



# **2nd German Professional Day on the CHARGE syndrome**

**16. – 17. June  
2016**

**Oberwesel,  
Germany**



# Rob Last

## 16<sup>th</sup> June – 02.30 p.m.

***“Quality not quantity – thoughts on communication, behavior, play and passions”***

The presentation will focus on early communication and behaviour, address the importance of establishing a meaningful communication system for children with CHARGE and the strategies that may be available for this. Play strategies will be demonstrated through video, photos and discussion. Passions/obsessions as educational opportunities will be discussed and illustrated through video and photos. We will discuss the importance of appropriate early intervention strategies to ensure positive outcomes. Case studies and photos will support this discussion. ‘Meltdowns’ will be discussed as a form of communication, why these may occur and strategies for managing these. Communication systems will be highlighted as well as the supports available in the acquisition these.

**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 for the state of Victoria and as Director of Outreach for Australia and New Zealand. Rob has the pleasure of meeting and being in contact with families from all over Australia and New Zealand as well as the CHARGE international community

# **CHARGE Conference - Germany - 16 June – 19 June 2016**

## **Quality not Quantity**

### **Thoughts on:**

## **Communication, Behaviour, Play and Passions**

**Rob Last**

**Director of Outreach, Director for Victoria**

**CHARGE Syndrome Association of Australasia**

**Teacher of the Deaf**

**Early Childhood Educator**

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Thanks for inviting to me to speak.

This is my 2<sup>nd</sup> German conference and it is a great pleasure to be here. It's a reunion, it's a search for new information and it's a celebration for those who have CHARGE, their families and the professionals who support them.

### **Introduction**

Conferences are filled with highly experienced experts, these being parents and professionals and those who have CHARGE.

So I hope to offer you some new and old thoughts on communication, behaviour, play and passions.

Throughout my career my primary focus has been communication, communication with babies, children, teenagers and adults.

I believe it is one of the keys to breaking through, to finding the person.

I also mean all kinds of communication, simple to complex and in it's many forms.

### **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 are still relevant.

I met Megan; mother of Nikki aged 3 and 1/2 and some members of her cochlear implant team.

## **(Slide 2 – Nikki)**

The meeting was to discuss the impact of CHARGE syndrome on Nikki's development.

Nikki had received a cochlear implant about 18 months previously. 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 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 the 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 give you an injection now') but don't add in touch cues, gestures, pictures, 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, would it be painful, 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 is typical in children with CHARGE.

'Anxious' is a word I hadn't often used before to describe behaviour in children with CHARGE.

I was surprised I hadn't used it more in this context.

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

### **Why would they be anxious?**

They need to know:

- what is about to happen
- when will it happen
- that it needs to happen now (so you won't change your mind)
- then what is going to happen after that
- and after that, after that ...

### **(Slide 3)**

#### **Other terms also used are:**

- obsessive compulsive disorder (OCD)
- autism spectrum disorder (ASD)
- repetitive behaviours
- attention deficit disorder
- tics
- self-harm
- non-compliance
- tantrums
- meltdowns.

We often talk about how all the behaviours we see in children with CHARGE are perhaps exhibited by everyone; it's just that people with CHARGE appear to amplify these behaviours.

I remember in one of Tim Hartshorne's presentations a few years ago he had a slide of the things that define Obsessive Compulsive Disorder. I must tell you I scored really well on that OCD screening test.

### **(Slide 4)**

Order, organisation and tidiness have a really important purpose for me. It keeps my world orderly, predictable and easy to access ... and I also think it looks better.

I think those words predictable, orderly and easy to access apply to many of those with CHARGE.

## **Meltdowns**

### **(Slide 5)**

We talk about Meltdowns a lot.

It seems to me that one of the contributing elements would be anxiety.

#### **In the early years**

- What are you doing to me?
- What are you going to do to me?
- I don't understand what's happening
- That hurt
- I feel sick

#### **In the later years**

- I want it now
- I want it to happen now

- You are not listening to me
- You do not understand what it is I want
- You didn't understand what I meant
- You just didn't understand
- You haven't explained it to me and I'm unsure as to what is happening or what is expected of me
- Will it happen now?
- What will happen next?
- What will happen after that ... then after that?

### **These anxieties may lead to**

#### **(Slide 6)**

- Distrust
- Fear
- Anxiety
- Outbursts
- Refusal
- Withdrawal

At that Skype meeting I explained how 'Meltdowns' are not restricted to age or development. I've seen 'meltdowns' in babies, children, teenagers and adults. From those with high support needs to those who are independent, mainstream educated and employed ... the whole spectrum.

What I've also 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.

#### **(Slide 7 - Belinda, who is legally blind, travels the world independently and doesn't use a cane).**

I've always felt we must use all senses as a means of providing meaningful information, even though we know all senses are affected. Therefore using visual language and touch cues to support spoken language is of great importance to me.

So for parents, educators, therapists and doctors it's our challenge to make every effort to make their world more predictable, more ordered, more organised and tidier, using all possible means to achieve this.

- what will happen now
- what will happen next
- what will happen after that
- then after that and so on

to reduce distrust, fear and anxiety.

## **I digress, back to Communication**

At that Skype meeting I reiterated my belief that it's our job is to help make sense of this chaotic, unpredictable world for the baby, child, teenager and adult.

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.

### **(Slide 8)**

Parents and professionals always strive to provide the best possible audition through: amplification, hearing aids, cochlear implants, bone aids, bone anchored hearing aids, 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, photos, drawings, symbolic drawings (boardmaker, proloquo2go) and reading and writing. Multimodal communication.

### **(Slide 9)**

## **About Learning Sign Language**

I acknowledge that acquiring a new language like Sign Language 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
- 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 signs language only

## Let's move on to 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 is building a trusting relationship through offering interactions and communication that are 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.

**(Slides 10 – 19 - Nikki's development in play)**

**(Slide 20)**

### Heiko and Jonas

I'd have three movie clips of a Dad, Heiko, and his son, Jonas, Yes the Junghans family. The movie shows them engaged in relaxed, pleasurable play. Watch how Heiko so naturally uses simple strategies to engage Jonas in play.

The movies are in German. I used these videos in Australia and USA to illustrate how much can be understood by following the visual communication when the spoken language is not understood.

**(Movie 21 – Heiko and Jonas)**

So what did you notice from the movie?

**(Slide 22)**

#### 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

### (Slide 23)

#### 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

### (Slide 24)

#### Movie 3

- This one depicts more adult directed play
- Heiko takes his time to ensure Jonas understands
- 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

### (Slide 25)

#### Heiko used

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

### (Slide 26)

#### 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.

**(Slide 27)**

## **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 be:

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

**(Slide 28)**

## **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:

- **Sean and Bailey – Lifts**  
**(Slides 29-32 - Photos of lifts excursion)**

- Trent – Laptop. iPad, Computer games  
(Slide 33-34 – Photo)
- David – Horse Riding)  
(Slides 35-39 - Photos)
- Sarah – Horse riding  
(Slides 40-42 - Photos)
- Phillip – Tapestries  
(Slide 43-44 – Photo)
- Belinda - Travel  
(Slide 44-46 - Photo)
- Ellen – Facebook  
(Slide 47-48 - Photo)
- Sean – Caravans  
(Movie 49-50)

### Text for Movie:

Rob: ‘Sean, I’d like to know what got you interested in caravans?’

Sean: ‘Um, when I bought my first magazine, um, I read it and asked my Mum for another one.’

Rob: ‘So that was about a magazine, right?’

Sean: ‘I bought a magazine’

Rob: ‘Oh you bought a magazine, OK got it, and it was about Caravans?’

Sean: ‘Yes’

Rob: ‘Alright, would you like to tell me about what’s up here?’

Sean: ‘These are my caravan lights’

Rob: ‘Caravan lights, beautiful, how far do they go?’

Sean: ‘Round about 20 metres down to the power point’

Rob: ‘And do you want to show me something down here?’

Sean: ‘This is one of my favourites of all the cars I’ve got’

Rob: ‘This is your favourite of all the cars or caravans or Both?’

Sean: ‘Both’

Rob: ‘Both, OK, alright, yes, I agree, this is my favourite too and there’s something else there you’ve got there you wanted to show everybody?’

Sean: ‘And this was my first magazine.’

Rob: ‘Oh your first magazine, is it old?’

Sean: ‘March twenty eleven edition’.

Rob: ‘March twenty ...’

Sean: ‘... eleven’

Rob: ‘Two Thousand and Eleven.’

Sean: 'My magazine collection started from this one and went all the way to there'

Rob: 'So the magazine collection starts there and goes all the way up there?'

Sean: 'Yes'

Rob: 'OK great. It's a terrific collection, wow.'

