



**Saturday, August 3, 2019**

**Breakout Session C17 • 2:45-3:45 pm • Chantilly Ballroom West**

## **CHARGE 103: Communication options and the importance of play and passions in the young child**

**Robert Last, CHARGE Syndrome Association of Australia  
and New Zealand**

**Emma Mayes, Deafblind Services Minnesota**

### **Presenter Information**

Rob Last is a teacher of the deaf who has a long history of working with children who have sensory disabilities, particularly in the areas of hearing and vision. Since the mid 1980's he has been particularly involved with children who have CHARGE syndrome and their families. He has been a presenter at the CHARGE Syndrome International Conferences since 1993, the Australian and New Zealand Conferences since 1994 and the German CHARGE Syndrome conferences since 2012. Rob is a Victorian Director and Director of Outreach for the CHARGE Syndrome Association of Australasia parent support group.

Emma Mayes is a Nationally Certified Deafblind Intervener and has been an intervener for three years. She also recently graduated with a bachelors in education and is a teacher for individuals who are deaf/deafblind/hard of hearing. She has a passion for providing high caliber services to the individuals she works with and has worked with several individuals with CHARGE Syndrome with varying ability levels.

### **Presentation Abstract**

Communication is key to both learning and social interaction. Play is the work of young children. Rob will focus on early communication and behavior and the importance of establishing a meaningful communication system as early as possible. Communication strategies from touch cues, pointing and pictures to sign and oral communication will be presented.. Play strategies will be demonstrated through video, photos and discussion. Emma will talk about optimizing educational settings for inclusive play. A challenge in the education of children with multiple sensory impairments is to help them acquire social skills which other children typically develop incidentally. These skills are needed for successful interactions with others in school and at home. Physical environments must be prepared for ease of movement, use of objects and toys. Staff must be educated so they understand and can help normalize the child's experiences within inclusive social settings (classroom, lunch, recess). Strategies will be presented, including the use of social stories, facilitating communication, teaching social language and norms, guiding appropriate interactions, and using play-based strategies to build strengths and facilitate the most accessible and inclusive socialization setting for the student. If time permits, Rob will present the use of passions in these strategies.

## **Learning Objectives**

- Learn several key features common in CHARGE syndrome
- To raise awareness of the range of communication options.
- To highlight the importance of play and illustrate this through a video presentation.
- To be aware of the educational opportunities by following the interests of the child.
- Meltdowns will be discussed as a form of communication, why these may be occurring and strategies to manage these.

## **HANDOUT FOR ATTENDEES**

**14<sup>th</sup> International CHARGE Syndrome Conference  
Dallas, Texas, USA, 2 – 5 August 2019**

### **CHARGE 103**

**‘Communication, Play and Passions’**

**A co-presentation with Rob Last and Emma Mayes**

#### **Rob Last AM**

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Director of Outreach and Director for Victoria, CHARGE Syndrome Association  
Retired Teacher of the Deaf and Early Childhood Educator  
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#### **Emma Mayes**

Nationally Certified Deafblind Intervener  
Licensed Special Education Teacher  
Email: [emmaikmayes@gmail.com](mailto:emmaikmayes@gmail.com)

#### **Introduction**

In this presentation Rob will be discussing communication, play and passions, including photos and videos to highlight the discussion.

Emma will be discussing strategies to integrate children with CHARGE with their same age peers by using play-based strategies and other strategies, using videos and photos to illustrate.

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#### **Rob Last: Communication**

My primary focus throughout my career has been communication; communication with babies, children, teenagers and adults.

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

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

Even though we know all senses are affected I've always advocated using all senses as a means of providing meaningful information,  
Therefore using visual language and touch cues to support spoken language is incorporated in all my communication.

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

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

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

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

- sign language
- key word signing
- gestures
- touch cues
- body language
- facial expression
- pointing
- mime
- real objects
- symbolic objects
- drawings
- symbolic drawings (Boardmaker, Proloquo2go)
- photos
- reading and writing.

This might be termed 'total communication' or 'multimodal communication'.

