, temperature, or other things will help a child with sensory integration difficulties settle in.
- Try to make dark/light, day/night contrast as clear as possible.

Adolescent and Adult Issues

Blake KD, Salem-Hartshorne N, Abi Daoud M, Grandstein J. 2005. Adult and adolescent issues in CHARGE syndrome. Clinical Pediatrics. 44:151-159.

❑30 participants

❑16 female; 14 male

❑Age range 13 to 30 years, mean 17.6

ADOLESCENT DEVELOPMENT

The CHARGE Experience

Kim Blake, M.D.

Nancy Hartshorne, Ph.D.

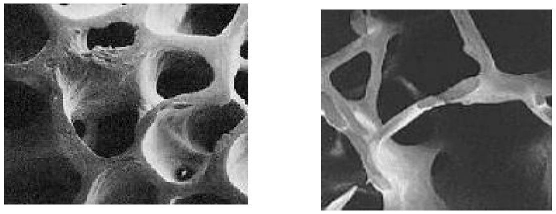
Medical Issues Found	Number	%
Scoliosis	19	63
Sleep Apnea	13	43
Abdominal Colic (Gas Pain)	12	40
Retinal Detachment/Cataract	10	33
Migraines	8	27
Seizures/Epilepsy	5	17
Urinary Tract Infections	5	17
Hypoglycemia	1	3

Osteoporosis also common

- 15 males and 15 females, ages 13 to 34 (average 19.6)
- Traumatic bony fractures were identified in 30% of the sample
- Delayed puberty was experienced by 87% with only 4 individuals (2 female, 2 males) having experienced normal puberty
- Feeding difficulties, inactivity and delayed puberty are all problems that lead to the development of poor bone health in CHARGE syndrome.

Forward KE, Cummings EA, & Blake KD. (2007). Risk factors for poor bone health in adolescents and adults with CHARGE syndrome. *American Journal of Medical Genetics. Part A. 143A*(8), 839-45.

Healthy and Unhealthy Bones



Osteoporosis

Osteoporosis, or porous bone, is a disease characterized by low bone mass and structural deterioration of bone tissue, leading to bone fragility and an increased susceptibility to fractures, especially of the hip, spine and wrist, although any bone can be affected.

Puberty Development

- Often delayed
- Girls tend to go into spontaneous puberty more often than boys, although it is usually delayed.
- Boys will often need hormone treatments to go through puberty.
- It is very important, medically, to go through puberty, to avoid osteoporosis. During puberty, we lay down bone mass.

Behavior can still be a difficult area in Adolescence

Behavioral Concern	Number	%
Aggressiveness/outbursts	16	53
Self-abuse	15	50
Sleep problems	15	50
Tactile Defensiveness	12	40

Final Words from David Brown

“There is no other identified sub-group within the population of people with multi-sensory impairment who have so many medical problems, of such complexity and severity, and with so many hidden or delayed difficulties, and yet no sub-group has shown such a consistent ability to rise triumphantly above these problems.”

How independent were the kids in the study?

Degree of Independence (N=30)

Activity	Degree of Independence					
	None	Little	Some	Most	All	N/A
Dressing self	10		2	5	13	
Toileting self	10		4	2	14	
Washing self	10	4	3	5	8	
Getting to/from work/school	15	1	2	3	6	3
Cleaning	12	4	7	3	3	1
Cooking	16	5	7			2
Shopping	19	3	3	2	2	1
Finances	25	2	1		1	1

Ca ots of trouble. The rest are learning or are somewhat independent. This gets again at the 50% who have low normal to normal intelligence.

Friday, July 28, 2017

Breakout Session #2: 1:00-2:00pm
Panzacola H-1/H-2

Your Journey Through a Special Needs Planning Program

Mary Anne Ehlert CFP,
Protected Tomorrows Inc.

Presenter Information

Mary Anne Ehlert, CFP®, is a financial professional and sister to an individual with disabilities. She is highly regarded as a specialist in working with families of individuals with disabilities and the elderly and speaks to conferences and television audiences on financial planning. Protected Tomorrows, Inc. helps families plan a safe and fulfilling life for their loved ones with special needs or who are aging. As President and Founder of Protected Tomorrows, Inc., Mary Anne serves as a member of the Board of Directors of several organizations providing services to children and adults with special needs, including; National Disability Institute in Washington D.C. and Illinois Special Olympics. She also serves on the Advisory Board of Integrative Touch for Kids. Mary Anne speaks to conferences and other audiences on financial planning, and has recently completed her book, entitled “The Gift I Was Given.”

Presentation Abstract

The presentation will be uplifting and educational, as well as provide a good basic understanding of some important facts. Participants will develop the foundation for their family’s own personal Future Care Plan. Some topics of discussion include: how to create a map of the future; how to prepare legally and financially; how to incorporate and maximize government benefits; how to prepare for transition; and how to communicate your Future Care Plan to your family.

Friday, July 28, 2017

Breakout Session #2: 1:00-2:00pm
Panzacola H-3/H-4

Behavior Management in the School Setting

Kasee Stratton, Ph.D., NCSP and Daniel Gadke, Ph.D., NCSP, BCBA
Mississippi State University

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.

Presentation Abstract

Knowing what behavioral supports are needed in the educational setting can be confusing and challenging for parents, particularly when various interventions are being used across settings. This presentation will discuss how to navigate behavior issues in the school setting and how to advocate for behavioral supports. Functional behavioral assessments and behavior intervention plans will be discussed in everyday language to guide parents and professionals.

TAKING CHARGE in 2017
ORLANDO
13th International CHARGE Syndrome Conference

Friday, July 28, 2017

Breakout Session #3: 2:15-3:15pm
Panzacola F-3/F-4

Managing the Sensory Environment

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

Presenter Information

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

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

Presentation Abstract

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

Friday, July 28, 2017

Breakout Session #3: 2:15-3:15pm
Panzacola G-1

Got the AAC Device…Now What?

Lisa Weir, MEd. (DHH), CTD.
Atlantic Provinces Special Education Authority (APSEA)

Presenter Information

Lisa is a special education consultant for students who are deaf or hard of hearing with additional challenges with the Atlantic Provinces Special Education Authority (APSEA) in the provinces of New Brunswick and Nova Scotia, Canada. Over the past several years, many of the training sessions she conducts with school teams relate to students who use Augmentative and Alternative Communication (AAC) devices, and how to employ strategies that will increase communication skills in those students. In addition to her role with APSEA, Lisa is also a parent to a nineteen year old daughter who has CHARGE syndrome and serves on the Executive Committee for the CHARGE Syndrome Foundation.

Presentation Abstract

Sometimes parents or even school teams secure a wonderful device to assist with the acquisition of expressive communication for their student/child. The device arrives and unfortunately sometimes, gets left on the shelf or repurposed to more of a game/movie device because, “They aren’t really using it.” We will look at some fundamental skills and starting points for families so they can better support communication development in their sons or daughters who have an Augmentative and Alternative Communication (AAC) device.

GOT THE AAC DEVICE, NOW WHAT?

LISA WEIR

13TH INTERNATIONAL CHARGE SYNDROME CONFERENCE

JULY 27-30, 2017

AGENDA

- AAC REVIEW
- AIDED LANGUAGE MODELING
- LANGUAGE: CORE AND FRINGE
- BEING INTERACTIVE
- MODELING VS. TESTING
- CREATING A POSITIVE COMMUNICATION ENVIRONMENT
- IDEAS FOR AT HOME
- REALITY CHECK

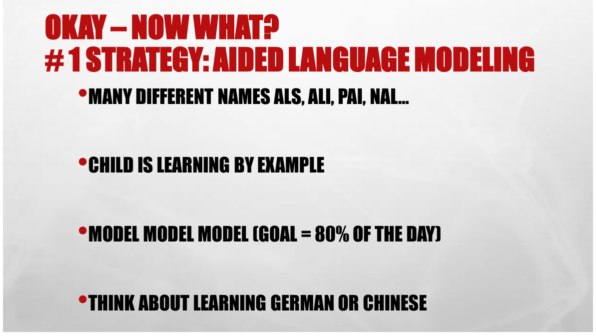
AAC: REVIEW

- A = AUGMENTATIVE
- A = ALTERNATIVE
- C = COMMUNICATION

AAC REFERS TO ANY METHOD OF NON-VERBAL COMMUNICATION THAT ADDS TO OR REPLACES SPOKEN LANGUAGE

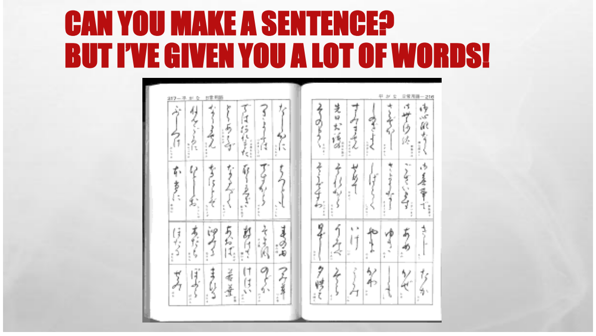
CAN BE NO TECH → HIGH TECH

- GESTURES, SIGN LANGUAGE, COMMUNICATION BOARDS OR BOOKS
- SWITCHES
- SPEECH GENERATING DEVICES
- IPADS WITH COMMUNICATION APPS

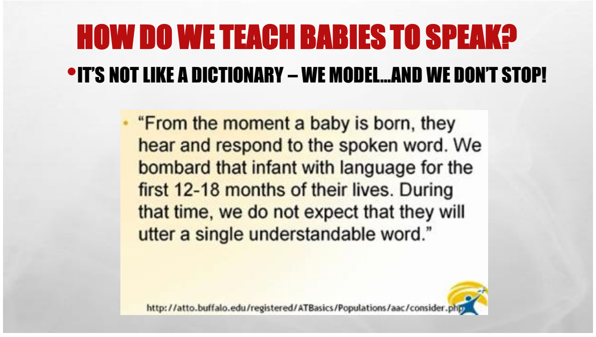


OKAY – NOW WHAT?
1 STRATEGY: AIDED LANGUAGE MODELING

- MANY DIFFERENT NAMES ALS, ALI, PAI, NAL…
- CHILD IS LEARNING BY EXAMPLE
- MODEL MODEL MODEL (GOAL = 80% OF THE DAY)
- THINK ABOUT LEARNING GERMAN OR CHINESE



CAN YOU MAKE A SENTENCE?
BUT I'VE GIVEN YOU A LOT OF WORDS!



HOW DO WE TEACH BABIES TO SPEAK?

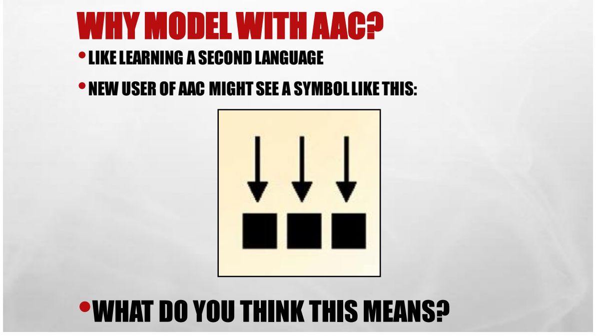
- IT'S NOT LIKE A DICTIONARY – WE MODEL…AND WE DON'T STOP!

> - "From the moment a baby is born, they hear and respond to the spoken word. We bombard that infant with language for the first 12-18 months of their lives. During that time, we do not expect that they will utter a single understandable word."

http://atto.buffalo.edu/registered/ATBasics/Populations/aac/consider.ph

Receptive First & Input = Output

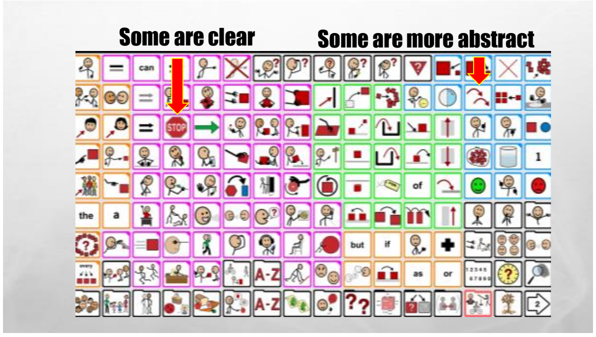
Typical language development – **receptive** comes first: We understand, "Go get the ball" before we say, "I want the ball."



WHY MODEL WITH AAC?

- LIKE LEARNING A SECOND LANGUAGE
- NEW USER OF AAC MIGHT SEE A SYMBOL LIKE THIS:

- WHAT DO YOU THINK THIS MEANS?



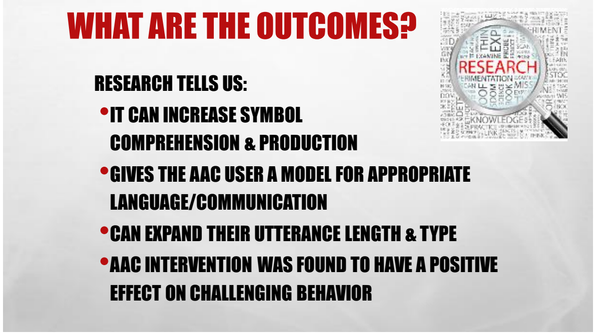
Some are clear

Some are more abstract

HOW DO WE DO IT?

- **COMMUNICATION PARTNERS** (SCHOOL, HOME, PEERS, ETC.) ARE GOING TO **USE VISUAL LANGUAGE** THEMSELVES BY **POINTING** TO THE SYMBOLS ON THE USER'S COMMUNICATION BOARD OR DEVICE **AND TALKING** AT THE SAME TIME.

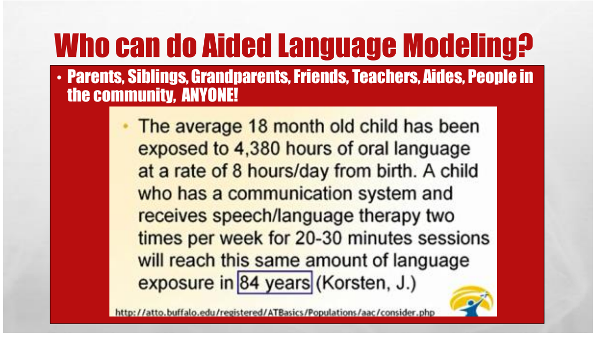
Aided Language Modeling



WHAT ARE THE OUTCOMES?

RESEARCH TELLS US:

- IT CAN INCREASE SYMBOL COMPREHENSION & PRODUCTION
- GIVES THE AAC USER A MODEL FOR APPROPRIATE LANGUAGE/COMMUNICATION
- CAN EXPAND THEIR UTTERANCE LENGTH & TYPE
- AAC INTERVENTION WAS FOUND TO HAVE A POSITIVE EFFECT ON CHALLENGING BEHAVIOR

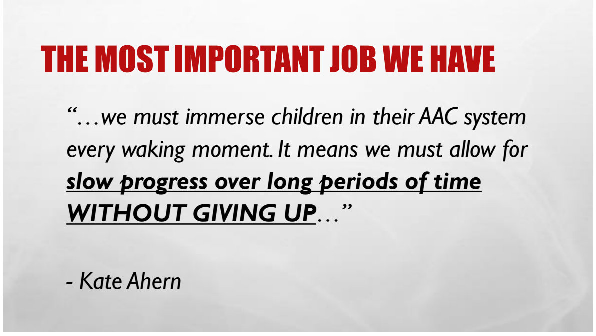


Who can do Aided Language Modeling?

- Parents, Siblings, Grandparents, Friends, Teachers, Aides, People in the community, ANYONE!

- The average 18 month old child has been exposed to 4,380 hours of oral language at a rate of 8 hours/day from birth. A child who has a communication system and receives speech/language therapy two times per week for 20-30 minutes sessions will reach this same amount of language exposure in 84 years (Korsten, J.)

http://atto.buffalo.edu/registered/ATBasics/Populations/aac/consider.php

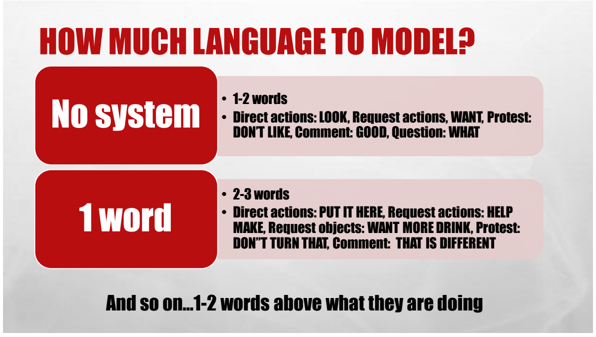


THE MOST IMPORTANT JOB WE HAVE

> *"…we must immerse children in their AAC system every waking moment. It means we must allow for **slow progress over long periods of time WITHOUT GIVING UP**…"*
>
> *- Kate Ahern*

GOT IT! WE NEED TO MODEL!
NOW WHAT CAN WE TALK ABOUT?