Rob: 'Alright, that's it, all done?'

Sean: 'Yes'

Rob: 'Thank you'.

- **Julia – Sorting and Organising**  
**(Slide 51-53 - Photos)**
- **Mitchell – Football and Spinning**  
**(Slide 54-56 – Photos)**
- **Sophie – Basketball**  
**(Movie 57-58)**

**(Slide 59)**

### **Passions/Obsessions**

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 – Sean and Bailey
- As a hobby
- For pleasure
- To provide relaxation
- To enhance self esteem
- As exercise
- To further encourage communication
- As a career plan

**(Slide 60)**

### **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.

**(Slide 61)**

## **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

**(Slide 62-69)**

## **Reading Tips**

Four Great Books

- 'An Exceptional Fellow' A Father's Story Svein Olav Kolset
- 'Far From The Tree' Andrew Solomon
- 'CHARGE Syndrome' Hartshorne, Hefner, Davenport, Thelin
- 'Why I Am Me' Ward, Patterson and Levett

**(Slide 70)**

## **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

**(Slide 71)**

## **Other Human Resources**

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

## **In Closing**

**(Movie 72)**

**Thank you Rob Last**

# David Brown

## 16<sup>th</sup> June – 04.30 p.m.

### ***“Posture and movement in CHARGE syndrome”***

The complex multiple anomalies involved in CHARGE syndrome present huge barriers to development. Children with this syndrome are forced to experiment and explore alternative ways of achieving what they want because the conventional, so-called ‘normal’, ways are not available to them. This is seen most clearly in the ways that they physically manage their bodies in space, to maintain postural security while also developing independent mobility. Observing and analyzing these behaviors from a multi-sensory perspective helps us to understand the way that their impaired sensory systems are working, and so gives us useful pointers to the best ways to work with them. This perspective can also help us to identify the ways in which the children use postures to self regulate. The presentation will feature many photographs demonstrating these unusual, apparently weird, but actually highly functional postural behaviors.

#### **Dr. David Brown, Educational Specialist**

David entered the specialist area of deaf-blindness in 1983 and has become a leading and well-published practitioner in the field particularly with reference to CHARGE syndrome. In his roles as Head of the Family Education and Advisory Service of SENSE (the National Deafblind Association) in the UK (1983- 2000), and as Educational Specialist for California Deaf-Blind Services (since August 2000), he has worked with over 150 children and young people with CHARGE. For 25 years David has been writing training manuals for universities and other training organizations, and publishing articles on a variety of offtopics in journals and magazines such as “Talking Sense”, “Deafblind Education”, “Eye Contact”, “Special Children”, “Deaf-Blind Perspectives”, “reSources”, “Deafblind International Review”, “The American Journal of Medical Genetics”, and “Child: Care, Health and Development”. His writings have been translated into French, Italian, Spanish, Portuguese, Danish, Norwegian, Swedish, Finnish, German, Greek, Japanese, and Russian. David has contributed to staff training courses in 14 countries, and he has presented at CHARGE Syndrome Conferences in England, the USA, Australia, New Zealand, France, Norway, Sweden, Denmark, Switzerland, and Germany. David has also worked as a consultant with the state deaf-blind projects in 18 states of the USA. David has a credential in the Education of Students with Multi Sensory Impairments from the University of Birmingham, an Honorary Doctorate of Science from Central Michigan University for his research work with children with deaf-blindness, and in 2013 was awarded the Deafblind International ‘Lifetime Achievement Award’ for “innovative and visionary work with people with deafblindness”.

## Posture & Movement in CHARGE syndrome

10<sup>th</sup> German CHARGE conference  
Oberwesel  
June 16th-19th, 2016  
David Brown  
Deaf-blind Education Specialist

1981 - 6 anomalies

- C - Coloboma
- H - Heart Defects
- A - Atresia of the Choanae
- R - Retarded Growth/Development
- G - Genito-urinary Defects
- E - Ear anomalies

2010 - 40 anomalies???

- Mutation of gene CHD 7
- Facial Palsy
- Cranial Nerve anomalies
- Semi-circular canal anomalies
- Dental anomalies
- Sense of smell anomalies
- Larynx & Pharynx anomalies

## Cranial Nerve Anomalies

- Nerve 1 - Smell (42%)
- Nerve 2 - Vision (80%)
- Nerve 7 - The Face (43%)
- Nerve 8 - Hearing & Balance (80%)
- Nerves 9 and 10 - Swallowing (50%)

(From CHARGE Foundation Parent Manual - 1999)

2005 – 38 anomalies?? (Continued)

- Atresia of the esophagus
- Tracheo-esophageal fistula
- Skeletal anomalies
- Sleep apnea
- Cleft lip / Cleft palate
- Hypocalcaemia
- Seizure disorder

David Brown - Am.J.Med.Gen. 2005

“Children with CHARGE syndrome are truly “multi-sensory impaired”, having difficulties not only with vision and hearing but also with the senses that perceive balance, touch, temperature, pain, pressure, and smell, as well as problems with breathing and swallowing, eating and drinking, digestion, and temperature control.”

CHARGE - the most 'multi sensory impaired' of all syndromes

Problems with the perception of:

- Vision
- Hearing
- Touch
- Proprioception
- Temperature
- Pain
- Vestibular
- Smell
- Taste

## “The Forgotten Senses”

### PROPRIOCEPTION

The receptors are in the muscles and joints throughout the body

Tells us about the position of our body and all of our limbs, and if anything is moving

### VESTIBULAR

The receptors are in the Inner Ears

Tells us about head position & the pull of gravity, detects motion, and it has very close links with the eyes and vision

Early effects of poor (or missing) vestibular function in children with CHARGE Syndrome

(Brown, American Journal of Medical Genetics, March 2005)

- Low muscle tone (“floppy muscles”)
- Poor head control & poor ability to resist gravity
- Strong postural insecurity when held upright
- Marked preference for being flat on the back
- Delayed mobility & unusual movement patterns (eg. back scooting, side-winding, five-point crawl)

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Early effects of poor (or missing) vestibular function in children with CHARGE Syndrome (Brown, *cont.*)

- “W” sitting for broader, more secure base
- Better visual, auditory and fine motor skills in supine than in the upright position
- Poor bilateral coordination, hand and eye dominance is either total or missing
- Fatigue after trying to resist gravity for periods of time
- Difficulties with self-regulation

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David Brown - Am.J.Med.Gen. 2005

“...the immense difficulties that children with CHARGE face in almost everything that they do, and, as a consequence, ... the very high levels of stress with which they must live for much or even all of their lives. Time spent trying to reduce stress levels, and trying to give the children acceptable strategies for doing this for themselves, must be one of the most precious gifts we can offer them, and one of the biggest favors we can do ourselves as educators, therapists, and family members.”

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YET,  
DESPITE EVERYTHING...

“ I know of no 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.”

-David Brown



-Mackenzie & Kennedy, showing off their indomitable spirit.

“The only function of the body is to carry the brain around”

Thomas Edison

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Why might movement be difficult? (1)

- Orthopedic issues: Skeletal/ Muscles & tendons/ Brain (ie. Cerebral Palsy)/ Poor quality connective tissue
- Sensory issues: / Blindness/ Deafness/ Vestibular/ Proprioceptive/ Tactile
- Drugs/medication
- Seizures
- Breathing problems
- Nutrition issues (feeding problems, poor absorption of food, low energy, poor bone growth & poor muscle growth)

Why might movement be difficult? (2)

- Stress
- Depression
- Fear
- Low expectations
- Poor awareness/poor motivation
- Distractibility
- A vicious circle – all these issues create movement problems, but also movement problems can compound and exaggerate these issues

I believe that most children with CHARGE syndrome are not in touch with/do not feel their bodies very well

Right from the start....

- Light sources and light levels
- Sound sources and sound levels
- The cot environment
- Touch cues (firm touch)
- Personal markers
- Slow and fully supported lifting and moving
- Reciprocal interaction games
- Communication/Language
- Educating others

17

The Resonance Board

Postures involving the legs

Postures involving bending/  
stretching

Postures involving hanging

Postures involving the hands

Planking

Propping

Squeezing

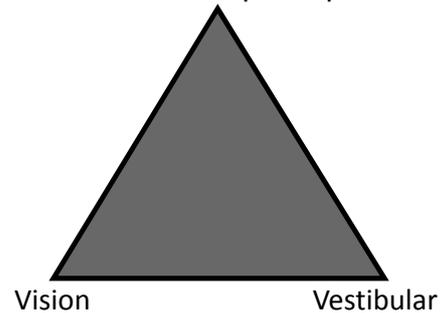
The 'W' sit

Early mobility

- Rolling
- Side-winding
- Back scooting
- Bottom shuffling
- 5-point crawling
- Regular crawling

The Equilibrium Triad

Touch/Proprioception



Walking

- Walkers
- Rolling gait
- Flat feet/ bent knees
- Foot slapping
- Tip-toe walking
- Feet roll inwards/ knees knock together
- Arms extended to the sides or in front
- Eyes fixed on a visual target ahead

Climbing

## Facial palsy and assisted smiling

## CHARGE handwriting

Why is all this so important, and why should we be observing for it?