### **About Learning Sign Language (Visual Language)**

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

Here are a few suggestions to assist in this process.

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

## **Play**

### **Play with Younger Kids**

Of course play is also communication.

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

sense, that will be understood, that will be fun, that will be interesting and will be rewarding and worthwhile.

### **Heiko and Jonas**

In this presentation I show three movie clips of a Dad, Heiko, and his son, Jonas, The movies shows them engaged in relaxed and pleasurable play.

Heiko uses simple strategies to engage Jonas in play.

The movie is in German so it is interesting to notice how much is understood without understanding spoken German, how much the visual communication explains what is going on.

### **(Movies – Heiko and Jonas)**

So what was noticed about play in the movies?

#### **Movie 1**

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

#### **Movie 2**

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

#### **Movie 3**

- This one depicts more adult directed play
- Heiko takes his time to ensure Jonas understands the game
- He revises the steps to ensure Jonas has every chance to succeed
- He allows Jonas to succeed without adult intervention
- Success is Jonas's reward

#### **Heiko used**

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

- Real objects
- Photos
- Drawings

To engage in successful play the adult must

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

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

### **PLAY - Play is Children's Work**

A parent reminded me to mention that often professionals engage in play without explaining what it is they are trying to achieve and what they are looking for.

Teachers and therapists understand that play is children's work and know that through play an assessment of abilities can be achieved. They note gaps in abilities and use play to teach to those gaps.

In the early years following the interests of the child in play is preferred to maximise the potential for success, which progresses into adult/teacher directed play later.

It should always be:

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

### **Play for Older Kids**

#### **Passions/Obsessions**

We all have them. We are much more content when we are able to engage in our passions/obsessions.

Using passions/obsessions to support learning is good teaching.

These may be through

- Rob – CD collection
- Sean and Bailey – Elevators
- Trent - Technology
- David – Horse riding
- Sarah – Horse riding
- Phillip - Tapestries
- Belinda - Travel

- Ellen – Facebook
- Sean – Caravans
- Julia – Sorting and Organising
- Mitchell – Football
- Sophie – Basketball

(Photos and video to illustrate)

Use these behaviours to:

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

AND

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

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## **Emma Mayes**

### **Supporting social development with peers**

- Preparing the physical environment
- Supporting the student with CHARGE

### **Preparing the physical environment**

- Staff/student inservicing
  - Especially helpful to have PARENTS do the inservicing.
  - Normalizes things like medical, behavioral and physical differences.
    - Peers are often very curious, inservicing helps them resolve their curiosity and reduce inappropriate responses to differences.
    - Explain appropriate medical information. (e.g., g-tube, trache, ears, vision, hearing, glasses, hearing aids, cochlear implants)
  - Helps peers view the child as someone like them
    - Talk about favorite colors, toys, games, foods, places, etc.
    - Make a powerpoint using pictures.
    - Explain visual differences between children.
    - Illustrate similarities

- Share about family, ask about their families.
- Teach peers to direct all questions to the child rather than to the intervener/paraprofessional/teacher when it pertains to the child.
- Work with the teacher to set up routines during morning meeting that the child is able to be involved in.
- Teach peers some signs to use with the child to help engagement and interaction.
- Model appropriate interactions with the child so peers can imitate the behaviors.

### **Supporting the child with CHARGE**

- Use play based strategies to engage peers with child.
  - An informal inservicing for peers about child's communication and play based styles.
- Parallel play
  - Keep children all close in proximity
  - Teach peers how to play with other children with disabilities.
- Peer responsibilities
  - Have a rotating schedule of play time with the child with CHARGE.
  - Have the child choose friends to walk or push them in their wheelchair to different places in the school or out to recess.
  - Child with CHARGE picks a friend to eat with him/her for lunch/snack time.
- Support student partnerships when students are paired up for small group work.
- Guide inappropriate interactions initiated from the child with CHARGE and turn them into beneficial results.
  - Redirect
  - Social stories
  - Humor
  - A "passion" to pull the child back to appropriate interactions
- Playing games
  - Identify child's strengths
  - Make games the child is able to do
  - Invite peers
- Teaching social language
  - SOCIAL STORIES
  - Peers as examples
  - Modeling
  - Role play
  - Practicing interactions
  - Guiding interactions
  - Repeat