- PARALLEL TALK – THAT LOOKS GOOD/YOU LIKE THAT/IT IS BIG
- SELF TALK – I LIKE THIS/MINE IS MELTING/I NEED HELP/THIS IS GOOD
- BREAK DOWN – DO YOU WANT MORE ICE CREAM? → YOU WANT MORE?
- BUILD UP – LOOK → LOOK AT HIS ICE CREAM

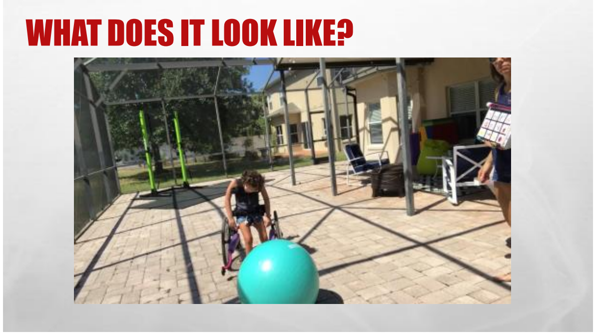


HOW MUCH LANGUAGE TO MODEL?

No system
- 1-2 words
- Direct actions: LOOK, Request actions, WANT, Protest: DON'T LIKE, Comment: GOOD, Question: WHAT

1 word
- 2-3 words
- Direct actions: PUT IT HERE, Request actions: HELP MAKE, Request objects: WANT MORE DRINK, Protest: DON"T TURN THAT, Comment: THAT IS DIFFERENT

And so on…1-2 words above what they are doing



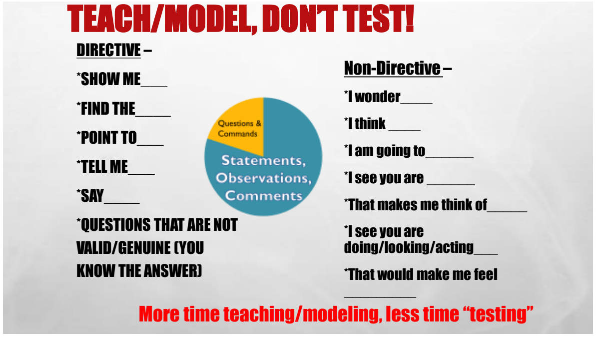
WHAT DOES IT LOOK LIKE?

CHARGE CONSIDERATIONS

- AMPLIFICATION
- SIZE, GLARE
- STURDY CASE
- PORTABILITY
- MOUNTS
- AND OF COURSE…POSTURE AND POSITIONING!

Be Interactive!

- Do as much as possible WITH your child.
- Get a copy of the materials and do it alongside them.
- Provides MANY opportunities for modeling using parallel & self talk!



TEACH/MODEL, DON'T TEST!

DIRECTIVE –

*SHOW ME___

*FIND THE____

*POINT TO___

*TELL ME___

*SAY____

*QUESTIONS THAT ARE NOT VALID/GENUINE (YOU KNOW THE ANSWER)

Non-Directive –

*I wonder____

*I think ____

*I am going to______

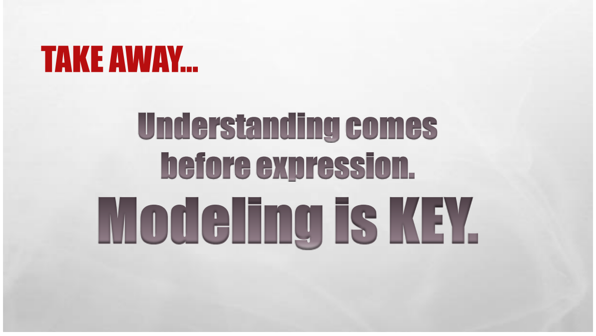
*I see you are ______

*That makes me think of_____

*I see you are doing/looking/acting___

*That would make me feel ________

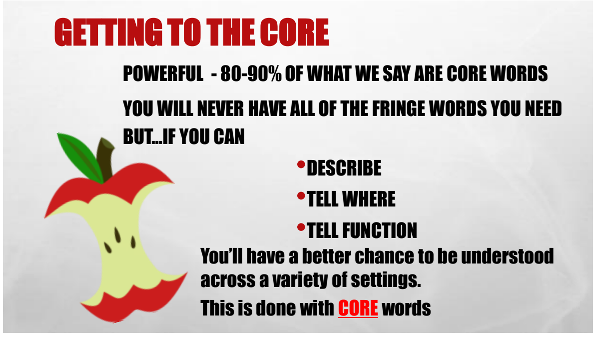
More time teaching/modeling, less time "testing"



TAKE AWAY...

Understanding comes before expression.

Modeling is KEY.



GETTING TO THE CORE

POWERFUL - 80-90% OF WHAT WE SAY ARE CORE WORDS

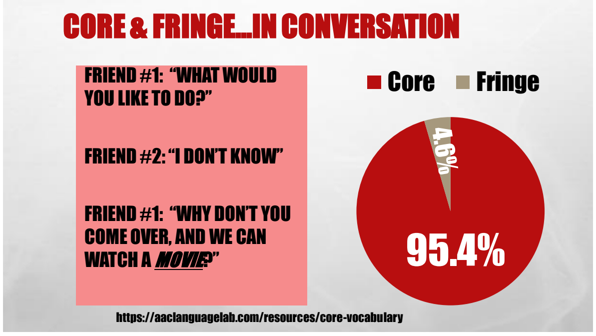
YOU WILL NEVER HAVE ALL OF THE FRINGE WORDS YOU NEED

BUT...IF YOU CAN

- DESCRIBE
- TELL WHERE
- TELL FUNCTION

You'll have a better chance to be understood across a variety of settings.

This is done with CORE words



CORE & FRINGE…IN CONVERSATION

FRIEND #1: "WHAT WOULD YOU LIKE TO DO?"

FRIEND #2: "I DON'T KNOW"

FRIEND #1: "WHY DON'T YOU COME OVER, AND WE CAN WATCH A ***MOVIE***?"

https://aaclanguagelab.com/resources/core-vocabulary

Core BOGGLE!

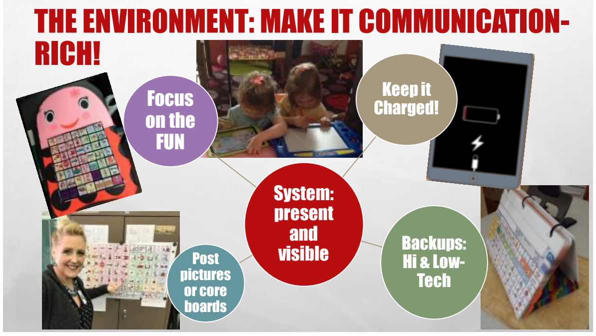
I	is	can	will	do	don't	what	where	who	when	why	how	big	little	not	more
you	we	could	want	like	need	have	get	to	from	with	now	later	again	too	all done
he	she	would	stop	go	come	give	make	here	away	in	on	up	good	bad	different
it	this	should	taste	drink	use	take	put	there	over	out	off	down	all	some	one
they	that	think	eat	wait	change	open	turn	about	under	for	of	at	yes	maybe	no
the	a	know	help	say	tell	ask	show	call	before	next	after	by	please	thank you	
any	find	move	see	look	watch	listen	sit	try	but	if	so	and			
every	let's	play	work	let			start	feel	because	then	as	or			

baby doll	ball pit	balloon	bean bag	board games
puzzle piece	rubber duck	scooter	sled	stacking ring
bubble wand	bucket	dollhouse	jump rope	puppet
switch toy	toy box	bumble ball	tricycle	wagon

Take Away…

DO MORE WITH

CORE



THE ENVIRONMENT: MAKE IT COMMUNICATION-RICH!

- Focus on the FUN
- Keep it Charged!
- System: present and visible
- Post pictures or core boards
- Backups: Hi & Low-Tech

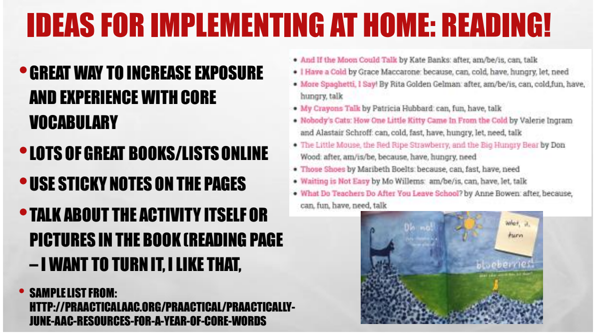
POSITIVE COMMUNICATION ENVIRONMENT

POSITIVE COMMUNICATION ENVIRONMENT

- EXPECTATION FOR COMMUNICATION (EXPECTANT PAUSE – HE KNOWS!)
- CREATE THE NEED TO COMMUNICATE
- RESPOND TO ALL COMMUNICATION ATTEMPTS
- DON'T OVER-HELP! (SOMETIMES PRE-EMPTS COMMUNICATION)
- DON'T OVER-PROMPT
- GIVE THEM WAIT TIME!
- STAY POSITIVE

FOCUS ON POTENTIAL OUTCOMES

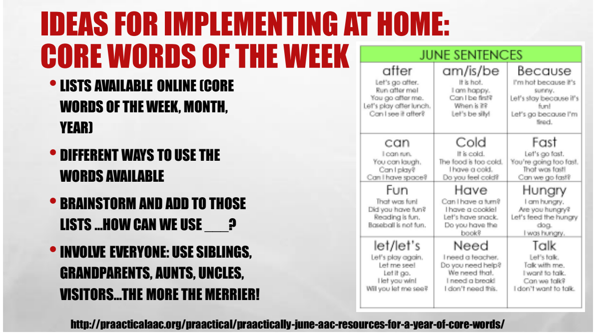
- MORE COMMUNICATION
- BETTER COMMUNICATION
- INCREASED INDEPENDENCE
- DEEPER RELATIONSHIPS



IDEAS FOR IMPLEMENTING AT HOME: READING!

- GREAT WAY TO INCREASE EXPOSURE AND EXPERIENCE WITH CORE VOCABULARY
- LOTS OF GREAT BOOKS/LISTS ONLINE
- USE STICKY NOTES ON THE PAGES
- TALK ABOUT THE ACTIVITY ITSELF OR PICTURES IN THE BOOK (READING PAGE – I WANT TO TURN IT, I LIKE THAT,
- SAMPLE LIST FROM: HTTP://PRAACTICALAAC.ORG/PRAACTICAL/PRAACTICALLY-JUNE-AAC-RESOURCES-FOR-A-YEAR-OF-CORE-WORDS

- And If the Moon Could Talk by Kate Banks: after, am/be/is, can, talk
- I Have a Cold by Grace Maccarone: because, can, cold, have, hungry, let, need
- More Spaghetti, I Say! By Rita Golden Gelman: after, am/be/is, can, cold,fun, have, hungry, talk
- My Crayons Talk by Patricia Hubbard: can, fun, have, talk
- Nobody's Cats: How One Little Kitty Came In From the Cold by Valerie Ingram and Alastair Schroff: can, cold, fast, have, hungry, let, need, talk
- The Little Mouse, the Red Ripe Strawberry, and the Big Hungry Bear by Don Wood: after, am/is/be, because, have, hungry, need
- Those Shoes by Maribeth Boelts: because, can, fast, have, need
- Waiting is Not Easy by Mo Willems: am/be/is, can, have, let, talk
- What Do Teachers Do After You Leave School? by Anne Bowen: after, because, can, fun, have, need, talk



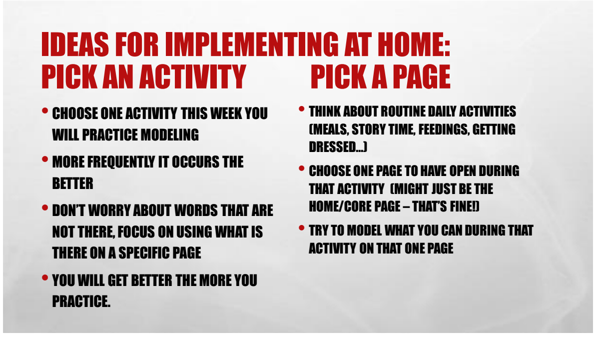
IDEAS FOR IMPLEMENTING AT HOME: CORE WORDS OF THE WEEK

- LISTS AVAILABLE ONLINE (CORE WORDS OF THE WEEK, MONTH, YEAR)
- DIFFERENT WAYS TO USE THE WORDS AVAILABLE
- BRAINSTORM AND ADD TO THOSE LISTS …HOW CAN WE USE ____?
- INVOLVE EVERYONE: USE SIBLINGS, GRANDPARENTS, AUNTS, UNCLES, VISITORS…THE MORE THE MERRIER!

JUNE SENTENCES

after Let's go after. Run after me! You go after me. Let's play after lunch. Can I see it after?	am/is/be It is hot. I am happy. Can I be first? When is it? Let's be silly!	Because I'm hot because it's sunny. Let's stay because it's fun! Let's go because I'm tired.
can I can run. You can laugh. Can I play? Can I have space?	Cold It is cold. The food is too cold. I have a cold. Do you feel cold?	Fast Let's go fast. You're going too fast. That was fast! Can we go fast?
Fun That was fun! Did you have fun? Reading is fun. Baseball is not fun.	Have Can I have a turn? I have a cookie! Let's have snack. Do you have the book?	Hungry I am hungry. Are you hungry? Let's feed the hungry dog. I was hungry.
let/let's Let's play again. Let me see! Let it go. I let you win! Will you let me see?	Need I need a teacher. Do you need help? We need that. I need a break! I don't need this.	Talk Let's talk. Talk with me. I want to talk. Can we talk? I don't want to talk.

http://praacticalaac.org/praactical/praactically-june-aac-resources-for-a-year-of-core-words/



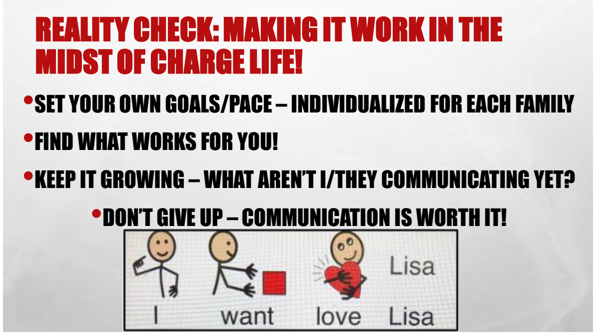
IDEAS FOR IMPLEMENTING AT HOME:

PICK AN ACTIVITY

- CHOOSE ONE ACTIVITY THIS WEEK YOU WILL PRACTICE MODELING
- MORE FREQUENTLY IT OCCURS THE BETTER
- DON'T WORRY ABOUT WORDS THAT ARE NOT THERE, FOCUS ON USING WHAT IS THERE ON A SPECIFIC PAGE
- YOU WILL GET BETTER THE MORE YOU PRACTICE.

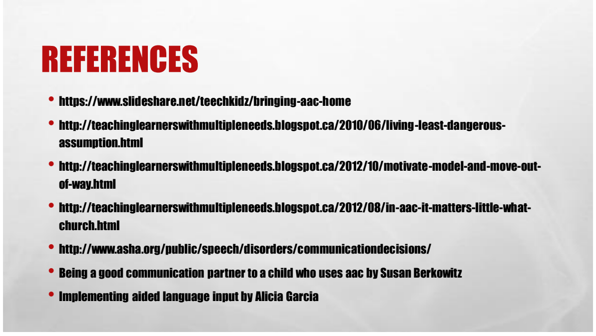
PICK A PAGE

- THINK ABOUT ROUTINE DAILY ACTIVITIES (MEALS, STORY TIME, FEEDINGS, GETTING DRESSED…)
- CHOOSE ONE PAGE TO HAVE OPEN DURING THAT ACTIVITY (MIGHT JUST BE THE HOME/CORE PAGE – THAT'S FINE!)
- TRY TO MODEL WHAT YOU CAN DURING THAT ACTIVITY ON THAT ONE PAGE



REALITY CHECK: MAKING IT WORK IN THE MIDST OF CHARGE LIFE!