- To understand the child's challenges
- To appreciate the child's adaptive behaviors
- To be able to introduce the child to other people
- To be aware of the fundamentally important things which often get overlooked or forgotten
- To remember that everything the child does takes more time, more planning, more energy, more concentration, and more attention, than it does for other children
- To realize that things that look crazy might really be functional and clever adaptations

\*Communication with one's own body

\*Communication with one's immediate environment

\*Communication with the wider world

## My take on Jean Ayres & Sensory Integration theory & Therapy (1)

- The constancy & inter-relatedness of sensory inputs
- The senses connect the brain to the body
- Sensory inputs have a significant & direct impact on arousal levels
- Some senses may be more important than others
- Most children with deaf-blindness are not in touch with/ do not feel their bodies very well

## My take on Jean Ayres & Sensory Integration theory & Therapy (2)

- We all self-stimulate (all the time?) to maintain alertness, to wake up, to calm down, to maintain postural control, to keep/ get comfortable, to occupy our minds, to self-regulate, to fight boredom, to maintain attention, to keep sane, and generally to improve our functioning to achieve our goals
- Sensory deficits and poor sensory perception make children with deaf-blindness self-stimulate in mostly normal ways – but often with more intensity, more persistence, and for a longer period of their lives than “normal”

My take on Jean Ayres & Sensory Integration theory & Therapy (3)

- For various reasons children with deaf-blindness may have poor social awareness, so self-stimulation behaviors may be more obvious
- Attempts to stifle and stop self-stimulation behaviors may result in worse self-regulation and generally less good functioning
- Observing how and when a child self-stimulates will offer invaluable insights into who they are and how they work, for assessment, teaching, behavior management, and relationship building

Yes, I believe that posture should be included as a “self-stimulation” and/ or a “self-regulation” behavior (especially for people with CHARGE syndrome)

If it isn't dangerous or illegal, ask “What does it mean?”, and then intervene to try to answer that question, NOT to stop the behavior as the primary aim

# Ulla Füller + Florian Drewes

## 16<sup>th</sup> June – 07.30 p.m.

**Ulla Füller interviewing her son Florian Drewes**  
***„My life with CHARGE syndrome“***  
***Everyday life and development of Florian Drewes***

**Ulla Füller**, member of the German CHARGE group and mother of a 25 years old son with CHARGE syndrome. She is working with joy and passion for almost 20 years in different fields of social work. Her focus are people with hearing impairments and young people with special needs and also people with CHARGE syndrome. She just finished her education as a presenter and coach for PCP (Person Centered Planning)

**Füßer und Co.** “

Welcome  
To...

„Finding a job and... **CHARGE**

Florian Drewes and Ulla Füber



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www.fuesserundco.de Fachkräftetagung CHARGE 16. Juni 2016

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**Füßer und Co.** “



We ...

... would like to show you Florian's way into working life!  
 ... This is only one possibility that fits to Florian's and our life!  
 ... There are many more possibilities depending on the person,  
 the family, the circle of supporters, and other conditions!

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**Füßer und Co.** “

Finding a job an ... **CHARGE**

How to do it?

What strengths and skills does Florian have?  
 Where does he feel comfortable, challenged and accepted?  
 Are there companies that adjust to the new situation?  
 Is there an alternative – besides a sheltered Workshop?

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**Füßer und Co.** “

One page about me

**Florian**  
26 years  
**Work?**  
... I like it colorful!

**Family**  
Friends  
Important people

**Hobbies:**  
Travelling  
Meeting Friends  
Going to the movies.. talking  
Drinking coffee

**Goals:**  
Living in a shared apartment  
Independency  
Meet nice people  
Having a girlfriend

**Communication**  
patience  
Speaking „face to face“  
Simple language

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**Füßer und Co.** “

How to support me

being patient  
Honest people  
Fun Humor

Simple language  
Explaining repetitive

travelling  
Discover new things  
Being active

Cozy room  
Cappuchino  
Good food

Writing articles

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**Füßer und Co.** “

Questions from parents?????????

Questions about life

Questions regarding school and job

Will Florian survive?  
How will he develop?  
Will we make it as parents/family?  
How? Together or ALONE?

Which Kindergarten is best?  
Which type of school to choose?  
What are Florian's options for his future working life?

... These and many more laid ahead of us and seemed out of reach...

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**Füßer und Co.** “

**Florian's first important stations in life**

Early childhood development	School for „Hearing and Communication“ (Florian: 2 years)
Kindergarten	School for „Hearing and Communication“ (Florian: 3 years)
Primary/elementary school	School for „Hearing and Communication“ (Florian: 6 years)
Secondary/High School	School for „Hearing and Communication“ (Florian: 10 years)

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1. internship      2. internship

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**Füßer und Co.** “

**Florian's point of view**

- Primary school/elementary has been a success! (great teacher, lots of things to do, awesome projects...)
- Secondary/High School has not been good! (no friends, alone on school campus,... )

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**Füßer und Co.** “

**Toy shop (e.g. toys r us)**  
(Florian: 15 years)



**Bank (e.g. Dresdner Bank)**  
(Florian: 16 years)



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**Füßer und Co.** “



Florian's point of view

- Toy shop has been awesome!!!  
(not difficult; was able to understand boss well; ...)
- Bank was exhausting!  
(dealing with money is exhausting for me; ...)

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**Füßer und Co.** “

School came to an end and we had no plan what's to come next!!!!

Parents without a clue and frustrated

Florian without a clue and with out a perspective

We need a solution/Plan B!!!!

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**Füßer und Co.** “



Florian's point of view

... Oops this has happened long ago, I can't remember!!!!!!!!!!!!

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**Füßer und Co.** “

**Remedial class „Berufskolleg Neandertal“**

**Target group:** youths and young adults with special needs „mental development and learning“

With a normal school period no chance on the 1st job market

Only sheltered workshop = insufficiently challenged

Goal: define competences / stabilizing > Integration 1st job market

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**Füßer und Co.** “



Florian's point of view

... I remember that we had done a testdrive!

... Too long ago!

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**Füßer und Co.** “

**Mentoring** of Internships by social educational mentoring programm of the school (close cooperation with the teachers)  
School was laid out to 2 years

1st Semester: combined lessons as a group  
(promotion of cultural techniques: cooking: how to wash clothes, handling a bank account,...)

2nd Semester: Internship (2 Weeks)  
1 Day a week internship

3rd Semester: 2 days a week internship

4th Semester: 3 days a week internship

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**Füßer und Co.** “



**Florian's point of view**

School was not good! Worse than „School for the deaf“

Teachers have been impatient!

Wrong friends! Have been mobbed!

Mrs „Social worker“ was nice! Took good care of me!

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**Füßer und Co.** “

**2 new internships**

**Home for the elderly: kitchen?** ... Close to home!  
... Florian was able to get to go to work by himself!  
... Communication??

(Florian: 18 years)

**Home for the elderly: Kitchen?** ... in Ratingen?  
... By train/ change trains?  
... Communication?

(Florian: 19 years)

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**Füßer und Co.** “



**Florian's point of view**

**1. internship (home for the elderly/ in Gerresheim)**

Start was very good!

Later colleagues have been impatient; not as nice as in the beginning; I noticed that I was capable of doing what was asked – was not difficult; unfortunately only a € 400 job = denied!!

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**Füßer und Co.** “



Florian's point of view

**2. Internship (Haus Salem in Ratingen)**

Here it was much better!!!!!!

I have had the best boss in the world!  
and  
... a super nice TEAM!

We have had lots of fun! And have helped each other!

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**Füßer und Co.** “

**Zusammenarbeit**  
IFD – Intergration agency – Agency for work - LVR

IFD (Joborientation ) intensive negotiation with agency

„Aid Money“ > working place (to fit Florian) planed

Contract of employment „Kitchen Aid“ (limited for one year)

Follow-up care for 6 months via IFD

Prolongation for another year/ since 2012 unlimited

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**Füßer und Co.** “

**“House Salem“ Retirement Home in Ratingen (near Düsseldorf)**  
Employed: FairDienst (Project of Integration)

**“Kitchen Helper“** in the canteen kitchen

TEAM: about 12 staff/colleagues

TASKS

fill and empty the dishwasher  
help the cooks  
help with “cold kitchen”  
do the laundry  
to clean  
...