### **Take Home Messages**

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



- Find your tribe.
- Use staff/student inservicing to help peers see similarities.
- Use play and interests to illustrate similarities between peers and the child with CHARGE.
- Parallel play is the starting point to initiate play with peers.
- Give peers responsibilities and the child the opportunity to pick a peer to play with as a routine daily.
- Use humor and passions to redirect inappropriate behaviors.
- Create games by building on child's strengths and abilities.
- Teach the social language directly.

**Thank you**  
**Rob Last & Emma Mayes**



Dedicated to Charlize Maree Schifsky

# CHARGE 103

Can we play? Bridging the gap  
between children with CHARGE  
and their peers

Rob Last & Emma Mayes

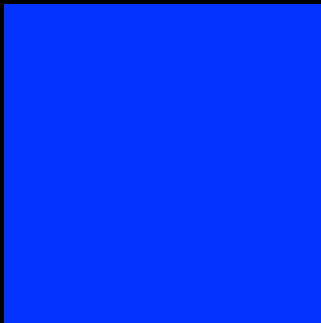
# Preparing the Physical Environment

- Staff/student inservicing/presentation
  - Especially helpful to have PARENTS do the inservicing
  - Normalizes things like medical, behavioral and physical differences
    - Resolves curiosity
    - Reduces inappropriate responses to differences
    - Explain appropriate medical information (e.g. g-tube, trache, ears, vision, hearing, glasses, hearing aids, cochlear implants, BAHA)
    - Try to use pictures of the child to help peers understand and apply information easier.



# Preparing the Physical Environment cont.

- How to set up the inservice:
  - Make a powerpoint using pictures
  - Draw on and illustrate similarities
  - Talk about favorites (e.g. colors, toys, games, foods, places, etc.)
  - Explain visual differences between children
  - Share about the child's family, ask about their families.



## Preparing the Physical Environment cont.

- Teach peers to direct all questions to the child rather than a staff member when it pertains to the child.
- Work with the teacher to set up routines during morning meeting/homeroom that the child is able to be involved in.
- Teach peers some signs to use with the child to help engagement and interaction. (e.g. hi, bye, hungry, thirsty, tired, happy, play, friend, walk, quiet)
- Model appropriate interactions with the child so peers can imitate the behaviors



# Supporting the Child with CHARGE

- Use play based strategies to engage peers with the child.
  - An informal inservicing for peers about the child's communication and play based styles.
- Parallel play
  - Keep children all close in proximity during play
  - Teach peers how to play with other children with disabilities



## Supporting the Child with CHARGE cont.

- Peer responsibilities
  - Have a rotating schedule of play time with the child with CHARGE.
  - Have the child choose friends to walk or push them in their wheelchair to different places in the school or out to recess.
  - Child with CHARGE picks a friend to eat with him/her for lunch/snack time.

\*\*\*General education peers find it incredibly fun and exciting to be a buddy.





## Supporting the Child with CHARGE cont.

- Support student partnerships when students are paired up for small group work.
- Guide inappropriate interactions initiated from the child with CHARGE and turn them into beneficial results
  - Redirect
  - Social stories
  - Humor
  - A “passion” to pull the child back to appropriate interactions



## Supporting the Child with CHARGE cont.

- **Playing games**

- Identify child's strengths
- Make games the child is able to do
- Invite peers



# Supporting the Child with CHARGE cont.

- Teaching social language
  - SOCIAL STORIES
  - Peers as examples
  - Modeling
  - Role play
  - Practicing interactions
    - Use hand-under-hand
    - Your hand under the child's hand, guide from underneath.
  - Guiding interactions
  - Repeat

It is time to be quiet please.



When I think about being loud I need to...  
STOP. THINK. BE QUIET.



Being quiet does not mean singing.



We need to be quiet.  
This will make everyone happy.



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