- SET YOUR OWN GOALS/PACE – INDIVIDUALIZED FOR EACH FAMILY
- FIND WHAT WORKS FOR YOU!
- KEEP IT GROWING – WHAT AREN'T I/THEY COMMUNICATING YET?
  - DON'T GIVE UP – COMMUNICATION IS WORTH IT!



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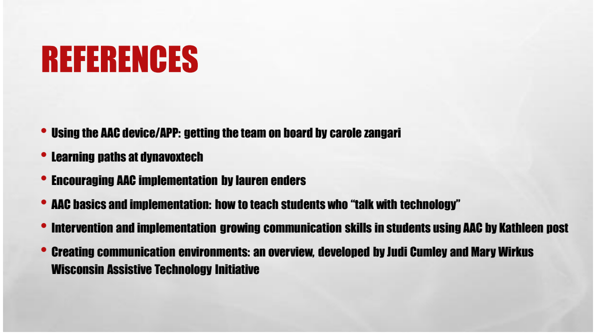
- http://www.asha.org/public/speech/disorders/communicationdecisions/
- Being a good communication partner to a child who uses aac by Susan Berkowitz
- Implementing aided language input by Alicia Garcia



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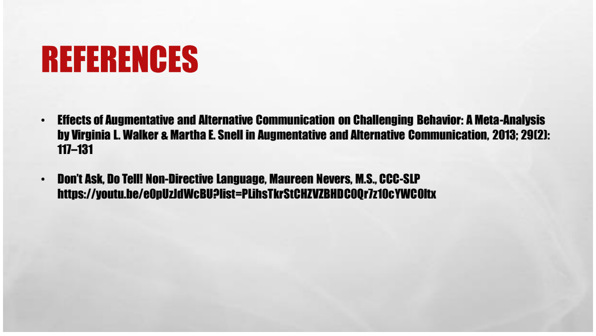
- AAC basics and implementation: how to teach students who "talk with technology"
- Intervention and implementation growing communication skills in students using AAC by Kathleen post
- Creating communication environments: an overview, developed by Judi Cumley and Mary Wirkus Wisconsin Assistive Technology Initiative



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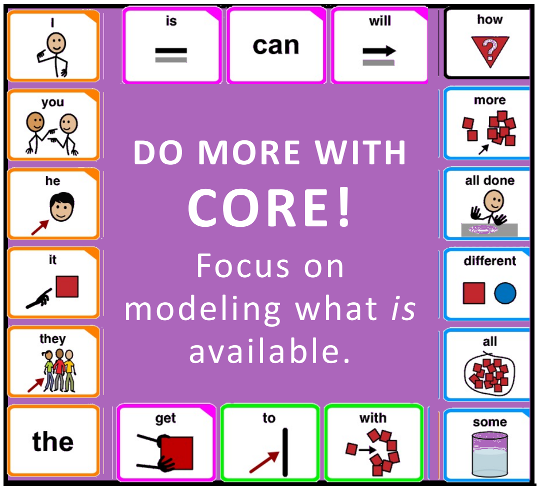
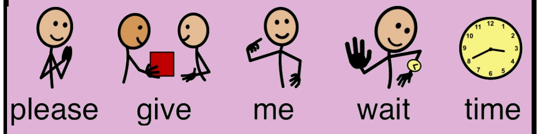


DO MORE WITH

CORE!

Focus on modeling what *is* available.

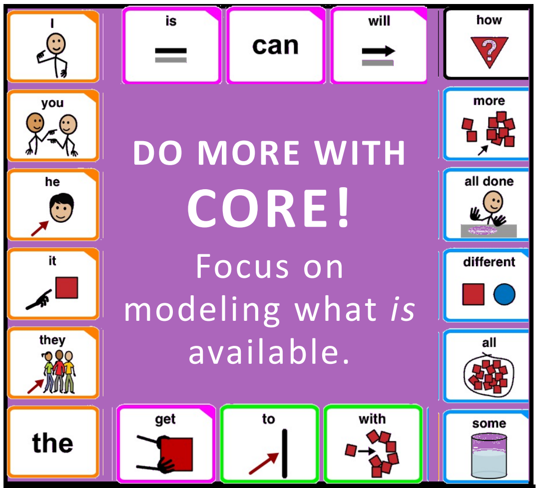


WAIT TIME: the greatest gift you can give. Using a prompt hierarchy consistently will help!

Use Non-Directive Language

Directive:
*Show me___
*Find the_____
*Point to____
*Tell me____
*Say_____
*Questions that are not valid/genuine (ones where you know the answer)

Non-Directive:
*I wonder_____
*I think _____
*I am going to_______
*I see you are _______
*That makes me think of______
*I see you are doing/looking/acting___
*That would make me feel __________



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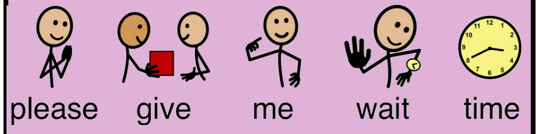

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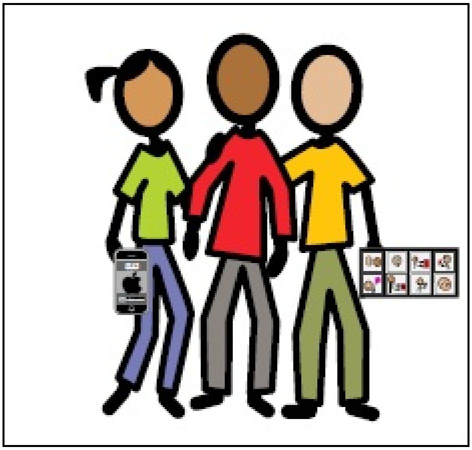
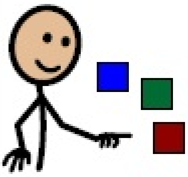
Communication Bill of Rights

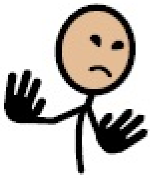


I have the right:

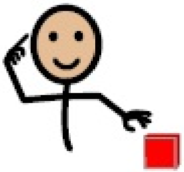
to be given
real choices



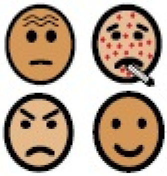
to say no, refuse
and reject choices



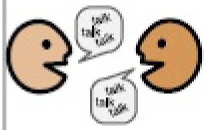
to ask for what I want



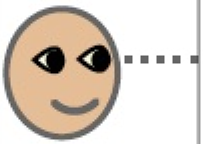
to share my feelings



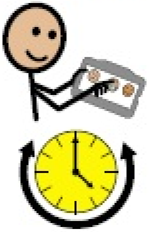
to be heard and
responded to
(even if the answer is no)



to ask for and
get attention
and interaction

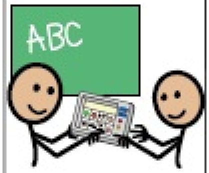


to have and use my
speech system
all the time



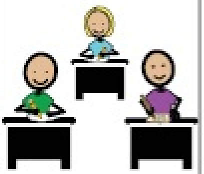
ask and know about my
schedule and world

to be taught how
to communicate

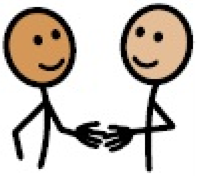


to have my
speech system
in working order
and to have a back up

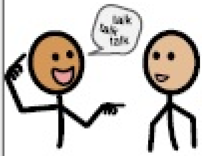
to be a full and equal
member of my community



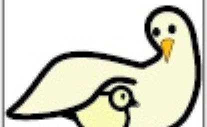
to be treated with
respect and dignity



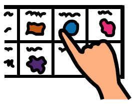
to be spoken with,
not about



to be communicated
with in a
sensitive manner



From the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992).
for meeting the communication needs of persons with severe disabilities. Asha, 34(Suppl. 7), 2–3. adapted by K. Al



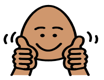
AAC BOOT CAMP

Getting AAC Users COMMUNICATING

regardless of AAC system used (no tech, low tech, high tech) or skill level...

DON'T do this......

- *DON'T* expect a user to know how to communicate w/o direct models & instruction
- *DON'T* do ALL the talking
- *DON'T* overprompt
- *DON'T* teach ONLY requesting
- *DON'T* re-prompt too quickly
- *DON'T* provide ONLY nouns
- *DON'T* focus on vocabulary that won't be functional/used tomorrow
- *DON'T* remove the device
- *DON'T* move symbols
- *DON'T* stop all "babbling" *(exploring, button pressing)*
- *DON'T* keep the AAC system in their desk, cubbie, or backpack
- *DON'T* expect sentences right away



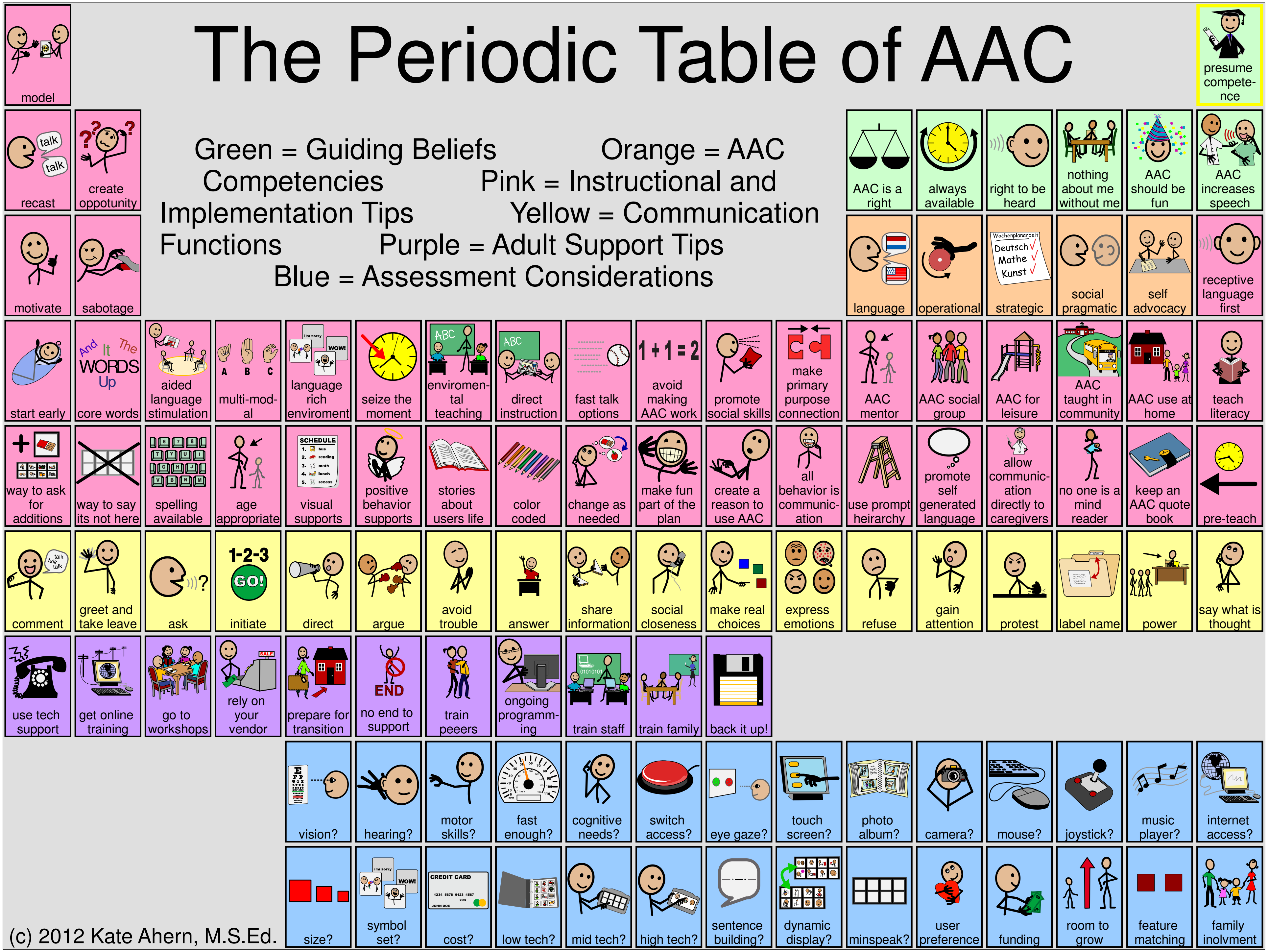
DO this......

- ✓ MODEL MODEL MODEL *model expected communication behaviors BEFORE expecting to see those behaviors from the user*
- ✓ PRESUME COMPETENCE
- ✓ FOLLOW prompt hierarchy
- ✓ TEACH language functions *including directing, commenting, requesting assistance, etc...*
- ✓ WAIT 10-20 sec. (w/an expectant look) before re-prompting!! *Count in your head!!* 
- ✓ PROVIDE CORE WORDS *including verbs & describing words (in addition to nouns)*
- ✓ COLOR CODE parts of speech
- ✓ KEEP icon placement constant *keep repeated icons in the same location on each page/screen*
- ✓ ALLOW user time to explore and learn the system
- ✓ MAKE AAC available at all times
- ✓ PROVIDE Aided Language Input
- ✓ ASK open-ended questions

Created by Lauren Enders with content by Lauren Enders, Pat Mervine, Melissa Skocypec, & Cathie VanAlstine - February 2013

The Periodic Table of AAC

Green = Guiding Beliefs
Orange = AAC Competencies
Pink = Instructional and Implementation Tips
Yellow = Communication Functions
Purple = Adult Support Tips
Blue = Assessment Considerations



model																	presume competence
recast	create opputunity											AAC is a right	always available	right to be heard	nothing about me without me	AAC should be fun	AAC increases speech
motivate	sabotage											language	operational	strategic	social pragmatic	self advocacy	receptive language first
start early	core words	aided language stimulation	multi-modal	language rich enviroment	seize the moment	enviromental teaching	direct instruction	fast talk options	avoid making AAC work	promote social skills	make primary purpose connection	AAC mentor	AAC social group	AAC for leisure	AAC taught in community	AAC use at home	teach literacy
way to ask for additions	way to say its not here	spelling available	age appropriate	visual supports	positive behavior supports	stories about users life	color coded	change as needed	make fun part of the plan	create a reason to use AAC	all behavior is communication	use prompt heirarchy	promote self generated language	allow communication directly to caregivers	no one is a mind reader	keep an AAC quote book	pre-teach
comment	greet and take leave	ask	initiate	direct	argue	avoid trouble	answer	share information	social closeness	make real choices	express emotions	refuse	gain attention	protest	label name	power	say what is thought
use tech support	get online training	go to workshops	rely on your vendor	prepare for transition	no end to support	train peeers	ongoing programming	train staff	train family	back it up!							
				vision?	hearing?	motor skills?	fast enough?	cognitive needs?	switch access?	eye gaze?	touch screen?	photo album?	camera?	mouse?	joystick?	music player?	internet access?
				size?	symbol set?	cost?	low tech?	mid tech?	high tech?	sentence building?	dynamic display?	minspeak?	user preference	funding	room to grow	feature matching	family inolvment

TAKING CHARGE in 2017 ORLANDO
13th International CHARGE Syndrome Conference

Friday, July 28, 2017

Breakout Session #3: 2:15-3:15pm
Panzacola G-2

CHARGE 103: Communication, Play and Passions

Rob Last
CHARGE Syndrome Association of Australia and New Zealand

Presenter Information

Rob Last is a special education teacher who has a long history working with children who have sensory disabilities, particularly in hearing and vision. Since the mid 1980’s he has been involved with children who have CHARGE syndrome and their families. He and a group of parents established the CHARGE Syndrome Association for Australia and New Zealand in the late 1980’s. Rob has been a presenter at many of the CHARGE Syndrome International Conferences since the first in St Louis in 1993 and the first CHARGE Syndrome Conference in Australia and New Zealand held in Sydney 1994. He presented at the CHARGE Syndrome Conference in Germany in 2012.