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**Füßer und Co.** “

Florian introduces his **WORKPLACE**



kitchen kitchen scullery pre-wash-up ingredients

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**Füßer und Co.** “

Florian introduces his **WORKPLACE**



the line-dishwasher

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**Füßer und Co.** “

Florian introduces his **WORKPLACE**



garbage station HEAD office :-> station for foodcarts going home ☺

... if it's empty here then ->

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**Füßer und Co.** “

Summer party in "House Salem" →



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**Füßer und Co.** “

A typical routine

05.00 h	Alarm clock rings!!! Stand up ☹
05.30 h	Nice taxi driver is waiting ahead!
6.00 h	Change clothes! Start of work!
bis	Wash up, help, do the laundry
ca. 10.00 h	Morning break (...hm tasty ☺)

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**Füßer und Co.** “

...and the 2nd day's march ☺

10.30 h	Let's continue!
12.30 h	Lunchtime wash-up of our station
ca. 13.00 h	Foodcart from house 2
ca. 13.45 h	Foodcart from house 3
ca. 14.30 h	Did it ☺ ... Going home!!!

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**Füßer und Co.** “

Florian's point of view

Worries???

New boss in August!  
Can he deal with disabled people?  
When I live in a shared flat, will I have people to talk about work?

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**Füßer und Co.** “

„What works well?“ „What works bad?“

Happy to have a job  
Money  
Nice, funny colleagues  
Great head!  
Got much skills!

To get up early  
MONDAY@  
Long way to work

To talk about problems  
Summer (it gets light in the morning!)  
Holiday / weekend

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**Füßer und Co.** “

What has changed since 2013?



Work tasks got more diversely...

Able to stand up alone by myself

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**Füßer**  
und Co. “

Arthur got retired ! ☺

Head will be gone in August?

Travel with train by myself! (Berlin, Nuremberg, Cologne) and come home by myself independently

Clean up my room/ buy in ... / want to become more independent...

I independently pack for travels – booking of travel I match with a bit of support

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**Füßer**  
und Co. “

Stay at home alone at the weekend

I can handle money much better

Looking for air and train connections on the internet for...

...moving in July in a shared flat (assisted living community) ☺☺☺

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**Füßer**  
und Co. “



... Wow, there happened so much in the last three years!!!

... I'm getting more and more independent!!!

... Oops, sometimes I'm feeling strange!

... I wonder, how ALL of this will develop!!!

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**Füßer und Co.** “

**Goals and Wishes**

Maybe trying another job!

Not to get up so early!

Enough money for travels!

Earning enough money!

Friends nearby!

Becoming more independent!

A girlfriend! ☺

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**Füßer und Co.** “

**Florian's point of view**

... I am so happy to have a job! Otherwise, I couldn't travel, go shopping and buy myself nice things!

... And just being at home – that's boring!

... But sometimes it's really hard for me - to get up so early!!!

... Now I'm very excited, how it'll be to live in a shared flat ;)

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**Füßer und Co.** “

Thank you for your attention and your patience!

... and an interesting and nice weekend for you! ☺

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# Julie Maier + David Brown

## 17<sup>th</sup> June – 09.00 a.m.

### ***„Looking at the world through rose-colored glasses“ Approaches to positive assessment***

This presentation is based upon two articles that Julie and David wrote for the CDBS newsletter in 2014. We will examine and discuss the perspectives and assumptions educators, medical professionals, and other related service providers often employ when viewing students with CHARGE Syndrome. These perspectives and assumptions then influence the direction taken during assessment and planning development of educational goals and programs for individuals with CHARGE Syndrome. We will share a more effective, child-centered approach.

**Julie Maier** is an Educational Specialist for CDBS. She provides technical assistance to students with deaf-blindness, families, and school teams. Julie also is a faculty member in the SFSU Department of Special Education and has served as a research assistant, guest lecturer, course instructor and fieldwork supervisor in the Moderate-Severe teaching credential and Masters degree programs since 1999. Julie has been involved in the field of special education since 1987 when she first met and taught individuals with deaf-blindness in community-based adult program and later in inclusive schools in Berkeley.

“Looking at the world through  
rose-colored glasses”  
Approaches to positive  
assessment

David Brown & Julie Maier  
California Deaf-Blind Services  
German CHARGE Syndrome Conference  
Oberwesel June 2016

Our presentation is based on two  
articles we wrote in 2014 about  
assessment approaches and practices  
with children who are deafblind.

David Brown (2014) “*What does ‘Follow the Child’ mean?*”. California Deafblind Services reSources, Volume 19, No. 1. Spring, 2014.

Julie Maier (2014). *Capacity or deficit? The lens we use to view students does a make a difference*. California Deafblind Services reSources, Volume 19, No. 1. Spring 2014.

The uniqueness (and complexity) of CHARGE syndrome

The changing nature of the population of children with CHARGE syndrome

David Brown - Am.J.Med.Gen. 2005

“Children with CHARGE syndrome are truly “multi-sensory impaired”, having difficulties not only with vision and hearing but also with the senses that perceive balance, touch, temperature, pain, pressure, and smell, as well as problems with breathing and swallowing, eating and drinking, digestion, and temperature control.”

CHARGE - the most ‘multi sensory impaired’ of all syndromes

Problems with the perception of:

- Vision
- Hearing
- Touch
- Proprioception
- Temperature
- Pain
- Vestibular
- Smell
- Taste

## Why do people assess children with CHARGE syndrome?

### Challenges to the Assessment Process

- CHARGE presents a very diverse and complex population of learners
- CHARGE presents a wide variety of idiosyncratic behaviors
- People doing assessments usually only know one type of assessment process
- There are limited resources and assessment tools available
- People doing the assessment often forget “The reason why” of assessment

## 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.
- Is 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.

## Why use a capacity-building framework?

- 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

## 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)



## Presume Competence

“Let’s consider the first few weeks Annie Sullivan spent with the young Helen Keller. What if she had only recognized a “wild child” who held no desire to communicate with others or potential to learn? What if she believed Helen was only a spoiled child with a bad temperament that would be permanently locked inside herself because she had lost her vision and hearing as a baby? Fortunately for Helen and her family and society as a whole, Ms. Sullivan took the approach of “presuming competence” and understood that Helen’s different behaviors and actions were certainly a form of communication and an indication of a deep desire know, learn, and grow.”



~J. Maier (2014)

## Two perspectives

Deficit model description	Capacity-building model
<p><i>Assessment of environmental signs from the PCI Environmental Print series:</i>            “While Juan was able to expressively identify many of the environmental signs by category, it is the opinion of the examiner that Juan’s responses were often not specific to the function of the sign in a true context. Examples include Juan stating, “What Mr. P does.” for recycling, as well as “You might fall” for slippery when wet sign. This indicates that Juan is able to rely on visual cues yet he may have difficulty when found within the natural environment, such as buildings and outdoor settings.”</p>	<ul style="list-style-type: none"> <li>• Juan is a visual learner with a good memory.</li> <li>• Juan can make inferences and associations when presented with information. (e.g. Recycling symbol associated with an activity his teacher performs)</li> <li>• Juan can predict events or problems and assess risk and act accordingly (e.g. be careful when you see “slippery when wet” sign and walk around it or walk carefully).</li> <li>• Juan would benefit opportunities in natural settings to learn to identify, read, and use environmental print.</li> </ul>

## 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
<p>A child with CHARGE Syndrome who has significant vision loss 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 are taught how to communicate, engage, and play with her. She receives support from an intervener and her team regularly meets to discuss her progress and support needs.</p>	<p>Now consider that same child assigned all day in 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.</p>

Which assumption is more dangerous to follow?

## Same view, different perspective

“This lens is not limited to identifying strengths, but rather **shifts the focus**. The view is of the same student, yet the perspective is very different. Educators who use a capacity lens **look beyond what the student with disabilities is “doing”** by describing the different or missing skills or behaviors, and instead **consider why the student is or isn’t doing something**, and will then identify and **consider systems of support** that could enhance and develop the student’s capabilities. These educators also understand that the “problems” that challenge them the most are actually evidence of student capability.”

