



**Saturday, August 1, 2015
Breakout Session #36: 2:15 - 3:15pm
Schaumburg A-B**

**Which Way is Up? – How behavior
reveals sensory processing
differences in children with CHARGE
Syndrome**

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Presenter Information:

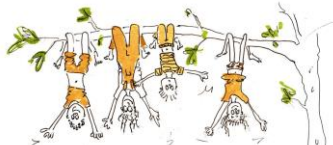
As a pediatric occupational therapist and single parent of a 25-year-old son with Autism, sensory processing/integration is a favorite topic of mine, both personally and professionally. I became interested in CHARGE Syndrome when I worked for the South Carolina Interagency Deaf-Blind Project from 2008 to 2013. At that time I was asked to “look into” sensory processing issues in CHARGE Syndrome – and hit the proverbial jackpot! Wow! What an amazingly complex set of sensory processing and integration issues children who have CHARGE Syndrome have to cope with! Thank goodness David Brown has written so many wonderful articles!

I attended my first CHARGE Conference in Chicago, then presented at the conferences in Florida and Arizona. People tell me I have a way of explaining complicated neurological processes (sensory-motor integration) in a way that “everyday people” can understand pretty easily. Now that I work in the Deafblind Program at Perkins School for the Blind, I provide OT services for many students with CHARGE Syndrome, and every day they teach me more about the unique ways they experience their own bodies and the world around them.

Presentation Abstract:

Children who have CHARGE Syndrome are known to have problems with sensory processing across multiple systems, which affects the way they experience themselves and the world around them. By understanding how the seven sensory systems operate differently in children with CHARGE Syndrome, families, caregivers, therapists, and teachers can learn to recognize behaviors that suggest specific sensory processing issues and needs.

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Which Way Is UP?

How behavior reveals
sensory processing differences
in children with CHARGE Syndrome



Basic Terms & Concepts

- Behavior = stuff we **DO** = **Motor function**
- Sensory Processing = how we **get** information about what is happening outside of, on, and inside of our bodies, and how we **understand** that information...
- “Sensory-Motor System”



The Brain



• Sensory in

- Messages (input) from all 7 sensory systems travel to the brain on “inbound” tracts of the nervous system.
- It is a one-way street.
- Sensory information only goes **IN**.

• Motor out

- Messages (output) travel to the muscles on motor pathways, or “outbound” tracts of the nervous system.
- It is a one-way street.
- Motor instructions only go **OUT**.

Seven Sensory Systems

- Vision
- Hearing
- Taste
- Smell
- Light touch
- Proprioception (deep pressure)
- Vestibular (head movement)



The Senses in CHARGE Syndrome

Individuals who have CHARGE Syndrome tend to have reduced (or altered) ability to receive input through some or all of their sensory systems.

For the most part, there are **STRUCTURAL DIFFERENCES** that make the accurate reception and processing of sensory information impossible.

Structural Differences

- **Vision** – Colobomas – absence of tissue
- **Hearing** – Malformation of the cochlea or the cochlear nerve (sometimes absent CN VIII)
- **Smell** – Absence or reduced number of olfactory bulbs and stems; nasal blockages
- **Vestibular** – Absence or hypoplasia of semicircular canals

Structural Differences

- **Taste** – Cranial nerve abnormalities; absence of smell reduces flavor
- **Proprioception** – structural difference? Don't know. But movement patterns resemble those of individual who lacks proprioceptive sense (see T. Jessell video)
- **Light Touch** – structural difference? Don't know. *Might* be an exception, but need more research...

The Brain and Experience

- Brain needs “experience” in order to grow, develop, make connections (“wrinkles”)
- Experience is sensory
- CHARGE Syndrome = “Multisensory impaired”
- “Hungry” for sensory input

“Sensory-Seekers”

“Sensory-Seeking” Behaviors

TO GET PROPRIOCEPTION

- **Walking** – feet turned out, extra slaps or taps with feet, exaggerated knee extension, walking on tip-toes (also compensatory))
- **Flapping** – hands, feet, arms, legs, fingers; repetitive and rapidly alternating flexion and extension
- **Posturing fingers** – habitually bending fingers into unusual positions, flicking fingers, moving fingers near eyes

“Sensory-Seeking” Behaviors

TO GET PROPRIOCEPTION

- **Hitting self** – Using fist, knuckles, or wrist to hit self on the face, head, chest, or stomach
- **Toe-walking** – Walking on tip-toes
- **Mouthing** – putting hands, fingers, or objects that are not food into the mouth
- **Lying on Back** – on floor, on bed, in beanbag, on sofa (also compensatory)
- **Chin propping** – elbow on table, chin propped in hand (also compensatory)

“Sensory-Seeking” Behaviors

TO GET VESTIBULAR + VISUAL

- **Spinning self** – turning own body in a circle, spinning on a swing or sit & spin toy
- **Spinning objects** – twirling things near the eyes
- **Upside Down** – hanging head back, over the edge of sofa or bed

Right side up,
I see the floor.

Upside down,
I see the ceiling.

“Look at the camera.”



Photo courtesy of California Deaf-Blind Services

Compensatory Strategies

- **Balance** comes from the interaction of the visual, vestibular, and proprioceptive systems, none of which functions optimally in an individual who has CHARGE Syndrome.
- **That makes staying upright against gravity very difficult, and very tiring.**
- Behaviors like chin propping, walking with feet turned out, and lying down on the back help compensate for decreased balance, and for the excess energy that has to be used in order to stay upright against gravity



Photo and quote below are from
The forgotten sense: Proprioception,
By David Brown in
Deafblind International Review,
July – December, 2006

"In order to use her residual vision to look at fine details in a book Amy needs to be horizontal with her entire body and head fully supported: having one ankle up on the other knee sends her brain a strong message, through the proprioceptive sense, that her lower body is fixed and stable and not moving."

- David Brown

What about – you know – *THAT*?

Let's talk about fecal smearing, okay?

- We hate it. They love it.
- What's the difference?

Sense of Smell

Is fecal smearing sensory-seeking or attention-seeking?

Videos

Let's watch some videos and see if we can figure out what the child's behavior tells us about his or her sensory processing differences.

<http://media.hhmi.org/hl/08Lect3.html>



References and Resources

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