Rob’s career has been as an Early Childhood Educator with The Royal Institute for Deaf and Blind Children in Sydney and the Royal Victorian Institute for the Blind and Vision Australia in Melbourne, Australia.

He continues his work with the CHARGE Syndrome Association of Australia and New Zealand as a Director and as Director of Outreach for Australia and New Zealand.

Rob has the immense pleasure of meeting and being in contact with families from all over Australia and New Zealand as well as the CHARGE international community.

Presentation Abstract

Rob will focus on early communication and address the importance of establishing meaningful communication systems for children with CHARGE and the strategies that may be available for this. Play strategies will be illustrated through discussion and video. Passions/obsessions will be explored as educational opportunities and illustrated through video and photos.

HANDOUT FOR ATTENDEES

13th International CHARGE Syndrome Conference
Orlando, USA, 27 – 30 July 2017

Communication, Play and Passions

Rob Last
Director of Outreach, Director for Victoria
CHARGE Syndrome Association of Australasia
Teacher of the Deaf
Early Childhood Educator
Email: roblast@iinet.net.au

Introduction

In this presentation I'll be discussing communication, play and passions, including photos and videos to highlight the discussion.

Communication

My primary focus throughout my career has been communication; communication with babies, children, teenagers and adults.
I also mean all kinds of communication, simple to complex and in it's many forms.

Nikki

(Photo of Nikki)
Not long ago I participated in a Skype meeting with a family I hadn't met. It was a really useful meeting as I realised many of the things I've been saying for years continue to be relevant.
I met Megan, mother of Nikki, who at the time was 3 and 1/2 years old. Nikki had received a cochlear implant about 18 months previously.
The meeting was to discuss the impact of CHARGE syndrome on Nikki's development.
The all too familiar CHARGE scenario was described, multiple hospitalizations, surgeries, a range of interventions, all completely overwhelming for Nikki and her family.

More recently things were just starting to settle down with less hospitalisations and illnesses.

Nikki was described as having been withdrawn and anxious and was now ‘emerging from her withdrawn behaviour’ with everyone around her being very excited by the changes.

As we know many things may happen to children with CHARGE without warning or preparation.

Educators familiar with children with dual sensory impairment strive to educate families, medical and therapy teams in strategies to alert the child as to what is about to happen. They often do this verbally (‘I’m going to pick you up now’, ‘It’s bath time’) but fail to add in touch cues, gestures, pictures and drawings, anything that will help prepare the child for what is about to happen.

Nikki needed to understand what was going on around her, what was happening to her, what was going to happen, Nikki needed information meaningful to her to ease the stress of her already chaotic and confusing life.

Nikki was described as being ‘anxious’ and I was asked is anxiety typical in children with CHARGE.

Yes of course children, teenagers, adults with CHARGE are anxious.

Why would they be anxious?

They need to know:

- what is about to happen
- that it will happen
- when will it happen
- that it needs to happen now
- then what is going to happen after that
  and after that and after that …

These anxieties may lead to

- Distrust
- Fear
- Anxiety
- Meltdowns
- Refusal
- Withdrawal

(Series of photos of Nikki)

What I’ve observed over the years is that nearly all of those who have CHARGE have functional vision. They may be legally blind but function extremely well visually.

Even though we know all senses are affected I’ve always advocated using all senses as a means of providing meaningful information,
Therefore using visual language and touch cues to support spoken language is incorporated in all my communication.
So for parents, educators, therapists and doctors it’s our challenge to make every effort to ensure their world is less chaotic, more predictable, more ordered and more organised, using all possible means to achieve this in order to reduce distrust, fear, anxiety, meltdowns, refusal and withdrawal.

In talking to Megan (Nikki’s Mum) about communication we discussed communication as a complete entity.

I often hear the focus being speech as communication and secondly sign language. Speech is of course the most desirable as it’s the mother tongue of the home and the world. The aim of speech being the most desirable outcome is an appropriate aim.

Parents and professionals always strive to provide the best possible audition through amplification:

- hearing aids
- cochlear implants
- bone aids
- bone anchored hearing aids (BAHA)
- FM systems

I also maintain we need to add all types of ‘visual language’.

- sign language
- key word signing
- gestures
- body language
- facial expression
- pointing
- mime
- real objects
- symbolic objects

- drawings
- symbolic drawings (boardmaker, proloquo2go)
- photos
- reading and writing.

This might be termed ‘total communication’ or ‘multimodal communication’.

About Learning Sign Language (Visual Language)

I acknowledge that acquiring a new language like American Sign Language (ASL) is a big challenge.

Here are a few suggestions to assist in this process.

- use teachers of the deaf fluent in sign language
- use signing dictionaries
- Google ‘American Sign Language’ and see what is out there
- use DVD’s teaching sign language
- seek out members of the deaf community
- seek out CODA’s (Children Of Deaf Adults)
- attend classes/courses
- attend events with the deaf community
- find a neighbour, friend of a friend, someone who is fluent in sign language
- choose voice off times to rely on visual language only

Play

Play with Younger Kids

Of course play is also communication.

Parents report that bonding and attachment is severely interrupted when they have a child with CHARGE. One of the challenges being to build a trusting relationship through offering interactions and communication that is meaningful, that will make sense, that will be understood, that will be fun, that will be interesting and will be rewarding and worthwhile.

Nikki is only just embarking on this journey.

Her parents and therapy team have progressed gently and cautiously. This has come from an understanding as to why her early experiences have caused her to withdraw into that inner place, that place where she feels safe.

The adults have engaged in careful and gentle encouragement to enable Nikki to trust and engage in the world outside her body.
They began by joining Nikki in her world.

Heiko and Jonas
In this presentation I show three movie clips of a Dad, Heiko, and his son, Jonas,
The movies shows them engaged in relaxed and pleasurable play.
Heiko uses simple strategies to engage Jonas in play.
The movie is in German so it is interesting to notice how much is understood without understanding spoken German, how much the visual communication explains what is going on.

(Movies – Heiko and Jonas)

So what was noticed about play in the movies.

Movie 1

- Heiko gains Jonas's attention
- He prompts turn taking
- He rewards imitation
- He pauses while Jonas looks at the camera.
- Rewards again with 'Bravo' and 'clap, clap'
- He allows looking away
- He uses speech, gesture, signs and more
- It was also interesting and fun

Movie 2

- Jonas is well supported on his dad's body
- Dad is also comfortable
- Dad follows Jonas's interests
- Allows time for Jonas to process information
- Responds to Jonas's request for a repeat
- Dad uses animated, interesting and rewarding facial expressions

Movie 3

- This one depicts more adult directed play
- Heiko takes his time to ensure Jonas understands the game
- He revises the steps to ensure Jonas has every chance to succeed

- He allows Jonas to succeed without adult intervention
- Success is Jonas's reward

Heiko used
- Speech
- Sign language
- Facial expression
- Singing
- Body language
- Gestures
- Mime
- Touch cues
- Symbolic objects
- Real objects
- Photos
- Drawings

To engage in successful play the adult must
- Follow the child's lead
- Capitalize on interests
- Provide interesting choices
- Break tasks into achievable steps
- Provide developmentally appropriate tasks
- Encourage and support self-discovery
- Provide meaningful communication
- Plan for success
- Experiential learning is often the best learning

And it's a good idea for the adult to rediscover their inner child

PLAY - Play is Children's Work

A parent reminded me to mention that often professionals engage in play without explaining what it is they are trying to achieve and what they are looking for. Teachers and therapists understand that play is children's work and know that through play an assessment of abilities can be achieved. They note gaps in abilities and use play to teach to those gaps.

In the early years it is following the interests of the child in play which progresses into adult/teacher directed play in the later years.

It should always be:

- Stimulating
- Rewarding
- Challenging
- Meaningful
- Enriching
- Experiential
- Fun

Play for Older Kids

Passions/Obsessions

We all have them. We are much more content when we are able to engage in our passions/obsessions.
Using passions/obsessions to support learning is good teaching.

These may be through

- Rob – CD collection
- Sean and Bailey – Elevators
- Trent - Technology
- David – Horse riding
- Sarah – Horse riding
- Phillip - Tapestries
- Belinda - Travel
- Ellen – Facebook
- Sean – Caravans
- Julia – Sorting and Organising
- Mitchell – Football
- Sophie – Basketball

(Photos and video to illustrate)

Use these behaviours to:

- Educate – for example; language building, reading, writing, maths, science, geography, social skills, self-help skills, organisational skills, planning skills and more
- To establish and develop friendships
- As a hobby
- For pleasure
- To provide relaxation
- To enhance self esteem
- As exercise
- To further encourage communication
- As a possible career plan

AND

- Focus on the passion
- Plan ways of engaging with the passion
- Involve friends in the passion
- Find others with the same passion
- Record through photos, filming and writing
- Have fun
- Remember experiential learning is the most powerful.

Take Home Messages

- Communication means auditory and visual expressive and receptive language
- Be thoughtful and thorough in preparing for routines and events
- Use play for learning and social outcomes
- Use passions/obsessions for learning and social connections … and maybe a career opportunity

Reading tips

Three Great Books

- CHARGE Syndrome' - Hartshorne, Hefner, Davenport, Thelin
  Available from Amazon
- 'Why I Am Me' - Ward, Patterson and Levett
  Purchase from the CHARGE Australian/New Zealand website:
  http://www.chargesyndrome.org.au
- 'An Exceptional Fellow' A Father's Story - Svein Olav Kolset
  To purchase: http://anexceptionalfellow.com/

Families as Resources

- Parents, siblings and grandparents
- Each and everyone here is a resource
- Find out who has similar issues
- Access each other via email, phone, social media, face-to-face
- Be a pro-active resource to others
- Notice with whom you feel a connection
- Swap contact details
- Use each other as needed

Other Human Resources

- All the speakers
- All the parents and grandparents
- All those who have CHARGE syndrome

Thank you

Rob Last

TAKING CHARGE in 2017 ORLANDO
13th International CHARGE Syndrome Conference

Friday, July 28, 2017

Breakout Session #3: 2:15-3:15pm
Panzacola H-1/H-2

Latest Advancements in Congenital Heart Surgery: Their Potential to Help Children with CHARGE syndrome and Congenital Heart Disease

David L.S. Morales, MD
Cincinnati Children's Hospital Medical Center

Presenter Information

David Luís Simón Morales, M.D. is a Surgeon and Director of Congenital Heart Surgery at Cincinnati Children's Hospital Medical Center. Dr. Morales has an academic appointment of Professor of Pediatrics and Surgery and is the Clark-Helmsworth Endowed Chair of Pediatric Cardiothoracic Surgery at the University of Cincinnati, College of Medicine.

Dr. Morales is board certified in surgery, thoracic surgery and congenital heart surgery. After completing his fellowship, he was recruited to Baylor College of Medicine and Texas Children's Hospital in 2004 and in 2012, moved to Cincinnati Children's Hospital.

At Cincinnati Children's Hospital Medical Center, Dr. Morales' current areas of investigative research include artificial devices, tissue engineered patch materials and national cardiothoracic data registries. His areas of clinical interest include cardiac surgery for Heterotaxy Syndrome, pediatric heart failure, mechanical circulatory support and heart transplantation, and tracheobronchial reconstruction in children. He made significant contribution in founding a lung transplant program at Cincinnati Children's Hospital which got its first transplant in December, 2014.

Presentation Abstract

Congenital Heart Defects (CHDs) are common in children with CHARGE syndrome (75-85%) and include typical ventricular/atrial septal defects, patent ductus arteriosi, but many have complex CHDs. New advances in mechanical circulatory support (i.e. artificial hearts) can be beneficial in the management of these problems when surgical options are no longer possible. 3D printing/animations as well as augmented reality are now starting to be used to better plan complex cardiac repairs more accurately and improve patient and family education about heart defects and the palliative/corrective operations. The development of tissue engineered patches and valves have started to be used clinically and may change how we approach some of these children's defects since placing a valve in infancy may now last a lifetime.

TAKING CHARGE in 2017 ORLANDO

13th International CHARGE Syndrome Conference

Friday, July 28, 2017

Breakout Session #3: 2:15-3:15pm
Panzacola H-3/H-4

Working Together to Support Families

Sheri Stanger, MA, Ed.M. and Megan Cote, MS Ed

Presenter Information

Sheri has worked in the disability field for 26 years and is currently the Director of Outreach for the CHARGE Syndrome Foundation. She also runs a national CHARGE tele-support group. Sheri received her Master's Degrees from Teachers College, Columbia University in Psychological Counseling. Prior to becoming Director of Outreach for the Foundation, she worked as a rehabilitation counselor and school counselor and as a consultant for the NY State Deaf-Blind Collaborative. She is a past president for the National Family Association for Deaf-Blind and a board member for 18 years. She started the agency's Affiliate Network. Sheri is the mother of a 23-year-old daughter with CHARGE syndrome.

Megan is the Initiative Lead at the National Center on Deaf-Blindness (NCDB) for the Center's Early Identification and Referral and Family Engagement Initiatives. In her 23-year career in special education, she has been a classroom teacher, educational consultant, and director of the Kansas Deaf-Blind Project, and has worked on multiple grant projects. Megan earned her Master's degree at the University of Kansas in Special Education. In her current role at NCDB she has collaborated with the CHARGE Syndrome Foundation to help expand and shape the CHARGE State Liaisons program and the outreach services they provide to families.

Presentation Abstract

Sheri and Megan will explain the distinct roles of the National Center on Deaf-Blindness, the CHARGE Syndrome Foundation, and the National Family Association for Deaf-Blind and describe how work conducted by the three organizations supports families to access the knowledge and services they need to promote better outcomes for their children who are deaf-blind. Attendees will learn what each organization offers and how to take part in the training and connections they provide.

Working Together to Support Families

Presenters:

Sheri Stanger, MA, Ed.M. – Director of Outreach for the CHARGE Syndrome Foundation - sheri@chargesyndrome.org

Megan Cote, MS Ed - Initiative Lead for Early Identification and Referral & Family Engagement for the National Center on Deaf-Blindness - megan.cote@hknc.org

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Session Goals:

- Provide knowledge of resources for families from NCDB, NFADB, and the CHARGE Syndrome Foundation
- Provide knowledge about how to join initiatives in these organizations
- Provide knowledge of how each organization connects families with similar needs and interests
- Describe how the organizations work together to assist families

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NFADB/CHARGE/NCDB: Working In Collaboration to Support Families

National Center on Deaf-Blindness

- A national technical assistance center funded by the U.S. Department of Education
- Works with state deaf-blind projects and national family organizations to improve quality of life for children who are deaf-blind and their families

What are the six NCDB Initiatives?

- Early Identification & Referral
- Family Engagement
- Interveners and Qualified Personnel
- Literacy
- National Child Count
- Transition

The National Deaf-Blind Child Count (1 of 2)

Annually, each state deaf-blind project conducts a census of children and youth who are deaf-blind (birth through age 21). Information from all states is compiled and reported in the *National Child Count of Children and Youth who are Deaf-Blind*.

To find out if your child is eligible for services through your state deaf-blind project, contact the project directly.