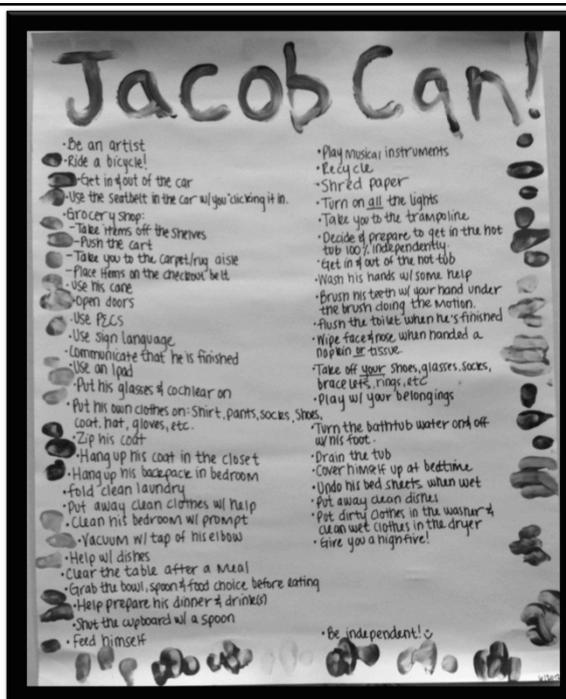
~J. Maier (2014)

## 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



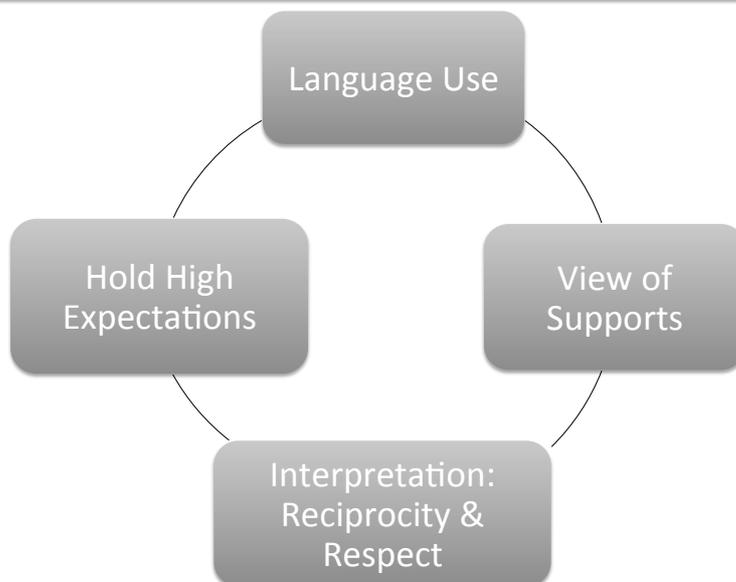
## Two views of Jacob

What Jacob CAN do...	What Jacob CANNOT do...
<ul style="list-style-type: none"> <li>• Ride a bike and can buckle seatbelt</li> <li>• Use sign language and picture symbols to communicate</li> <li>• Put his glasses and cochlear on</li> <li>• With some help can wash hands and brush teeth</li> <li>• Push a grocery cart &amp; put items on the checkout conveyer belt</li> <li>• Shred paper</li> <li>• Put away clean dishes</li> <li>• Put dirty clothes in the washer and wet clothes in the dryer</li> <li>• Choose to use hot tub &amp; get in and out independently</li> </ul>	<ul style="list-style-type: none"> <li>• Cannot drive a car</li> <li>• Cannot speak</li> <li>• Is deaf-blind</li> <li>• Cannot wash his hands or brush his teeth independently</li> <li>• Cannot read a recipe</li> <li>• Cannot cook a meal</li> <li>• Cannot grocery shop, wash dishes, or do laundry independently</li> <li>• Rips paper, so he he should not have paper</li> <li>• Cannot live alone</li> </ul>

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?

### Capacity-building Assessment Practices



## 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 his 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 a 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.

## Our view of assessment.....

- Is unusual!
- Is positive
- Looks at positive skills & achievements
- Looks at learning styles
- Looks at preferences & interests
- Looks at the whole child
- Credits the child with intelligence

## Our view of assessment (2).....

- Seeks to improve our understanding of the child
- Seeks to help us to build a positive relationship with the child
- Seeks to help us to know what to teach and how best to teach it
- Seeks to give us a clear focus for measuring progress

## 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 & to develop
- Assessment is summarized in terms of strengths and next steps for intervention

### Areas of the Van Dijk Assessment Framework

- Ability to maintain & modulate state
- Preferred learning channels
- Ability to learn, remember & anticipate routines
- Accommodation of new experiences with existing schemes
- Problem solving approaches
- Ability to form social attachments and interact
- Communication modes

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

## CHARGE Communication

\*Communication with one's own body

\*Communication with one's immediate environment

\*Communication with the wider world

Assessment should be regarded as  
a Process not a Product

- ◆ Trial and Error (child-guided, fluid,)
- ◆ Always a work in progress
- ◆ Questions not answers
- ◆ Why?

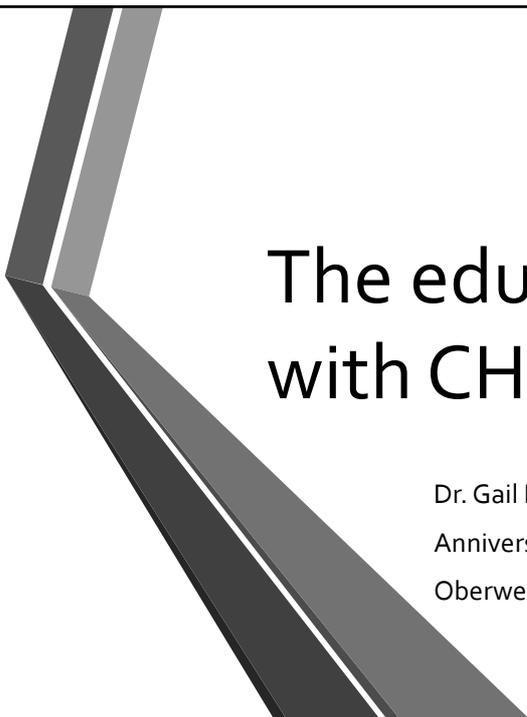
# Gail Deuce

17<sup>th</sup> June – 10.45 a.m.

## „Potential learning characteristic and teaching strategies”

“The education of learners with CHARGE syndrome” - CHARGE syndrome is now considered to be the major genetic cause of congenital deafblindness. There has been some discussion as to whether learners with CHARGE are distinct from the wider deafblind population and Gail has recently completed her PhD studies exploring this issue and the education of learners with CHARGE.

**Gail Deuce, PhD** has approximately 30 years experience in the field of special education, working initially in schools for children with severe learning difficulties and then a school for the deaf before moving into peripatetic work focusing on learners who are deafblind. Gail currently works as a specialist MSI (deafblind) outreach teacher for a school in a London borough and is also a freelance consultant, in addition to becoming an Associate for Sense. Gail is also a tutor for the University of Birmingham on the education of learners who are MSI. Gail has a particular interest in CHARGE syndrome and is on the committee for the CHARGE Family Support Group in the UK. She has recently successfully completed her PhD, exploring education of learners with CHARGE.



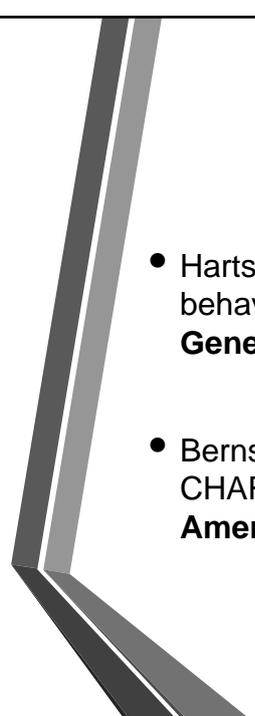
# The education of learners with CHARGE syndrome

Dr. Gail Deuce

Anniversary CHARGE conference: 17th – 19th June, 2016

Oberwesel, Germany

1



## INDIVIDUALS WITH CHARGE AS PART OF THE WIDER DEAFBLIND POPULATION

- Hartshorne, T. Grialou, T., and Parker, K. (2005a) Autistic-like behavior in CHARGE syndrome. **American Journal of Medical Genetics**. 133A: (3): 257-261
- Bernstein, V. and Denno, L. (2005) Repetitive behaviors in CHARGE syndrome: Differential diagnosis and treatment options. **American Journal of Medical Genetics** 133A: (3): 232-239

2

## THE RESEARCH QUESTIONS

CHARGE syndrome is a medical diagnosis. Can it also be considered as an educational diagnosis?

- What are the factors within the child likely to affect learning?
- What strategies are likely to be effective in supporting the learning of children with CHARGE?
- What aspects of CHARGE might be distinct from the more general deafblind/MSI population?
- What specialist support is provided from other professionals and through assessments, to teachers working with a child with CHARGE?