The National Deaf-Blind Child Count (2 of 2)

- There were 9,574 children, birth through 21, on the 2015 National Child Count
- Of those, 926 had been diagnosed with CHARGE syndrome
  - CHARGE syndrome is the single most common etiology for infants who are deaf-blind, age birth-2
- Every state and territory except the US Virgin Islands have children diagnosed with CHARGE syndrome (the number ranges from 1 to 92 depending on the state)

December 2015 Deaf-Blind Child Count (1 of 4)

State	CHARGE syndrome	All Kids	% CHARGE
Alabama	8	174	4.6%
Alaska	2	19	10.5%
Arizona	23	222	10.4%
Arkansas	9	145	6.2%
California	92	1008	9.1%
Colorado	7	133	5.3%
Connecticut	10	55	18.2%
Delaware	2	77	2.6%
District of Columbia	1	16	6.3%
Florida	50	534	9.4%
Georgia	24	273	8.8%
Hawaii	2	65	3.1%

December 2015 Deaf-Blind Child Count (2 of 4)

State	CHARGE syndrome	All Kids	% CHARGE
Idaho	8	61	13.1%
Illinois	40	365	11.0%
Indiana	33	193	17.1%
Iowa	21	78	26.9%
Kansas	6	120	5.0%
Kentucky	15	119	12.6%
Louisiana	4	92	4.3%
Maine	8	41	19.5%
Maryland	25	187	13.4%
Massachusetts	22	260	8.5%
Michigan	39	332	11.7%
Minnesota	40	385	10.4%
Mississippi	3	47	6.4%
Missouri	23	201	11.4%
Montana	2	51	3.9%

December 2015 Deaf-Blind Child Count (3 of 4)

State	CHARGE syndrome	All Kids	% CHARGE
Nebraska	7	100	7.0%
Nevada	8	110	7.3%
New Hampshire	5	69	7.2%
New Jersey	28	184	15.2%
New Mexico	7	120	5.8%
New York	48	347	13.8%
North Carolina	34	269	12.6%
North Dakota	5	31	16.1%
Ohio	31	347	8.9%
Oklahoma	3	150	2.0%
Oregon	11	82	13.4%
Pacific Basin	1	54	1.9%
Pennsylvania	26	402	6.5%

December 2015 Deaf-Blind Child Count (4 of 4)

State	CHARGE syndrome	All Kids	% CHARGE
Puerto Rico	3	45	6.7%
Rhode Island	1	36	2.8%
South Carolina	23	124	18.5%
South Dakota	3	29	10.3%
Tennessee	19	255	7.5%
Texas	77	690	11.2%
Utah	9	130	6.9%
Vermont	1	27	3.7%
Virgin Islands	0	18	0.0%
Virginia	15	167	9.0%
Washington	17	239	7.1%
West Virginia	5	102	4.9%
Wisconsin	18	153	11.8%
Wyoming	2	41	4.9%
TOTAL	**926**	**9574**	**9.7%**

Number of Children with CHARGE by Age

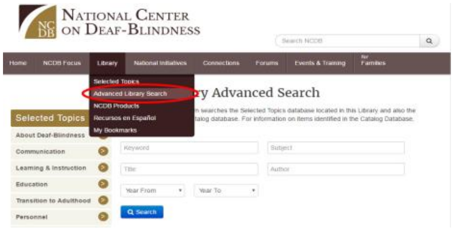
	Birth-4	5-11	12-21
December 2015 Deaf-Blind Child Count Results	145	372	409

On the NCDB website you can . . .

1. Create a profile and join initiatives of interest to you
2. Learn about upcoming trainings
3. Browse the Resource Library (includes an “Advanced Search” feature)
4. Visit the “For Families” section and view “Families Matter Stories”
5. Find contact information for the State Deaf-Blind Projects and other resources
6. Follow us on Facebook and Twitter

How to Create a Profile on the NCDB site

How to do an Advanced Library Search



n searches the Selected Topics database located in this Library and also the talog database. For information on items identified in the Catalog Database.

How to Find Your State Deaf-Blind Project

[Deaf-Blind Projects by State]

Massachusetts Affiliated Agency/New England Consortium of Deafblind Technical Assistance and Training

Project Director: Tracy Evans-Luiselli
175 North Beacon St.
Watertown, MA 02472

Ph: (617) 972-7515
TTY: (617) 924-5525
Fax: (617) 972-7354
View project details
View project website

State Deaf-Blind Project Services

- Opportunities for connections to other parents and resources in a state
- Local training and support for families & teams
- And much, much more!

OHOA Deaf-Blind Intervener Learning Modules

A national resource designed to increase awareness, knowledge, and skills related to the process of intervention for students who are deaf-blind. Developed by National Center on Deaf-Blindness.

For a list of partners and contributors visit:
nationaldb.org/ohoamoodle/contributors.html

For more information:
Go to nationaldb.org/ohoamoodle/

National Family Association for Deaf-Blind (NFADB) (1 of 2)

- The National Family Association for Deaf-Blind (NFADB) is a nonprofit organization that has served families of individuals who are deaf-blind since 1994.
- Originally started by and for families, NFADB’s membership is now extended to any person or organization that supports individuals and families who are deaf-blind

National Family Association for Deaf-Blind (NFADB) (2 of 2)

- Advocating for all persons who are deaf-blind of any age and cognitive ability
- Serving as a unified voice that supports and advocates for national policies
- Connecting people to information and resources
- Partnering with national organizations to build strong service systems
- Bringing consumer and family voices to researchers and state/national discussions about deaf-blindness
- Providing opportunities for state parent groups to become NFADB Affiliates

The NFADB Affiliate Network

IADB
Illinois Advocates for the Deafblind

PPDB
Pennsylvania Partnership for the Deafblind

The Deaf-Blind Multihandicapped Association of Texas

NYPADB

Asociación Nacional de Familias de Sordo-Ciegos
Puerto Rico

Purpose of NFADB Affiliates

- Create a stronger national network of families
- Conduit for information sharing
- Improve advocacy at the national, state and local levels
- Influence national trends and legislation
- Leadership development

For more information, go to:
National Family Association for Deaf-Blind State Affiliates
http://nfadb.org/who-we-are/state-affiliates/

National Family Association for Deaf-Blind (NFADB)

Check the website for information about upcoming trainings:

- Twice per year, NFADB offers an online study just for parents and other family members on the Role of Interveners in Educational Settings. It's primarily via self-study, but hosts are available to provide assistance. For more information, contact Patti McGowan at pmcgowan@pattan.net
- Spanish webinars
- Upcoming Conferences

National Family Association for Deaf-Blind (NFADB)

- Contact and Membership Information: 1-800-255-0411
- E-Mail: nfadbinfo@gmail.com
- Website: NFADB Website
- Facebook: NFADB Facebook page
- Address: 141 Middle Neck Road
  Sands Point, NY 11050-1129

CHARGE Syndrome Foundation Vision

"A Better World For People With CHARGE Syndrome"

CHARGE Syndrome Foundation Mission

To lead and partner to improve the lives of people with CHARGE syndrome locally, nationally, and internationally through outreach, education, and research.

CHARGE Syndrome Foundation: Who We Are

- A 501(c)(3) charitable membership-based organization founded in 1993
- Volunteer board of directors/advisors/scientific advisory board/clinical advisory board
- Provides support and outreach to families, individuals with CHARGE syndrome and professionals
- Provides information, promotes awareness and research

CHARGE Syndrome Foundation Director of Outreach

Sheri Stanger

A position to build capacity, increase collaboration and support, and inform and connect families.

Contact Information:

Toll Free Number – 855-5-CHARGE
(855)524-2743
E-Mail – Sheri@chargesyndrome.org

Training offered by the CHARGE Foundation

- 4 webinars/year
- International biennial conferences
- Lighthouse-Guild – bi-weekly tele-support groups around various eye conditions.

Resources offered by the CHARGE Foundation

- E-news
- Quarterly electronic newsletters
- Questions can be sent to info@ or an 800 #
- Director of Outreach with toll free #
- Listserv
- Facebook page for information
- Facebook group for discussion and support
- Parent-to-parent contact lists by state, province, country
  - Provider Database
- State Parent Liaison Project - https://www.chargesyndrome.org/for-families/get-support/

CHARGE Syndrome Foundation Family Assistance

- EWRAP (Ethan Wolfe Recreational Assistance Program) – provides financial support to individuals with CHARGE for a wide variety of recreational activities and equipment
- Conference Scholarships

CHARGE Syndrome Foundation Website

The CHARGE Syndrome Foundation

- Info about CHARGE syndrome
- Free Resources
- Foundation Information
- Research Information
- Upcoming Events/Conference Information
- Social Media Sites
- Search for Information

CHARGE Syndrome Foundation Contact & Membership Information

Toll Free #: 800-442-7604
Email: info@chargesyndrome.org
Website: CHARGE Syndrome Website

Director of Outreach: 855-5CHARGE

(855-524-2743)

sheri@chargesyndrome.org

Mailing Address: 318 Half Day Road #305
Buffalo Grove, IL 60089

Other Family Resources (1 of 3)

- Family2Family Connections – Online groups that bring family members together across state lines to get to know one another, share information and resources, & offer support. Interested? Contact Carol Darrah at cdarrah@uga.edu
- State and Local Parent Centers - http://www.parentcenterhub.org/

Other Family Resources (2 of 3)

- iCanConnect – Federally-funded program that provides free distance communication technology to people with combined vision and hearing loss (http://www.icanconnect.org)
- Helen Keller National Center for Deaf-Blind Youths & Adults – Provides individualized residential training for teens & adults on their campus in New York and information about local resources and services via regional representatives throughout the country (https://www.helenkeller.org/hknc)

Other Family Resources (3 of 3)

- Monthly tele-support call for Spanish speaking families that have a child with CHARGE syndrome of any age. Contact Myrna Medina if interested medinam66@sbcglobal.net
- National Coalition on Deafblindness provides information and advocacy to policy makers, fiscal agents, educational professionals and community leaders on behalf of children and youth who are deaf-blind. (thedbcoalition.org)

Group Activity

- What topics would you like more information about (list top 3)?
- What resources have been most helpful to you (list top 3)?
- In what ways and how often do you prefer to receive information?

(Generate a list and then rank order them with dots. Get group consensus. We will create forums on these topics in the Family Engagement Initiative on the NCDB website in the upcoming months.)

Thanks so much for joining us today!

Friday, July 28, 2017

Breakout Session #4: 3:30-4:30pm
Panzacola F-3/F-4

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

David Brown and Daniel Choo, MD

Presenter Information

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

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

Presentation Abstract

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

Vestibular issues and behavior in CHARGE syndrome

David Brown

- For most children with CHARGE the trauma of disconnect begins internally, even before birth. CHARGE usually, and increasingly, involves ‘multi sensory impairment’ and the lack of good information coming through the sensory systems to the brain leaves the brain disconnected from the body, and so not knowing where it is and what it is doing. Hierarchically this takes precedence over the brain’s simultaneous lack of awareness about the surrounding environment outside the body, including the whole social world of other people.

- It is important to understand the central position of the vestibular system within all of the sensory systems.

- Difficulties with balance and postural control against gravity are the most obvious observable indicators of vestibular problems, and are also the best known.

- BUT, bilaterality, understanding visual and auditory sequencing, visual function, and self-regulation are also closely involved with the vestibular system, and difficulties with all of these areas are commonly seen in CHARGE.

- Multi sensory impairment of some degree is almost universal in CHARGE, but specific sensory deficits (whether involving sensory receptors, nerve pathways, and/or the brain) will be made more complex and more significant by the impact of vestibular dysfunction on all the other senses. Eyes and ears may indeed be intact and “normal”, but vestibular dysfunction will cause functional problems with both of these distance senses.

- The senses connect the brain to the body, so multi sensory impairment results in a disconnect – the brain has difficulty knowing where all parts of the body are and what they are doing. As a result self-stimulation behaviours develop to intensify sensory feedback, especially through the tactile and proprioceptive senses, to re-establish or strengthen the brain/ body connection.

- When the brain/ body connection is not working effectively, the need to re-establish or strengthen it is a top priority – this has to be done first before the brain is available for other activities such as looking, listening, fine manipulation with the hands, and so on. The most common early solution to this problem is to minimize the challenge of gravity by getting the body fully supported in supine or on the side.

- These self-stimulation behaviours are mostly postural but also sometimes involve movement, often with a strong rhythmic component. Effective postures may involve the entire body, the arms and hands, the legs and feet, the head, or just the mouth and the teeth. Most of these postures help to provide answers to the two key questions “Where is my head?” and “Am I safe against falling?”

- The brain is ‘biologically wired’ to prioritise a series of needs. Maintenance of an open airway is the most urgent, followed by the need for postural security against gravity. The brain needs to know that postural security is in place before it can focus on other things like looking and listening and reaching and active waiting.

- These postural behaviours are also a means of self-regulation, deep pressure being a calming input. Improving the brain and body connection leads to the brain becoming more available for attention and so more available for effective functioning and learning.

- As a result the child’s spontaneous self-stimulation behaviours, including preferred postures, are innately satisfying and quickly acquire a self-regulatory function so that the child may use them instinctively to rouse themselves or calm themselves. This is why such behaviours, as long as they are not dangerous or illegal, need to be observed and learned from by us so that we are in a better place to gain the child’s attention and so begin to build a relationship, which will be the key to future teaching and learning.

- Why is it important to notice these behaviours and interpret them correctly? Observation of these behaviours will help us to learn what works for the child and what is needed by the child, and should then point us towards interventions which can improve the brain/body connection so that the child will be more available for learning from what happens in the surrounding environment, including our interactions with and offerings to them.

- The role of the physical therapist and of the occupational therapist are crucially important for the entire population of young children with CHARGE, but the therapists will need help and guidance from us when they first begin to work with the child because CHARGE is such a complex and rare condition.

- What else helps? Amongst other things, activities which improve muscle tone and controlled movement, and reinforce the body/brain connection (eg Adapted PE, Tai Chi, Yoga, martial arts, climbing, dancing). Deep pressure inputs (eg jumping, massage, swimming). The use of spandex pressure clothing. Horse riding. Good physical support and appropriate postures for efficient functioning, plus variety in postures and movement. Controlled environments. Individualized rest sessions. Encouraging and/or adapting the child’s self-taught strategies. Teaching and using appropriate vocabulary for body parts, for movements, for physical feelings, for emotional states, and for desired activities. Often the use of one or more of these approaches can help to get the child in a better place for physical functioning (including gross and fine motor activities) and for improved attention, even if only for a limited period of time.

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The Vestibular Sense

David Brown continues with his series of articles highlighting some of the less well-known senses

Function

Our other sensory systems provide information about ourselves or about the environment around us, but the Vestibular system is unique in providing a continuous flow of information about the 'fit' between the two, the person and the environment; it tells a person how they are interacting in the environment and it enables the individual to remain oriented in space and in time. This is the sense that tells us about the position of our heads in relation to the pull of gravity, it tells us which way is 'up', and it detects motion. As a consequence of this it monitors and directs muscular activity and body position to maintain secure and functional postures whatever we are doing, working very closely with the touch and proprioceptive senses. It also has very close links with the visual sense, in particular stabilizing the fixation point of the eyes when the head moves which enables us to maintain a stable visual image of the world as we move. Since the Vestibular system only provides information about the position and movement of the head it relies on well-integrated links with the senses of proprioception and vision to facilitate postural adjustments in the rest of the body. If, for any reason, the Vestibular system is not working then these other two senses (vision and proprioception) can, with great conscious effort, be made to compensate to some extent and provide a degree of postural control and security.

Two writers give interesting broader perspectives on this sensory system that really emphasize the great extent of its contribution to all of our functioning:

"In the final analysis, one may have a well-developed sensory map of the external world and a well-developed motor map of movement from one place to another, but if one does not know where they are with respect to that map, they are virtually incapable of using that spatial mapping information. And the Vestibular system appears to be the system that gives information about the individual's location in the overall spatial map" (neurologist S.J. Cool in 1987).

Jean Ayres, an occupational therapist and the creator of Sensory Integration Theory and Therapy, is more concise and states simply that:

"The Vestibular system is the unifying system. All other types of sensation are processed in reference to this basic Vestibular information. The activity in the Vestibular system provides a framework for the other aspects of our experiences."

Most importantly, Ayres declared that the Vestibular sense plays a key role in helping us to develop effective self-regulation of our arousal level, our ability to maintain a calm but alert state. So this is a sensory system that plays an extremely important role in enabling us to do almost everything that we do in our daily lives, and yet very few people know about it. In sensory terms, this is the big one.

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Structure

The Vestibular apparatus shares space in the inner ear with the cochlea, which is part of the auditory system. The Vestibular apparatus is divided into two sets of receptors to monitor the two different kinds of head movement, angular acceleration (which happens when we shake or nod our heads, bend over, or roll over in bed) and linear acceleration (which is what happens when we are in an elevator moving up or down or in a car moving forwards). Let's look at these two sets of receptors.

The semi circular canals

First the semicircular canals. There are three of these in each inner ear, arranged at right angles to each other so that they meet up in just the same configuration that two walls and the floor meet in the corner of a room. These angles correspond to the three planes in which we move (horizontal, vertical, and on the diagonal), so each of the three semicircular canals is designed to detect motion in a single plane. Their job is to detect angular acceleration of the head and by acting together as two matching sets, one left and one right, they tell our brains exactly what position our head is in at all times, and what direction it is moving. The matching sets of Vestibular apparatus on each side of the head are designed to work together, of course. If infection or damage causes the semicircular canals on one side of the head to send the brain information that disagrees with information sent by the semicircular canals on the other side of the head, then the brain gets confused about what the head is doing and the resulting conflict will lead to feelings of vertigo and nausea.

> “For many children with deafblindness, especially children with CHARGE syndrome, all three of these sensory systems are likely to be missing, impaired, or malfunctioning.”

The vestibulo-ocular reflex (VOR)

As they monitor all movements of the head, the semicircular canals also organize compensatory movements of the muscles that control eye movements, so that the fixation point of the eyes remains on a stable base rather than moving about the same as the head; specific head movements trigger specific semicircular canals to activate specific pairs of eye muscles in specific ways that enable this. This is a remarkably complicated but quick acting reflex sequence. The amazing thing is that although it stabilizes our visual fixation for us, we can then superimpose voluntary eye movements upon this stable base whenever we wish to. This compensatory reflex, complex and smooth and rapid, yet something that we don't need to think about at all, is called the vestibulo-ocular reflex. You can identify the reflex at work with a simple experiment. If you hold a book very still and try to read part of it as you move your head side to side and up and down and round in circles, it might not be particularly comfortable, but it is perfectly possible to keep your eyes reading and following the lines of print, thanks to your semicircular canals which are being activated by your head movements. But if you keep your head absolutely still and somebody else keeps moving the book around in front of you it is impossible to read along the lines of print since your semicircular canals are not being activated by any head movements, and your voluntary eye movements are totally incapable of keeping pace with the movements of the lines of print in the book. This gives you a small idea of what it must be like to try to use your vision when the semicircular canals are damaged in some way.

The utricles and the saccules

The other set of receptors in the Vestibular system are two sack-like structures called the utricles and the saccules. The utricles lie horizontal when the head is upright and they detect linear motion in the horizontal plane, while the saccules lie vertical in the upright head and they detect movement up and down and forward and back. These two pairs of organs keep us vertically oriented with respect to gravity, and any movement away from upright triggers the head-righting reflex, which leads to correcting postural adjustments. When we think we are standing quite still and vertical we are, in fact, rocking very slightly back and forth or side to side in order to trigger this reflex to help us to maintain correct vertical posture.

The Equilibrium Triad

Postural and gravitational security, and a good sense of equilibrium, both depend upon the effective development and functioning of three different but interdependent sensory systems (an "Equilibrium Triad"), namely the vision sense, the Vestibular sense, and the combined tactile/proprioceptive senses.

For many children with deafblindness, especially children with CHARGE syndrome, all three of these sensory systems are likely to be missing, impaired, or malfunctioning, which largely explains the slow development of large motor skills and mobility, but also makes it remarkable that so many of these children do eventually stand up and walk. The good news is that any input and experience that helps to improve the functioning of any of the sensory systems in this Equilibrium Triad can, therefore, be regarded as making a contribution to the development of good postural control that might result in independent standing and walking – it is not only about the Vestibular sense.

Why does the Vestibular sense go wrong?

- A damaged, or missing, Vestibular system.
- Cerebral palsy and other sorts of brain damage which result in abnormal muscle tone, limited movement abilities, and problems with tactile and proprioceptive perception.
- Certain infections, medications (and alcohol!).
- Over-stimulation (for example, motion sickness), which can result in feelings of nausea and vomiting.
- Blindness, low-vision and visual perception difficulties.
- Lack of use resulting from movement difficulties, from feelings of insecurity and fear, or from a generally low level of motivational drive due to limited stimulation, limited sensory perception, or ill health. Like all sensory systems, if the Vestibular sense is not stimulated, challenged, and used it will not develop effectively.

> "We could see that visual processing problems were central to learning disorders, but we needed to look beyond vision."

The Vestibular sense and deafblindness

When we look at the list above it is possible to imagine that many children with deafblindness will have difficulties with their Vestibular perception, either because of malfunctioning or absence of the Vestibular apparatus (as is common with CHARGE Syndrome, for example), or because of other issues that are on the list. Because the Vestibular apparatus plays a crucial role in organizing sensory perception through all the other sensory channels this problem has a profound effect on all areas of functioning and behavior for the entire life of the child. However, its importance and impact is usually over-looked and under-played, especially once the child is standing and walking independently.

Jean Ayres realized a long time ago that knowledge of Vestibular function was crucially important when considering a child's visual difficulties. In 1981 she wrote that as early as the mid-60s:

"We could see that visual processing problems were central to learning disorders, but we needed to look beyond vision. If you just look at children from a behavioral standpoint and do behavioral type research and modeling, you'll never really discover that a main foundation to visual perception is the Vestibular system, with proprioception and other senses also contributing."

She went on to discover more about the central importance of this sensory system that we all need to study and understand if we are to work successfully with children with deafblindness. Here are some of the important connections:

Vision

So there are strong links between the Vestibular sense and vision, as already explained. Problems with Vestibular perception may affect the ability to maintain a stable visual field, but it may also make it difficult to follow objects smoothly with the eyes as they move, and to differentiate whether it is the object or oneself that is moving. Some children may appear to 'go blind' if their postural security is too challenged, but they may surprise us by showing some well-developed visual (and other) skills once they are flat on their back or on their side on a stable surface. This apparent paradox shouldn't surprise us because Jean Ayres told us a long time ago that, after air to breathe, postural security is our next most urgent priority; without postural security none of us is going to focus our attention on reading a magazine, or on listening carefully to a radio broadcast, or on carrying out a complex fine motor task like sewing or writing. First we save ourselves from falling, or reorganize our position to get more secure and physically comfortable, and then we do our reading or listening or sewing. As they get older, children may use residual vision to help them to stay upright (think about the Equilibrium Triad), compensating for having a poor Vestibular sense by using the strong visual impressions made by horizontal and, especially, vertical lines in a room (for example corners, the edges of windows, doors, table tops, and wall-mounted pictures). They may have much less equilibrium outdoors where these strong visual markers are largely absent or beyond their range of vision. One result might be a reluctance to go outdoors, for example during recess at school, and another might be an inability to perform certain tasks when they are outdoors that they perform very well indoors. For children who are reading, the use of a typoscope (a letter-box shaped frame) can help by isolating one single line of text at a time. Similarly, the use of large print on a computer might be very helpful to a student, not because their visual acuity is poor but because they need help to isolate the line of text on which they should be visually fixating.

In addition to vision, the Vestibular sense links with many other areas of functioning:

Hearing and understanding sequencing

There are links between the Vestibular sense and the ability to process sound, to perceive and remember auditory sequences, and so to develop spoken language. For children with Vestibular issues this has implications in addition to other hearing difficulties, and a truly collaborative approach that brings together a teacher of the deaf, a speech therapist, and an occupational therapist trained in Sensory Integration Therapy (or any combination of these) should be very helpful. Difficulties processing auditory input contribute to problems with language development, and also to problems with memory and with learning many basic academic skills. We all need to move to some extent in order to listen, but children with Vestibular problems may need to move even more to listen and to understand, so that, when they are standing, telling them to "Stand still and listen" could be counter-productive. Understanding and remembering visual and movement sequences are also likely to be more challenging if the Vestibular sense is significantly impaired.

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Memory

An absent Vestibular sense is likely to have a negative impact on the development of memory, which, with the difficulties with the effective use of vision (especially fine central vision), and with the processing of auditory input, will have a cumulative impact on speech and language development, and on receptive understanding of visual language (for example sign language, finger spelling, written language). Resultant difficulties with expressing themselves, or the constant experience of having their expressive communications misinterpreted, can lead some children to give up, or to resort to explosive behaviors that may be construed as unpredictable, irrational, or emotionally disturbed. Significant problems with the Vestibular sense can also inhibit the development of effective body language, since postural control, equilibrium, muscle tone and motor coordination will all be impacted.

Attention/ distraction and levels of arousal

If arousal levels are abnormally high or low, and the child has very limited ability to self-regulate because of problems with the Vestibular sense, they may never attain that 'calm but alert' state that is essential for effective learning.

Muscle tone/ postural control and security

Very persistent low muscle tone is often associated with severe Vestibular problems. Low tone is also associated with low vision, breathing difficulties, and generally reduced sensory inputs, hence reduced perceptual awareness. The problem is then compounded by the lack of motivation to move and the resulting lack of "exercise." Protective reactions, standing, cruising, and independent walking usually develop very late. When children do walk, there is often a characteristic gait, some aspects of which may remain evident for many years – the feet spaced widely apart, the knees bent to lower the center of gravity, the body rolling from side to side with each step, the feet sliding along the floor or planted down very firmly on the floor with each step (maybe several times, almost like patting the floor with the foot), and the arms held up like a tightrope walker. Some children walk with repeating swaying circular movements of the upper body and head, as if trying to keep aware of the danger areas at the limits of safe posture by alternating from one 'danger' position to another. On-going monitoring by a physical therapist is important because there is a high risk of the development of neuromuscular scoliosis (curvature of the spine) in childhood and the teenage years.

Bilateral coordination/ orientation and mobility

Bilateral coordination, the ability to use both left and right sides of the body independently and also together, may be significantly affected, with one side so dominant that the other side of the body is ignored. Hand dominance and eye dominance may be very late developing, or one hand and eye might be so dominant that the child is effectively functionally one-eyed and one-handed. Remember also that, when it is working effectively, this is the sense that tells a person how they are interacting in the environment, enabling them to remain oriented in space and in time. Add these challenges to blindness, and to poor body awareness due to limited tactile and proprioceptive feedback, and it seems amazing that many children with deafblindness do manage to learn and remember routes at all.

Breathing/ feeding skills/digestion and nutrition

Because of resultant low tone, poor head control, preferred horizontal postures, and limited movement, these are all likely to be adversely impacted.

Sociability

As can be seen from this list, significant difficulties with the Vestibular sense cause disorientation and confusion in most aspects of daily living, particularly when there are other sensory impairments present also. Unless people involved with the child are prepared to understand these difficulties and adopt a supportive and non-judgmental attitude, then the child is likely to develop a strong distrust and dislike of others. This is especially regrettable when people repeatedly stop the child doing the very things that enable them to function – things like adopting specific postures or using self-regulation strategies that are interpreted negatively as 'self-stimulating behaviors'.

What can we do to help?

- Respect compensatory behaviors as functional, and help the child to make their own choices. Prohibit anything dangerous, of course, but otherwise do not attempt to remove or replace any of these compensatory behaviors until their function has been established.
- Suggest evaluation by an occupational therapist (preferably

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trained in Sensory Integration Therapy) and a physiotherapist, and implement their suggestions. Regular input from therapists is very important for all children with Vestibular dysfunction, but these therapists will need to be informed about the existence of severe balance problems and about the implications of this.

- Pace activities to facilitate optimal functioning and to minimize fatigue and stress. Functioning with little or no Vestibular information is an extremely challenging and tiring business, so breaks and rest periods may need to be frequent and extensive.
- Remember that work that improves the functioning of other sensory channels can help to ameliorate the impact of Vestibular difficulties.
- Younger children, and those with physical disabilities, may need to be lifted and carried, which could be very threatening for them if they have poor Vestibular functioning combined with other sensory impairments. Handle them to minimize stress, for example, by using consistent anticipation cues, using an appropriate speed & direction of movement, and providing adequate physical support for both the head and the limbs during movement as well as for the child’s body.
- Always make appropriate physical support available (for example, seating, a table, things to lean against, or you yourself). As these children get older the problems with fatigue, postural control, and sitting or standing unsupported may be less evident but still present. Sometimes the student will benefit from using an adapted chair, with arms and a footrest, possibly also with the seat tilted forwards to encourage more active sitting against gravity. Alternately, some children may benefit from provision of mobile seating such as a suitably sized therapy ball, which can facilitate repetitive rhythmic motion of the lower trunk and legs which helps the brain to know where the body is and that it is all secure and under control (rather like the way we all sway around slightly when we think we are standing quite still). There may still be a great need to support the head by propping it up or by resting it on one or both arms or even down on the desktop itself, in order to read or write. Also remember that extended periods standing still and entirely unsupported are usually particularly challenging.
- Allow periods of movement or repose, as appropriate, for reorganization of the whole body and all its sensory systems. Some older children and teenagers can seem to function quite well at their desk for extended periods of time, but they then need periodically to get up and move around, or to get into a horizontal position to relax and to re-charge their energy levels for the next exertions. They may also need periods in the horizontal position to reorganize their sensory systems using behaviors like leg kicking, hand flapping, shoulder shrugging, hyperventilating, or gazing at bright light.
- Observe for indications of under-arousal or over-arousal and know what to do about it (if the child cannot do this themselves).
- Think about the total demands made on the child by every activity in every situation (in other words, think multi-sensory). Many otherwise well planned activities fail because the child is being challenged or distracted by a sensory challenge that has not been noticed by the adults involved with them.
- Isolate lines of text (for example, large font on screen, typoscope) if necessary.

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Vestibular issues and behavior in CHARGE syndrome

David Brown

- For most children with CHARGE the trauma of disconnect begins internally, even before birth. CHARGE usually, and increasingly, involves ‘multi sensory impairment’ and the lack of good information coming through the sensory systems to the brain leaves the brain disconnected from the body, and so not knowing where it is and what it is doing. Hierarchically this takes precedence over the brain’s simultaneous lack of awareness about the surrounding environment outside the body, including the whole social world of other people.

- It is important to understand the central position of the vestibular system within all of the sensory systems.

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- BUT, bilaterality, understanding visual and auditory sequencing, visual function, and self-regulation are also closely involved with the vestibular system, and difficulties with all of these areas are commonly seen in CHARGE.

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- When the brain/ body connection is not working effectively, the need to re-establish or strengthen it is a top priority – this has to be done first before the brain is available for other activities such as looking, listening, fine manipulation with the hands, and so on. The most common early solution to this problem is to minimize the challenge of gravity by getting the body fully supported in supine or on the side.

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As they monitor all movements of the head, the semicircular canals also organize compensatory movements of the muscles that control eye movements, so that the fixation point of the eyes remains on a stable base rather than moving about the same as the head; specific head movements trigger specific semicircular canals to activate specific pairs of eye muscles in specific ways that enable this. This is a remarkably complicated but quick acting reflex sequence. The amazing thing is that although it stabilizes our visual fixation for us, we can then superimpose voluntary eye movements upon this stable base whenever we wish to. This compensatory reflex, complex and smooth and rapid, yet something that we don't need to think about at all, is called the vestibulo-ocular reflex. You can identify the reflex at work with a simple experiment. If you hold a book very still and try to read part of it as you move your head side to side and up and down and round in circles, it might not be particularly comfortable, but it is perfectly possible to keep your eyes reading and following the lines of print, thanks to your semicircular canals which are being activated by your head movements. But if you keep your head absolutely still and somebody else keeps moving the book around in front of you it is impossible to read along the lines of print since your semicircular canals are not being activated by any head movements, and your voluntary eye movements are totally incapable of keeping pace with the movements of the lines of print in the book. This gives you a small idea of what it must be like to try to use your vision when the semicircular canals are damaged in some way.

The utricles and the saccules

The other set of receptors in the Vestibular system are two sack-like structures called the utricles and the saccules. The utricles lie horizontal when the head is upright and they detect linear motion in the horizontal plane, while the saccules lie vertical in the upright head and they detect movement up and down and forward and back. These two pairs of organs keep us vertically oriented with respect to gravity, and any movement away from upright triggers the head-righting reflex, which leads to correcting postural adjustments. When we think we are standing quite still and vertical we are, in fact, rocking very slightly back and forth or side to side in order to trigger this reflex to help us to maintain correct vertical posture.

The Equilibrium Triad

Postural and gravitational security, and a good sense of equilibrium, both depend upon the effective development and functioning of three different but interdependent sensory systems (an "Equilibrium Triad"), namely the vision sense, the Vestibular sense, and the combined tactile/ proprioceptive senses.

For many children with deafblindness, especially children with CHARGE syndrome, all three of these sensory systems are likely to be missing, impaired, or malfunctioning, which largely explains the slow development of large motor skills and mobility, but also makes it remarkable that so many of these children do eventually stand up and walk. The good news is that any input and experience that helps to improve the functioning of any of the sensory systems in this Equilibrium Triad can, therefore, be regarded as making a contribution to the development of good postural control that might result in independent standing and walking – it is not only about the Vestibular sense.

Why does the Vestibular sense go wrong?