3

## THE RESEARCH PROCESS

- Document analysis
- Questionnaire
- Interviews

4

## DEMOGRAPHICS- QUESTIONNAIRE

- 93% reported to have a visual impairment
- 94% reported to have a hearing impairment
- Combined VI and HI reported in 87%

5

## DEMOGRAPHICS- AGE RANGE

<b>Phase</b>	<b>Number of children from study in each Key Stage N=52</b>
Early Years Foundation (Under 5's)	4 (8%)
Key Stage1 (5-7 years)	9 (17%)
Key Stage 2 (7-11 years)	14 (27%)
Key Stage 3 (11-13 years)	12 (23%)
Key stage 4 (13-16 years)	13 (25%)

6

## DEMOGRAPHICS- TYPES OF EDUCATIONAL PROVISION

Type of school	Total number of children N=52
Severe Learning Difficulties/Profound and Multiple Learning Difficulties (of which 4 are in a sensory/MSI resource)	21 (40%)
Specialist school for the deaf	12 (23%)
Specialist school for speech & language impairment	2 (4%)
Specialist school for physical disabilities/Moderate Learning Difficulties	1 (2%)
Mainstream primary school (including 2 in a Hearing Impairment resource)	10 (19%)
Mainstream secondary school (including 2 in a Hearing Impairment resource)	6 (12%)

7

## POTENTIAL LEARNING CHARACTERISTICS (1)

- A combination of sensory impairments (true MSI)
- Behaviours arising from poorly developed or under-stimulated vestibular and proprioceptive systems
- Sensory integration difficulties and poor self-regulation
- High levels of fatigue, stress and anxiety
- A preference for using different communication modes for both receptive and expressive communication
- Easier to form relationships with adults than peers
- Difficulty understanding/expressing own emotional state and empathising with peers
- Additional time to process information

8

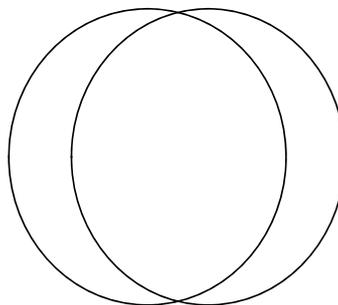
## POTENTIAL LEARNING CHARACTERISTICS (2)

- Development of concrete concepts a strength
- Abstract concepts more difficult
- Problem-solving a strength
- Needing high level of routine and structure, and use of concrete cues to support transitions- difficulty coping when not established
- Executive function difficulties
- A need to be in control and a requirement for a level of negotiation
- Fine motor difficulties and poor pencil/handwriting skills

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## PEDAGOGY FOR LEARNERS WITH CHARGE

CHARGE  
syndrome



Deafblind

10

## STRATEGIES: SENSORY RESPONSES

- A combination of sensory impairments (true MSI)
- Behaviours arising from poorly developed or under-stimulated vestibular and proprioceptive systems
- Sensory integration difficulties and poor self-regulation
- Additional time to process information
  
- Place a priority on all the child's sensory needs
- Ensure against sensory overload
- Respond to their sensory integration difficulties
- Work closely with the QTVI/ QTHI/ QTMSI

11

## STRATEGIES: COMMUNICATION

- A preference for using different communication modes for both receptive and expressive communication
  
- A sensitive communication partner and contingent responses to all communication attempts
- Support for receptive and expressive communication
- A Total Communication environment
- Access to sign language/sign support and appropriately skilled adults
- Recognition of child's preferred communication modes
- Use of a concrete component to overcome executive function difficulties

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## STRATEGIES: CONCEPTUAL DEVELOPMENT

- Development of concrete concepts a strength
- Abstract concepts more difficult
- Problem-solving a strength- adaptive behaviours
  
- Relevant and meaningful experiences presented in context
- A balance between familiar and unfamiliar activities
- Monitoring to protect against development of 'splinter skills'
- Use of strategies to keep child on task
- Use of concrete components

13

## STRATEGIES: ORIENTATION, MOBILITY AND MOVEMENT

- Behaviours arising from poorly developed or under-stimulated vestibular and proprioceptive systems
- Sensory integration difficulties and poor self-regulation
- Fine motor difficulties and poor pencil/handwriting skills
  
- Activities to support development of gross motor skills and body awareness
- Regular opportunities to engage in large movements and large movement play activity
- Structured support to explore new environments and route planning
- Active/supportive seating and different working positions. Time to adopt a horizontal position if needed
- Assessment of hand function and fine motor activities
- Alternative recording methods made available

14

### STRATEGIES: OWNERSHIP OF LEARNING

- A need to be in control and a requirement for a level of negotiation
- Sharing control with the child and supporting active involvement
- Regular choice making opportunities throughout the day
- Working at the child's pace (considering burst-pause style)
- A flexible approach responding to child's changing needs/ recognition of levels of responsiveness
- Not placing too many demands on the child when a 'difficult' day
- Recognition of executive function difficulties
- Support to develop self-help and self-organisational skills

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### STRATEGIES: RESPONSES TO ROUTINES AND CHANGES

- Needing high level of routine and structure, and use of concrete cues to support transitions- difficulty coping when not established
- Clear structure and routines implemented consistently throughout the school day
- Use of mini routines
- Awareness of the impact of change
- Use concrete cues to support sequencing an activity, transitions and daily routine
- Consistent approach adopted by all adults

16

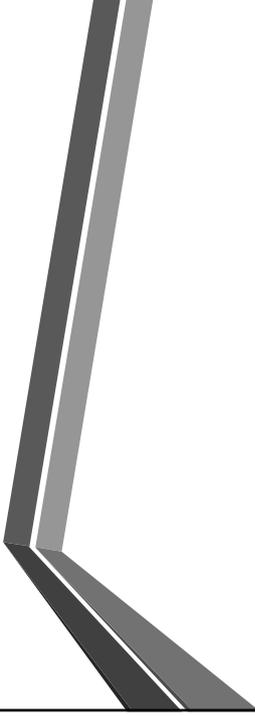
## STRATEGIES: SOCIAL RELATIONSHIPS AND EMOTIONAL DEVELOPMENT

- High levels of fatigue, stress and anxiety
- Easier to form relationships with adults than peers
- Difficulty understanding/expressing own emotional state and empathising with peers
  
- Key people with whom strong, trusting relationships are formed
- Structured programmes to support peer interactions
- Support to develop understanding of emotions
- Activities to ensure success and therefore build confidence
- Recognition of the impact of fatigue
- A safe rest area

17

## THE CLASSIFICATION OF SPECIAL EDUCATIONAL NEEDS DEBATE

18



Gail's thesis can be downloaded from:  
<http://etheses.bham.ac.uk/6175/>

[gaildeuceconsultancy@gmail.com](mailto:gaildeuceconsultancy@gmail.com)



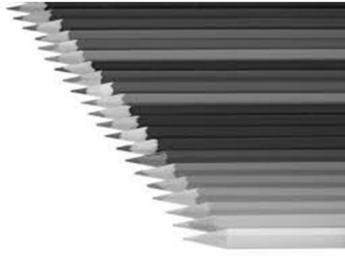
# Nancy Salem-Hartshorne

## 17<sup>th</sup> June – 02.00 p.m.

### *Behaviors and OCD “Why does my child do that?”*

All of us have repetitive or compulsive behaviors. All of us have hobbies. But when we see these obsessions and compulsions in our children with CHARGE, they can look odd or disturbing, or may prevent them from accomplishing all that they can, and we worry. Anxiety is the key! Dr. Hartshorne will talk about strategies to address anxiety and OCD-like behaviors in children with CHARGE syndrome.

**Nancy Salem-Hartshorne Ph.D.** is an Assistant 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 20years. She advocates for individuals with disabilities, teamwork, thorough planning, and forward thinking for quality life outcomes for all individuals.



# Why Does My Child Do That?

Compulsive Behaviors and OCD in CHARGE Syndrome

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

### **Obsessions**

Recurrent and persistent thoughts, urges, or impulses that are experienced, at some time during the disturbance, as intrusive and unwanted, and that in most individuals cause marked anxiety or distress. (Typically irrational fears.)

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

### **Compulsions**

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

The behaviors or mental acts are aimed at preventing or reducing anxiety or distress, or preventing some dreaded event or situation; however, these behaviors or mental acts are not connected in a realistic way with what they are designed to neutralize or prevent, or are clearly excessive.

## Obsessions: Disturbing, Intrusive Thoughts or Fears (Irrational)

Typical Obsessive Fears/Thoughts
Harm to property: burglars, fire, electrical fire, losing something important
Contamination: deadly disease, germs crawling into skin
Harm to a loved one or fear you will harm someone
Magical thoughts
A number or day is good or bad
Step on a crack...
Hearing or saying bad words will produce bad results
Making a religious mistake/sinning will result in going to hell
Fear of not having everything "just right"

## Compulsions: Behaviors/Actions to alleviate worry over the irrational thoughts

Obsession	Typical Compulsions
Harm to property	Check locks, oven, hoard objects
Contamination	Wash hands
Harm to loved one	Text or call repeatedly to check
Magical thoughts	Avoid cracks
Numbers	Avoid using or ending on that number
Bad words	Fix the bad word by saying something else
Religious mistake	Repetitive and excessive prayer
Everything just right	Neatness, orderly, line up, make symmetrical

## OCD is a disorder related to anxiety.

- You feel stress or anxiety
- You perform compulsive acts to relieve it
- You can try to stop your behavior, but it will only increase anxiety

- A pattern that has developed through reinforcement.
- Relief after compulsion felt as a temporary reward.
- You want that reward again, so you'll do the compulsive act again.
- If it's in the way of your life, it's considered a disorder.



## Example: Nancy at age 16

- Obsession over sin/fear of hell: Excessive, repetitive prayer
- Fear of not waking up: Staying up all night
- Rigidly applying rules: Counting: 7, 15, 17, 25, 37; Saying/touching things 7 times; don't step on cracks; unwind when you turn around
- Fear of darkness/night: Sit outside and watch sunset until gone, panicking
- Fear of sin/hell: Repeating religious swear words heard under breath with alternatives (gosh, heck, darn)
- This was utterly debilitating. It took ALL of my time to attend to these things.

## I suggest to you.....

- Most individuals with CHARGE syndrome don't have *true* OCD.
  - Someone with true OCD has irrational thoughts leading to irrational anxiety.
  - The treatment involves exposure to the irrational thought, and prevention of the compulsive response.
- 
- Individuals with CHARGE have TRUE circumstances that lead to UNDERSTANDABLE anxiety!
  - In other words, the EXPOSURE is happening all the time, and is unavoidable. The compulsive response is an understandable defense for dealing with the anxiety.

## OCD-like behaviors seen in CHARGE

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

## Prevalence of OCD-Like Behaviors in CHARGE

Salem-Hartshorne, N., Blake, K., (in process): 53  
Participants. 33 male. Ages 13+

- 49.1% OCD-Like Behaviors
- 45.3% Anxiety

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

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

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



What could  
our kids  
possibly have  
to be anxious  
about?

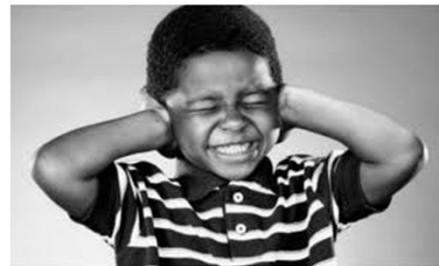
The following things may produce real and understandable anxiety for individuals with CHARGE syndrome. These triggers may cause fear and anxiety, which then produce compulsive behavior.

# 1. PAIN

It doesn't often  
come with a big  
sign



## 2. Sensory overload or underload issues



## How about just plain boredom?

- When you're waiting/bored, do you:
  - Tap a pencil
  - Bounce your legs when sitting
  - Play with your hair
  - Bite your nails
  - (Now that we have smartphones, we do other things as well).

These are all ways of keeping ourselves occupied, or of keeping ourselves aroused and alert.

What do your kids do that look like these, but may not seem as "normal?"



## How about checking?

**“Checking” is an OCD compulsion. For example, checking to see if the oven has been turned off....seven times....**

David Brown's Thoughts:

If you don't have all of the sensory information you need to be reassured, if you never get complete information about your surroundings, if your environment is chaotic and constantly changing, these behaviors make a sort of sense:

- Tapping things with your hand
- Running your hand along the edge of a table
- Arranging items in regular rows or stacks
- Confirming where things are
- Constantly checking if things have changed (has the chair moved, etc?)

If small things can change, then it's scary to think that bigger things in the world can change as well. If I can control the small things, it helps with the anxiety over the bigger things.

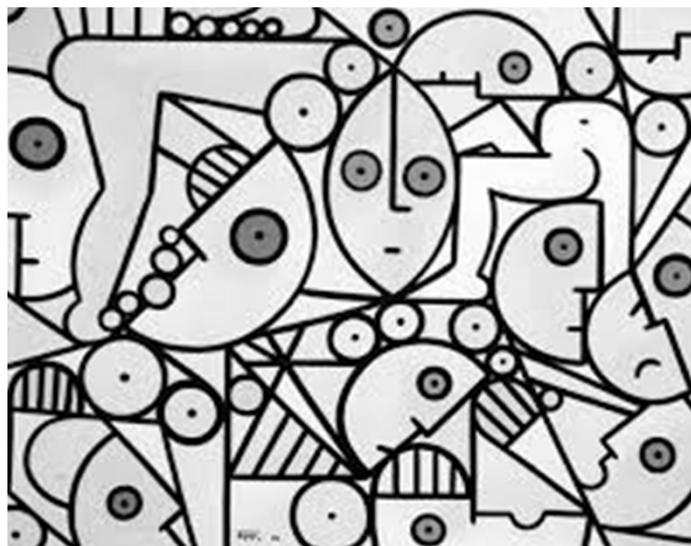


### 3. Sleep

- Sleep and anxiety are related in the general population
  - Fuller, Waters, Binks, & Anderson (1997) found a strong association between high anxiety/worry and clinically significant sleep disturbance
- Salem-Hartshorne & Blake (in process) found almost 60% had sleep problems in adolescent/adult CHARGE sample.
- If there's any way to increase sleep quality, anxiety may decrease.
- Also, reducing anxiety by increasing predictability, helping with sensory issues, and alleviating pain may help sleep quality.

### 4. Stress

- Life is chaotic.
- I cannot hear/see/balance/predict what's going to happen next.
- I want to escape/control the chaos.



Steps to Help

**To do**  
**or**  
**not to do?**

Step One:

Figure out the purpose of the behavior.

- What is its goal? What function does it serve for the individual?

## What looks like an inappropriate goal may be masking something else.

Repetitive questions: “What color is your car, what color is your house?”

- Need for social interaction but not having social skills to initiate true conversations—they know they are supposed to do something. This is what they know how to do.
- Need to do something to organize a chaotic situation with many people around—they are overwhelmed and this is one way to make the situation understandable.
- Need to know more about people to feel safe around them—they are among strangers.

“I want to be a professor...”  
--a story



## Step Two: How urgent is it?

### Urgency of Intervention Questions (D. Brown, 2015)

1. Is this a behavior that just bugs you personally, so that it can be accepted and ignored?
2. Is this a behavior that seems to help the child to function in a positive way, so that it can be accepted and ignored?
3. Is this a behavior that seems to help the child to function in a positive way, but could be reduced, or replaced by another more appropriate behavior?
4. Is this a behavior that is undesirable and really needs to be reduced or replaced over time?
5. Is this a behavior that needs to be prevented immediately?
6. Finally, how much can we improve things by changing our behavior and the environment that the child is in, rather than directly trying to change them?

## Step Three: Intervention (if necessary)



# Pain

Communication of pain may devolve until you get someone's attention, especially if your communication skills are limited or you have difficulty understanding what's happening to you when you are in pain.

**Level 1. Avoiding work, putting my head down, or lying on the floor**

**Level 2. Crying, whining, complaining, acting out**

**Level 3. Hitting, biting, pulling hair**

- This person is communicating, but we aren't understanding. So they change their communication mode until we notice!
- There is a need to help them find a way to more appropriately identify and communicate pain.
- For some, pain behaviors, although worrisome, can be quite helpful.
  - When Jacob blows raspberries repeatedly, we know it's gas pain or cramping
  - When Jacob digs things into his neck, we know his ears are hurting.
  - He doesn't have other ways (yet) to tell us these things.

## CHARGE Non-Vocal Pain Assessment

(Stratton, 2012) (Excerpt)

### • ACTIVITY/CHALLENGING BEHAVIORS

• Less active or quiet	0	1	2	3
• Restless/agitated	0	1	2	3
• Self-injurious behaviors				
• (Biting self, banging/hitting head)	0	1	2	3
• Aggressive				
• (e.g. hitting others, throwing objects)	0	1	2	3
• Acts out/Misbehaves	0	1	2	3
• Disturbed sleep	0	1	2	3
• Change in eating habits	0	1	2	3
• Resists being moved	0	1	2	3
• Increase in OCD-like behaviors	0	1	2	3

## Sensory Issues

- Sensory Integration (deep pressure, weighted garments, etc., to bring arousal level down)
- Sensory breaks (to bring arousal level up or down)
- Allow to withdraw when overwhelmed
- Set up a better sensory situation for environment

## Boredom

Example: Waiting in a doctor's waiting room or at a meeting or restaurant can bring on all kinds of strange-looking behaviors in Jacob.