- A damaged, or missing, Vestibular system.
- Cerebral palsy and other sorts of brain damage which result in abnormal muscle tone, limited movement abilities, and problems with tactile and proprioceptive perception.
- Certain infections, medications (and alcohol!).
- Over-stimulation (for example, motion sickness), which can result in feelings of nausea and vomiting.
- Blindness, low-vision and visual perception difficulties.
- Lack of use resulting from movement difficulties, from feelings of insecurity and fear, or from a generally low level of motivational drive due to limited stimulation, limited sensory perception, or ill health. Like all sensory systems, if the Vestibular sense is not stimulated, challenged, and used it will not develop effectively.

> "We could see that visual processing problems were central to learning disorders, but we needed to look beyond vision."

The Vestibular sense and deafblindness

When we look at the list above it is possible to imagine that many children with deafblindness will have difficulties with their Vestibular perception, either because of malfunctioning or absence of the Vestibular apparatus (as is common with CHARGE Syndrome, for example), or because of other issues that are on the list. Because the Vestibular apparatus plays a crucial role in organizing sensory perception through all the other sensory channels this problem has a profound effect on all areas of functioning and behavior for the entire life of the child. However, its importance and impact is usually over-looked and under-played, especially once the child is standing and walking independently.

Jean Ayres realized a long time ago that knowledge of Vestibular function was crucially important when considering a child's visual difficulties. In 1981 she wrote that as early as the mid-60s:

"We could see that visual processing problems were central to learning disorders, but we needed to look beyond vision. If you just look at children from a behavioral standpoint and do behavioral type research and modeling, you'll never really discover that a main foundation to visual perception is the Vestibular system, with proprioception and other senses also contributing."

She went on to discover more about the central importance of this sensory system that we all need to study and understand if we are to work successfully with children with deafblindness. Here are some of the important connections:

Vision

So there are strong links between the Vestibular sense and vision, as already explained. Problems with Vestibular perception may affect the ability to maintain a stable visual field, but it may also make it difficult to follow objects smoothly with the eyes as they move, and to differentiate whether it is the object or oneself that is moving. Some children may appear to 'go blind' if their postural security is too challenged, but they may surprise us by showing some well-developed visual (and other) skills once they are flat on their back or on their side on a stable surface. This apparent paradox shouldn't surprise us because Jean Ayres told us a long time ago that, after air to breathe, postural security is our next most urgent priority; without postural security none of us is going to focus our attention on reading a magazine, or on listening carefully to a radio broadcast, or on carrying out a complex fine motor task like sewing or writing. First we save ourselves from falling, or reorganize our position to get more secure and physically comfortable, and then we do our reading or listening or sewing. As they get older, children may use residual vision to help them to stay upright (think about the Equilibrium Triad), compensating for having a poor Vestibular sense by using the strong visual impressions made by horizontal and, especially, vertical lines in a room (for example corners, the edges of windows, doors, table tops, and wall-mounted pictures). They may have much less equilibrium outdoors where these strong visual markers are largely absent or beyond their range of vision. One result might be a reluctance to go outdoors, for example during recess at school, and another might be an inability to perform certain tasks when they are outdoors that they perform very well indoors. For children who are reading, the use of a typoscope (a letter-box shaped frame) can help by isolating one single line of text at a time. Similarly, the use of large print on a computer might be very helpful to a student, not because their visual acuity is poor but because they need help to isolate the line of text on which they should be visually fixating.

In addition to vision, the Vestibular sense links with many other areas of functioning:

> “A truly collaborative approach that brings together a teacher of the deaf, a speech therapist, and an occupational therapist trained in Sensory Integration Therapy (or any combination of these) should be very helpful.”

Hearing and understanding sequencing

There are links between the Vestibular sense and the ability to process sound, to perceive and remember auditory sequences, and so to develop spoken language. For children with Vestibular issues this has implications in addition to other hearing difficulties, and a truly collaborative approach that brings together a teacher of the deaf, a speech therapist, and an occupational therapist trained in Sensory Integration Therapy (or any combination of these) should be very helpful. Difficulties processing auditory input contribute to problems with language development, and also to problems with memory and with learning many basic academic skills. We all need to move to some extent in order to listen, but children with Vestibular problems may need to move even more to listen and to understand, so that, when they are standing, telling them to "Stand still and listen" could be counter-productive. Understanding and remembering visual and movement sequences are also likely to be more challenging if the Vestibular sense is significantly impaired.

Memory

An absent Vestibular sense is likely to have a negative impact on the development of memory, which, with the difficulties with the effective use of vision (especially fine central vision), and with the processing of auditory input, will have a cumulative impact on speech and language development, and on receptive understanding of visual language (for example sign language, finger spelling, written language). Resultant difficulties with expressing themselves, or the constant experience of having their expressive communications misinterpreted, can lead some children to give up, or to resort to explosive behaviors that may be construed as unpredictable, irrational, or emotionally disturbed. Significant problems with the Vestibular sense can also inhibit the development of effective body language, since postural control, equilibrium, muscle tone and motor coordination will all be impacted.

Attention/ distraction and levels of arousal

If arousal levels are abnormally high or low, and the child has very limited ability to self-regulate because of problems with the Vestibular sense, they may never attain that 'calm but alert' state that is essential for effective learning.

Muscle tone/ postural control and security

Very persistent low muscle tone is often associated with severe Vestibular problems. Low tone is also associated with low vision, breathing difficulties, and generally reduced sensory inputs, hence reduced perceptual awareness. The problem is then compounded by the lack of motivation to move and the resulting lack of "exercise." Protective reactions, standing, cruising, and independent walking usually develop very late. When children do walk, there is often a characteristic gait, some aspects of which may remain evident for many years – the feet spaced widely apart, the knees bent to lower the center of gravity, the body rolling from side to side with each step, the feet sliding along the floor or planted down very firmly on the floor with each step (maybe several times, almost like patting the floor with the foot), and the arms held up like a tightrope walker. Some children walk with repeating swaying circular movements of the upper body and head, as if trying to keep aware of the danger areas at the limits of safe posture by alternating from one 'danger' position to another. On-going monitoring by a physical therapist is important because there is a high risk of the development of neuromuscular scoliosis (curvature of the spine) in childhood and the teenage years.

Bilateral coordination/ orientation and mobility

Bilateral coordination, the ability to use both left and right sides of the body independently and also together, may be significantly affected, with one side so dominant that the other side of the body is ignored. Hand dominance and eye dominance may be very late developing, or one hand and eye might be so dominant that the child is effectively functionally one-eyed and one-handed. Remember also that, when it is working effectively, this is the sense that tells a person how they are interacting in the environment, enabling them to remain oriented in space and in time. Add these challenges to blindness, and to poor body awareness due to limited tactile and proprioceptive feedback, and it seems amazing that many children with deafblindness do manage to learn and remember routes at all.

Breathing/ feeding skills/digestion and nutrition

Because of resultant low tone, poor head control, preferred horizontal postures, and limited movement, these are all likely to be adversely impacted.

Sociability

As can be seen from this list, significant difficulties with the Vestibular sense cause disorientation and confusion in most aspects of daily living, particularly when there are other sensory impairments present also. Unless people involved with the child are prepared to understand these difficulties and adopt a supportive and non-judgmental attitude, then the child is likely to develop a strong distrust and dislike of others. This is especially regrettable when people repeatedly stop the child doing the very things that enable them to function – things like adopting specific postures or using self-regulation strategies that are interpreted negatively as 'self-stimulating behaviors'.

What can we do to help?

- Respect compensatory behaviors as functional, and help the child to make their own choices. Prohibit anything dangerous, of course, but otherwise do not attempt to remove or replace any of these compensatory behaviors until their function has been established.
- Suggest evaluation by an occupational therapist (preferably

> “Think about the total demands made on the child by every activity in every situation (in other words, think multi-sensory).”

trained in Sensory Integration Therapy) and a physiotherapist, and implement their suggestions. Regular input from therapists is very important for all children with Vestibular dysfunction, but these therapists will need to be informed about the existence of severe balance problems and about the implications of this.

- Pace activities to facilitate optimal functioning and to minimize fatigue and stress. Functioning with little or no Vestibular information is an extremely challenging and tiring business, so breaks and rest periods may need to be frequent and extensive.
- Remember that work that improves the functioning of other sensory channels can help to ameliorate the impact of Vestibular difficulties.
- Younger children, and those with physical disabilities, may need to be lifted and carried, which could be very threatening for them if they have poor Vestibular functioning combined with other sensory impairments. Handle them to minimize stress, for example, by using consistent anticipation cues, using an appropriate speed & direction of movement, and providing adequate physical support for both the head and the limbs during movement as well as for the child’s body.
- Always make appropriate physical support available (for example, seating, a table, things to lean against, or you yourself). As these children get older the problems with fatigue, postural control, and sitting or standing unsupported may be less evident but still present. Sometimes the student will benefit from using an adapted chair, with arms and a footrest, possibly also with the seat tilted forwards to encourage more active sitting against gravity. Alternately, some children may benefit from provision of mobile seating such as a suitably sized therapy ball, which can facilitate repetitive rhythmic motion of the lower trunk and legs which helps the brain to know where the body is and that it is all secure and under control (rather like the way we all sway around slightly when we think we are standing quite still). There may still be a great need to support the head by propping it up or by resting it on one or both arms or even down on the desktop itself, in order to read or write. Also remember that extended periods standing still and entirely unsupported are usually particularly challenging.
- Allow periods of movement or repose, as appropriate, for reorganization of the whole body and all its sensory systems. Some older children and teenagers can seem to function quite well at their desk for extended periods of time, but they then need periodically to get up and move around, or to get into a horizontal position to relax and to re-charge their energy levels for the next exertions. They may also need periods in the horizontal position to reorganize their sensory systems using behaviors like leg kicking, hand flapping, shoulder shrugging, hyperventilating, or gazing at bright light.
- Observe for indications of under-arousal or over-arousal and know what to do about it (if the child cannot do this themselves).
- Think about the total demands made on the child by every activity in every situation (in other words, think multi-sensory). Many otherwise well planned activities fail because the child is being challenged or distracted by a sensory challenge that has not been noticed by the adults involved with them.
- Isolate lines of text (for example, large font on screen, typoscope) if necessary.

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TAKING CHARGE in 2017 ORLANDO
13th International CHARGE Syndrome Conference

Friday, July 28, 2017

Breakout Session #4: 3:30-4:30pm
Panzacola G-1

Neurological issues in CHARGE syndrome: our experiences so far

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

University Medical Center Groningen

Presenter Information

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

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

Presentation Abstract

Most people with CHARGE syndrome experience some neurological symptoms. However, comprehensive research on the neurological problems in CHARGE is lacking.

In 2014 we started a project in our CHARGE expert center aimed at creating a comprehensive dataset on neurological issues in CHARGE. We have focused on collecting broad data; on the relationship between cerebellum abnormities and balance/coordination; and on the occurrence and cause of sloping shoulders. In this presentation we will give an overview of our results so far.

Friday, July 28, 2017

Breakout Session #4: 3:30-4:30pm
Panzacola G-2

Connect the Dots: An open forum question-and-answer session focused on sensory and motor issues in CHARGE Syndrome

Kate Beals, OTR/L and Danielle Bushey, PT, DPT, NCS

Presenter Information

Kate Beals, OTR/L, is a pediatric occupational therapist. She has worked with children who have CHARGE Syndrome at the South Carolina School for the Deaf and the Blind, in the South Carolina Interagency Deafblind Project, and in the Deafblind Program at Perkins School for the Blind. She is presently employed at McCarthy Teszler School in Spartanburg, SC. Kate has served as a Consultant for Perkins International in China, and has provided training for international participants in Perkins' Educational Leadership Program.

Danielle is a physical therapist specializing in working with children and adults with neurological impairments. She has worked at Perkins School for the Blind with children with CHARGE syndrome for 7 years. She works at Perkins School for the Blind and Spaulding Rehabilitation Hospital in Boston, MA. Danielle has served as a consultant for Perkins International in China and has lectured on Motor Control at Northeastern University as adjunct faculty.

Presentation Abstract

Huh? What's all this stuff about sensory processing? What does that even mean? And why do they keep talking about balance problems? What can I do to help? Got questions about how it all fits together? Bring your questions – even if you're not quite sure how to ask them – to this informal session with a PT and an OT, who will help you "connect the dots" about sensory and motor issues in CHARGE syndrome.

CHARGE 104

Facilitating Sensorimotor Development Through Play

Kate Beals, OTR/L and Danielle Bushey, DPT

13th International CHARGE Syndrome Conference (2017)

Change the ENVIRONMENT	Change the TASK	Change the CHILD
Can you change the spatial, auditory, or visual elements of the environment?	Can you change the materials, complexity, or duration?	Think about the child's position. And remember that the more EXPERIENCES the child has, the stronger the muscles will become, and the more "wrinkles" the brain will grow.

TAKING CHARGE in 2017 ORLANDO

13th International CHARGE Syndrome Conference

Friday, July 28, 2017

Breakout Session #4: 3:30-4:30pm
Panzacola H-1/H-2

Dreaming Your Way into your Future

Catherine Allen and Rachel Allen

Presenter Information

Catherine is a mentor and guide to those who walk the overwhelming and inspiring path through the medically complex and special needs world. She has a degree in Sports Science and is a trained Massage Therapist & Life Coach, but she most loves Writing and Speaking about the sometimes brutal, but always amazing life with her daughter, Rachel, who she considers one of her greatest teachers. She is the Founder of The Singing Pink, a Social-Purpose Business whose mission is to bring awareness to Deafblindness and to issues important to Deafblind Individuals and those who champion their cause.

Rachel is a performer who loves to sing and dance. She is a long-time groupie of Drill Teams and the Girls and Directors who so openly welcome her into their circle. She is a courageous and imaginative dreamer who continues to ask for what she wants, even when it seems impossible. Rachel is currently in an Adult Transition Program and is an Intern with The Singing Pink, training to become an Actress & Public Figure specializing in Awareness and Fundraising for Charitable Causes.

Together, Rachel and Catherine are a powerful team on a mission to create “Moments of Joy” wherever they go.

Presentation Abstract

How do I plan for the future when I can barely get through each day? There is a place and there will come a day when ‘official life & career planning’ will be urgently scribbled on your TO-DO list. But, it’s never too early to adopt a philosophy of Life Design based on the unique desires, needs, and dreams of an individual and his/her family. Quality of life improves and career paths become clearer when all choices are filtered through that design rather than through disabilities and obstacles.

TAKING CHARGE in 2017 ORLANDO
13th International CHARGE Syndrome Conference

Friday, July 28, 2017

Breakout Session #4: 3:30-4:30pm
Panzacola H-3/H-4

Oh the Places You'll Go…after High School

Beth Jordan, Med and Divya Goel, AAS

Presenter Information

Beth is the Great Plains Regional Representative for the Helen Keller National Center, serving people who have both vision and hearing loss and their families in Iowa, Kansas, Missouri and Nebraska. Ms. Jordan has worked in this capacity for over 25 years.

Ms. Jordan received her Master of Education degree from the University of Arkansas majoring in rehabilitation counseling and independent living with an emphasis in deafness. Prior to her work at HKNC, she worked four years as a VR counselor with a deaf caseload in Pasadena, Texas. Ms. Jordan is a certified rehabilitation counselor (CRC). She resides in Olathe, Kansas.

Divya is an assistant instructor in Independent Living at the Helen Keller National Center on Long Island. She has been a mentor and then facilitator for several years to the HKNC Young Adult Summer Program, assisting young adults from across the country with their own journey of self-determination during their final years of high school.

Ms. Goel was born in Ontario, Canada until she relocated to Orlando, Florida where her family still resides. Divya is Deaf and has vision loss due to unknown cause. She was crowned the queen in the Florida School for the Deaf Beauty Pageant and also participated in the DeafBlind Citizens in Action, meeting the president of the US. She has an Associate's degree from Valencia College in Orlando, Florida.

Presentation Abstract

High school graduation. Does that idea cause you anxiety or excitement? If it's anxiety, consider learning more about the summer programs available to young adults at HKNC. With the passage of recent legislation, it's never been a better time to be a young adult who is interested in college and work after high school. Let's generate some excitement!