- Rocking
- Blowing
- Hand-flapping

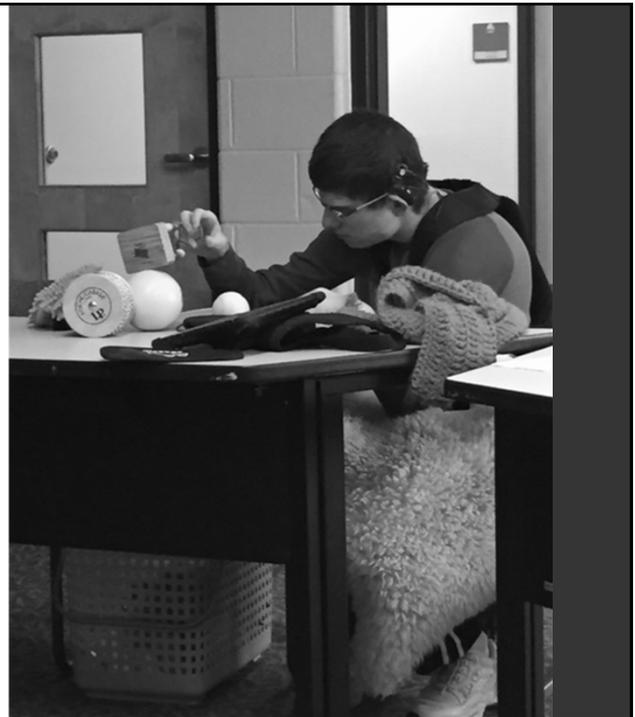
Why?

He can't see or hear the TV everyone else is watching

He doesn't have a smart phone. (What did we do without those?)

He needs something to stimulate his brain.

**For Jake, sensory toys really help.  
What would work for you?**



# Checking

These behaviors may be necessary to alleviate the anxiety brought on by not having full availability of sensory information.

Interventions:

- Allow the behavior, as it serves a clear purpose for the individual
- If the person arranges things in a way that work for them, don't move things back.
- Make the environment as stable and predictable as possible

# Sleep

If sleep and anxiety are related, there are two things that might help:

## **1. Improve quality of sleep**

1. Sleep Hygiene
2. Pay attention to sensory overload
3. Melatonin has been used by some to help bring on sleepiness

## **2. Reduce anxiety**

Stress/Anxiety: The Key is *Predictability*  
*Dr. Tim will be talking about this, later!*



Questions,  
Comments,  
Concerns?





# Tim Hartshorne

## 17<sup>th</sup> June – 04.15 p.m.

### *“Anticipation and Behavior”*

Anxiety about what is occurring or going to happen is one source of challenging behavior for children with CHARGE. This presentation reviews calendar systems and activity routines as ways to increase the predictability of life for those who have CHARGE, and to reduce the experience of anxiety and the incidence of challenging behavior.

**Prof. Dr. Tim Hartshorne, PhD** 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 deafblind in Michigan. He has been researching and presenting about CHARGE syndrome since 1993, motivated by the birth of his son with CHARGE in 1989. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. He is first editor of the book *CHARGE Syndrome*.

# Anticipation

Prof. Dr. Tim Hartshorne  
2<sup>nd</sup> Professional Day on the CHARGE syndrome/10th  
CHARGE-Conference 17. July 2016

# Anxiety

- “A feeling of worry, nervousness, or unease, typically about an imminent event or something with an uncertain outcome.”



## What does anxiety look like in children?



- \*Pessimism and negative thinking patterns
- \*Anger, aggression, restlessness, irritability, tantrums, defiance
- \*Constant worry about things that might happen or have happened
- \*Crying
- \*Physical complaints such as stomachaches, headaches, fatigue
- \*Avoidance behaviors
- \*Sleeping difficulties
- \*Perfectionism
- \*Excessive clinginess and separation anxiety
- \*Procrastination
- \*Poor memory and concentration
- \*Withdrawal from activities and family interactions
- \*Eating disturbances

<http://www.kathyugster.com/articles/article004.htm>

## One difficulty is that the same behavior can reflect different experiences

- Sleep problems
  - Pain
  - Circadian rhythm and melatonin problems
  - Self-regulation issues
  - Anxiety
- Tantrums
  - General complaints
  - Frustration and Anger
  - Pain
  - Anxiety



## Things to be anxious about

- **Novelty**
- **Predictability**
- **Event uncertainty**
- **Imminence**
- **Duration**
- **Temporal uncertainty**
- **Ambiguity**



# What's Happening

We like to know what is going on.

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



## When we are not sure...

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

Hitting  
mom



shutterstock - 211012960

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

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



## One way to increase predictability

June 2016

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17 ✓	18
19	20	21	22	23	24	25
26	27	28	29	30		

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## Why use a calendar system?

- Security of knowing what comes next
- Being able to anticipate things – looking forward
- Alert to unexpected changes in routine
- Allows for participation in decisions about events
- Allows for conversation about what has happened
- Provides a mutually understood topic for dialogues
- Clearly represents the passage of time
- Reduces anxiety about what has, is, and will happen

## Passage of time

- From when you got up this morning
  - Your plan for the day
- To when you get home this evening
  - Future plans
- Reflecting back on the day
  - “Wow, the presentations were great!”

This is so much of what we talk about.

## Imagine waking up and...

- No idea what time it is
- No idea of what will happen today
- No idea how soon something might happen
- No idea of the expectations for what will happen
- Problems detecting the true passage of time
  - “Today the minutes seem like hours, the hours go so slowly, and still the sky is light.”
- Will I like it?

## To start a calendar system

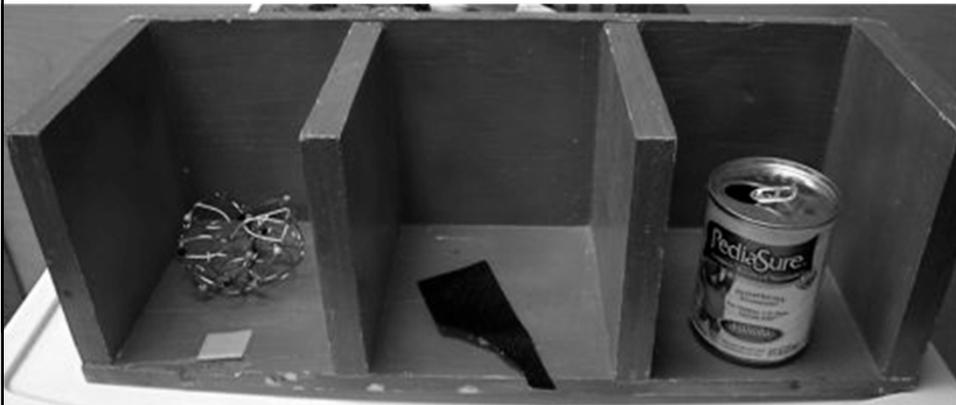
- The child needs to have a communication system of some kind and a plan for its development
  - Objects
  - Pictures
  - Signs
  - Words
- Activity routines must be in place
  - A calendar makes things more predictable
  - So you have to have a predictable schedule



## This is an anticipation calendar

- Two distinctive baskets
- One has an object that represents an activity
- The other is the finish basket where the object will be placed once the activity is done.
- The object may represent “free play time.”
- When the child feels the object, the child knows it is time to go into the play room and do whatever he or she wishes.
- When play time is over, the object will be put in the finish basket by the child.

## A bit more sophisticated



This is a simple daily calendar. It shows a sequence of events.

## Shift planning



## Finished



## Predicting the week



## If each day is distinct or highlighted



## Activity routines



## On the Ipad



## Checking it off and moving to next



## Changes

- There will always be unanticipated changes in routine
- In advance you can
  - Read a social story about the upcoming change
  - Adjust the calendar to reflect the change
  - Talk about it
- When it could not be anticipated
  - Point to the change on the calendar
  - Put it in context for the day – where does it fit in?
  - Communicate about what the change is and what it means

## Communication

- Calendars provide an opportunity for conversation around the schedule.
  - What we are doing now
  - What we are doing later
  - What we just did
- At the end of each shift ideally go through the finish box and talk about what happened
- Life is good with a bit of predictability and review

**“A feeling of worry, nervousness, or unease, typically about an imminent event or something with an uncertain outcome.”**

- You still should consider pain, self-regulation, and changes in routine.
- But all of these can also lead to anxiety.
- Calendar systems and activity routines can reduce anxiety by making life more predictable.



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