July, 2017

Oh the Places You'll Go...after High School

Presented by Divya Goel, Deaf-Blind Advocate and Beth Jordan, Helen Keller National Center

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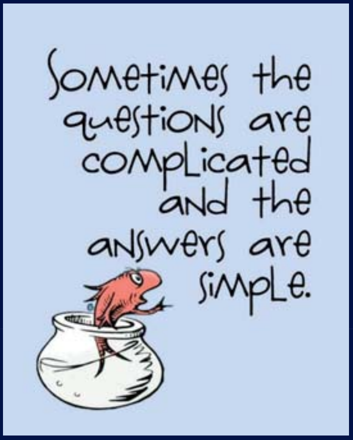
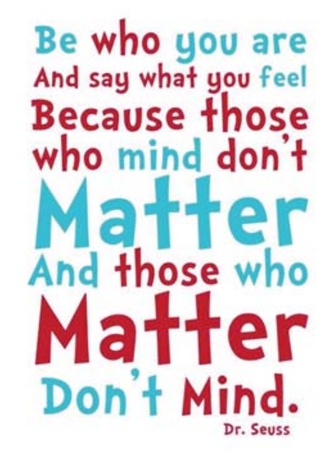
Overview


Sometimes the questions are complicated and the answers are simple.

- Divya's Message
- HKNC Programs for Young Adults
- WIOA legislation
- Questions

Divya's Personal Message of Self-Determination


Be who you are
And say what you feel
Because those who mind don't Matter
And those who Matter Don't Mind.
Dr. Seuss

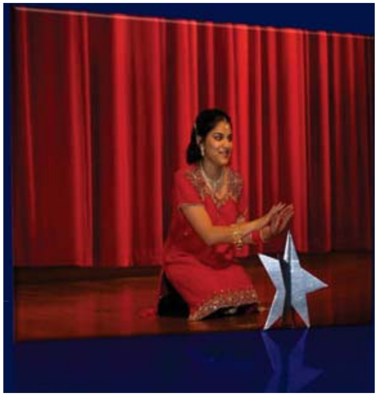
What is Self-Determination?

- Help deaf-blind people learn how to make their own decision and plans.
- Step-by-step to follow their dreams. Deaf-blind individuals will make it no matter how long it takes!
- Empowerment and encouragement
- We learn from our mistakes how to make the right decisions.
- Families and friends help/support the person's decisions.

Self-Determination Can Include:

- College/Technical/Vocational School
- Job
- Marriage
- Family
- Live independently or with family
- Vacations
- And MORE…

Self-Determination Can Include:



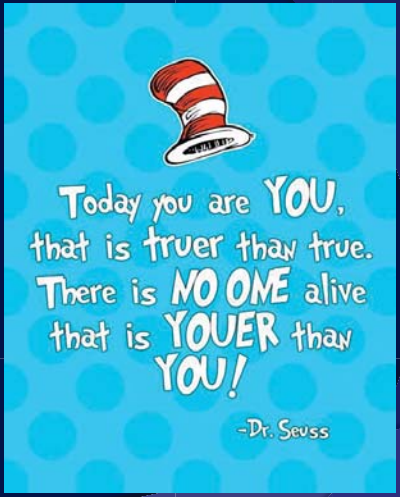
- Play games/sports
- Clubs
- Volunteer and community service
- Communication styles
- Technology for accommodations to vision and hearing
- And MORE…

Personal Self-Determination

Individuals Show their Determination in Various Ways

- Volunteering to help others
- Training
- Making new friends using various communication styles
- Sharing talents
- Having fun
- Travel independence
- Communication experiences

HKNC Programs for Young Adults



Young Adult Summer Program (2 weeks)

- 21st Annual Event – **July 17-28, 2017**
- Vocational/College Exploration

Summer Youth Vocational Program (6 weeks)

- 3rd Annual Event - Summer, 2017
- Paid community work experience
- Self-awareness of strengths/abilities

Summer Assessment Program (8 weeks)

- Assessment in all aspects of life
- Individualized instruction
- Ability to socialize with other young adults at HKNC

Traditional Program (6-12 months)

- Employment outcome driven
- Individualized instruction

Deaf-Blind Immersion Seminar (1 week)

- For Individuals who are DB and have intellectual disabilities
- Partnered with 3 of the person’s direct care staff and/or job developer

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Frequently Asked Questions (FAQ)

- How do I pay for HKNC training?
- How do I keep in touch with my family?
- How far is HKNC from NY City?
- Can I go for a tour?

https://www.helenkeller.org/hknc/frequently-asked-questions

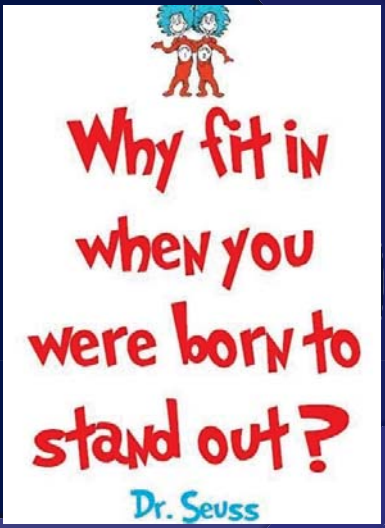
HKNC is not the only game in town…

- Southeast Family DB Transition Institute
- June 22-25, 2017
- Talladega, AL
- Walker.Melvin@aidb.state.al.us

- Midwest Transition Institute
- July 13-16, 2017
- Terre Haute, IN
- Lisa.Poff@indstate.edu
- www.INDBServices/test

WIOA Legislation

(Workforce Innovation & Opportunity Act)



WIOA

Workforce Innovation & Opportunity Act

- Enacted in July, 2014
- Fully implemented in July, 2015
- Impacts ALL states
- Mandates collaboration with partners
- Important changes for people with disabilities

WIOA Goals

- Assist job seekers to access employment, education, training and support services to succeed in the labor market AND

- Match employers with the skilled workers they need to compete in the global economy.

WIOA Key Components

- Vocational Rehabilitation (VR) agencies must expend 15% of their funds for services to students in transition (ages 16-21) in who are eligible or potentially eligible for VR services.

WIOA Key Components

- 50% of an agency's **Supported Employment** funds must be expended on pre-transition students (ages 16-21).
  - **Supported Employment** is for persons:
    - With the most significant disabilities;
    - Who need intensive or ongoing job support;
    - Who have traditionally been excluded from competitive work settings or
    - Whose work has been interrupted or intermittent.

WIOA Key Components

- Supported Employment expanded from 18 to 24 months. It must lead to **integrated competitive employment**.
  - Through collaboration with schools, VR will provide work experiences in the community for all students with disabilities to demonstrate their ability to work in an integrated environment.
  - Students cannot transition directly to sheltered employment without these opportunities.

WIOA Key Components

Customized Employment is a provided service.

- Individualizing the employment relationship between employer and employee to meet the needs of both
- May include job carving
- Assumes reasonable accommodations

What Can VR Agencies Fund During Transition?

Pre-Employment Transition Services (Pre-ETS)

1) Job exploration & counseling/guidance

2) Work-based learning experiences
   - May include in-school or after school opportunities, experiences outside of the traditional school setting, and/or internships.

What Can VR Agencies Fund During Transition?

Pre-Employment Transition Services (Pre-ETS)

3) Counseling for enrollment in transition or post-secondary education at college/higher education

4) Workplace readiness training
   - To develop social skills and independent living
   - Training in skills of blindness and deaf-blindness

5) Instruction in self-advocacy

This is addition to what the education programs/school is already providing!

WIOA Big Picture

Shared Responsibility

+

Collaboration (with partners)

=

Positive Outcomes for Students

WIOA Resources

- US Department of Labor WIOA site
  https://www.doleta.gov/WIOA/eta_default.cfm
- WinTac Pre-Employment Transition Services
  http://www.wintac.org/topic-areas/pre-employment-transition-services
- Iowa WIOA Explanation (example)
  https://www.educateiowa.gov/sites/files/ed/documents/WIOABasics_DrewJackson.pptx

Resources

> You have BRAINS in your HEAD.
> You have FEET in your SHOES.
> You can STEER yourself in any
> DIRECTION you CHOOSE.
> – Dr. Seuss

Who ya gonna call?

HKNC Regional Representative

- Advocacy, info/referral to consumers/families
- Facilitate application process to/from HKNC
- Lifelong point of contact (transition age – senior adults)
- Support consumer organizations
- NDBEDP capacity building
- Professional development training/resources
- Collaboration with service providers/employers
- National Registry

https://www.helenkeller.org/hknc/nationwide-services

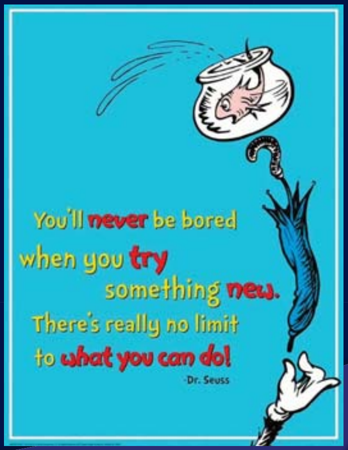
HKNC Regional Offices

HKNC Field Staff

Helen Keller National Center (HKNC)

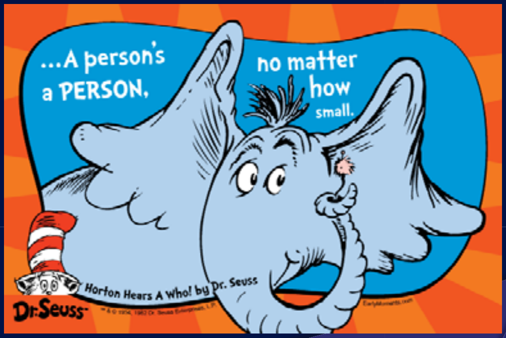
- HKNC's National Registry
- *CONNECT! electronic* newsletter
- On-Line Training Modules

Beth.Jordan@hknc.org
913-677-4562 voice or
913-227-4282 videophone
www.HelenKeller.org/hknc



Would love to hear from you…

- Divya Goel
- dgoel86@gmail.com



HKNC On-Line Modules

- Working with Individuals who are Deaf-Blind: A Course for VR Counselors
- Touch Signals
- Confident Living Program
- Future courses

https://www.helenkeller.org/hknc/online-courses

Welcome to
Helen Keller National Center
Online Courses

Questions?

Oh the Places You'll Go…after High School presented by Divya Goel, Deaf-Blind Advocate and Beth Jordan, Helen Keller National Center

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Graphic: "Be who you are and say what you feel Because those who mind don't Matter And those who Matter Don't Mind." Dr Seuss quote

What is Self-Determination?

- Help deaf-blind people learn how to make their own decision and plans.
- Step-by-step to follow their dreams. Deaf-blind individuals will make it no matter how long it takes!
- Empowerment and encouragement
- We learn from our mistakes how to make the right decisions.
- Families and friends help/support the person's decisions.

Self-Determination Can Include:

- College/Technical/Vocational School
- Job
- Marriage
- Family
- Live independently or with family
- Vacations
- And MORE…

Self-Determination Can Include:

- Play games/sports
- Clubs
- Volunteer and community service
- Communication styles
- Technology for accommodations to vision and hearing
- And MORE…

Personal Self-Determination/Individuals Show their Determination in Various Ways

- Volunteering to help others
- Training
- Making new friends using various communication styles
- Sharing talents
- Having fun
- Travel independence
- Communication experiences

HKNC Programs for Young Adults
Graphic: "Today you are YOU, that is truer than true. There is NO ONE alive that is YOUER than YOU!" Dr. Seuss quote

Young Adult Summer Program (2 weeks)

- 21st Annual Event – **July 17-28, 2017**
- Vocational/College Exploration

Summer Youth Vocational Program (6 weeks)

- 3rd Annual Event - Summer, 2017
- Paid community work experience
- Self-awareness of strengths/abilities

Summer Assessment Program (8 weeks)

- Assessment in all aspects of life
- Individualized instruction
- Ability to socialize with other young adults at HKNC

Traditional Program (6-12 months)

- Employment outcome driven
- Individualized instruction

Deaf-Blind Immersion Seminar (1 week)

- For Individuals who are DB and have intellectual disabilities
- Partnered with 3 of the person's direct care staff and/or job developer

Frequently Asked Questions (FAQ)

- How do I pay for HKNC training?
- How do I keep in touch with my family?
- How far is HKNC from NY City?
- Can I go for a tour?

https://www.helenkeller.org/hknc/frequently-asked-questions

HKNC is not the only game in town…

- Southeast Family DB Transition Institute
- June 22-25, 2017
- Talladega, AL
- Walker.Melvin@aidb.state.al.us
- Midwest Transition Institute
- July 13-16, 2017
- Terre Haute, IN
- Lisa.Poff@indstate.edu
- www.INDBServices/test

WIOA Legislation (Workforce Innovation & Opportunity Act)

- Enacted in July, 2014
- Fully implemented in July, 2015
- Impacts ALL states
- Mandates collaboration with partners
- Important changes for people with disabilities

Graphic: “Why fit in when you were born to stand out?” Dr. Seuss quote

WIOA Goals

- Assist job seekers to access employment, education, training and support services to succeed in the labor market AND
- Match employers with the skilled workers they need to compete in the global economy.

WIOA Key Components

- Vocational Rehabilitation (VR) agencies must expend 15% of their funds for services to students in transition (ages 16-21) in who are eligible or potentially eligible for VR services.

WIOA Key Components

- 50% of an agency’s **Supported Employment** funds must be expended on pre-transition students (ages 16-21).
- **Supported Employment** is for persons:
  - With the most significant disabilities;
  - Who need intensive or ongoing job support;
  - Who have traditionally been excluded from competitive work settings or
  - Whose work has been interrupted or intermittent.

WIOA Key Components

- Supported Employment expanded from 18 to 24 months. It must lead to **integrated competitive employment.**

    - Through collaboration with schools, VR will provide work experiences in the community for all students with disabilities to demonstrate their ability to work in an integrated environment.
    - Students cannot transition directly to sheltered employment without these opportunities.

WIOA Key Components

- **Customized Employment** is a provided service.
    - Individualizing the employment relationship between employer and employee to meet the needs of both
    - May include job carving
    - Assumes reasonable accommodations

What Can VR Agencies Fund During Transition?
Pre-Employment Transition Services (Pre-ETS)

1) Job exploration & counseling/guidance
2) Work-based learning experiences
    - May include in-school or after school opportunities, experiences outside of the traditional school setting, and/or internships.
3) Counseling for enrollment in transition or post-secondary education at college/higher education
4) Workplace readiness training
    - To develop social skills and independent living
    - Training in skills of blindness and deaf-blindness
5) Instruction in self-advocacy

This is addition to what the education programs/school is already providing!

WIOA Big Picture

Shared Responsibility + Collaboration (with partners) = Positive Outcomes for Students

WIOA Resources

- US Department of Labor WIOA site
- https://www.doleta.gov/WIOA/eta_default.cfm
- WinTac Pre-Employment Transition Services
- http://www.wintac.org/topic-areas/pre-employment-transition-services
- Iowa WIOA Explanation (example)
- https://www.educateiowa.gov/sites/files/ed/documents/WIOABasics_DrewJackson.pptx

Resources

Graphic: “You have Brains in your HEAD. You have FEET in your SHOES. You can STEER yourself in any DIRECTION you CHOOSE.” Dr. Seuss quote

Who ya gonna call? HKNC Regional Representatives

- Advocacy, info/referral to consumers/families
- Facilitate application process to/from HKNC
- Lifelong point of contact (transition age – senior adults)
- Support consumer organizations
- NDBEDP capacity building
- Professional development training/resources
- Collaboration with service providers/employers
- National Registry

https://www.helenkeller.org/hknc/nationwide-services

Helen Keller National Center (HKNC)

- HKNC's National Registry
- *CONNECT! electronic* newsletter
- On-Line Training Modules
- Beth.Jordan@hknc.org
- 913-677-4562 voice or
- 913-227-4282 videophone
- www.HelenKeller.org/hknc

Graphic: You'll never be bored when you try something new. There's really no limit to what you can do." Dr. Seuss quote

Would love to hear from you…

- Divya Goel
- dgoel86@gmail.com

Graphic: "A person's a PERSON, no matter how small." Dr. Seuss quote

HKNC On-Line Modules

- Working with Individuals who are Deaf-Blind: A Course for VR Counselors
- Touch Signals
- Confident Living Program
- Future courses
- https://www.helenkeller.org/hknc/online-courses

Questions

Graphic: "Today is your DAY! Your Mountain is waiting so get on your WAY!" Dr. Seuss quote