



Koninklijke  
Kentalis

# On the road together Ensemble en voyage

**CHARGE-conference september 2018,  
Poitiers, France**

22 september 2018 – Esther Keller  
Marga Leefkens

Royal Dutch Kentalis

# Introduction

## Esther Keller

Communication coach for persons with deafblindness, using Video Interaction Guidance

## Marga Leefkens

Orthoptist and Teacher for children with deafblindness with and without CHARGE



# Royal Dutch Kentalis



is a national organization in the Netherlands that has over the last **225 years** specialized in:

Providing **diagnostics, care and educational services** for people who

- are deaf or hard of hearing
- have a specific language impairment
- are deafblind

*Sometimes in combination with an intellectual disability, autism spectrum and/or motor difficulties.*



# Locations

- 38 school(units) for special education
- 80 locations for care and diagnostics
- 6 audiological centres



# Services deafblindness

- Specialized services to deafblind clients
- Staff Training for diagnostics, education/schools and care units
- Cooperation with other organizations for the Deafblind in the Netherlands: DB connect
- Strong linkages with the academic chair on Congenital Deafblindness at University of Groningen, Prof. M. Janssen
- Participation in international exchange worldwide.



# Video Interaction Guidance...

**to improve the quality of interaction...**

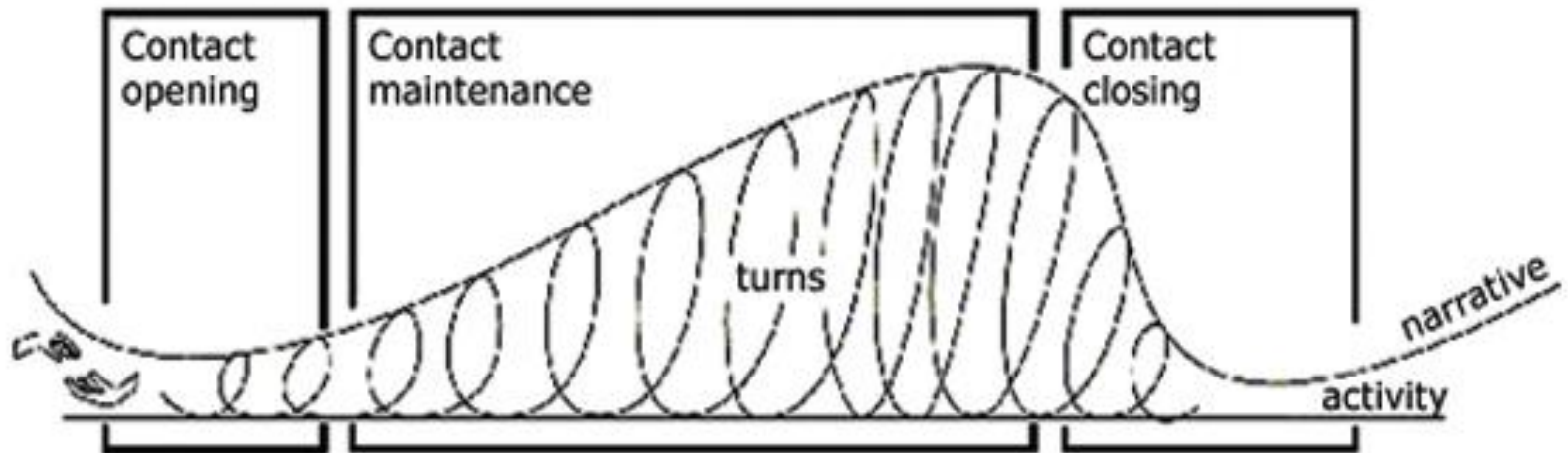
***with persons who have CHARGE-syndrome and  
their communication partners***



# The process of interaction

**INTERACTION MODEL for the DEAFBLIND**  
 Bernadette van den Tillaart 2001

**The Interaction-episode:**





# Questions...

- **What could we do to create the best opportunities for people with CHARGE syndrome to start, maintain and end a conversation?**
  
- **What do we see in someone who is a great communication partner?**
  
- **Is this specific? Or is it a general characteristic we should always keep in mind?**

# Meet R!



# A young boy, having CHARGE...

## His vision:

- Coloboma on the left - not central
- No clear vision
- Details very close (7 cm)
- Sees objects on his right and from below

## His hearing:

- 80 decibel

## No vestibular sense

# Contact!?



- 1. What position? Why?**
- 2. What do I do? What does R do?**
- 3. What is important? What works?**

# R tell us something about...

- **Position !**
- **The right moment**
- **Processing time**
- **Closing contact**

***What do you recognize?***

# The role of vision and touch in joint attention and congenital deafblindness



**Marga Leefkens- van den Broek**  
**Master communicatie en doofblindheid**  
**Rijksuniversiteit Groningen 2015**



# Joint attention

- **What is joint attention?**
- **Why is it important**
- **Dialogicality**
- **The role of vision and touch**

## Video material of the case study

- **D, a boy with CDB due to the CHARGE syndrome**
- **Questions in mind**
- **Analysis**
- **Discussion**

## Results of my study



# Joint attention

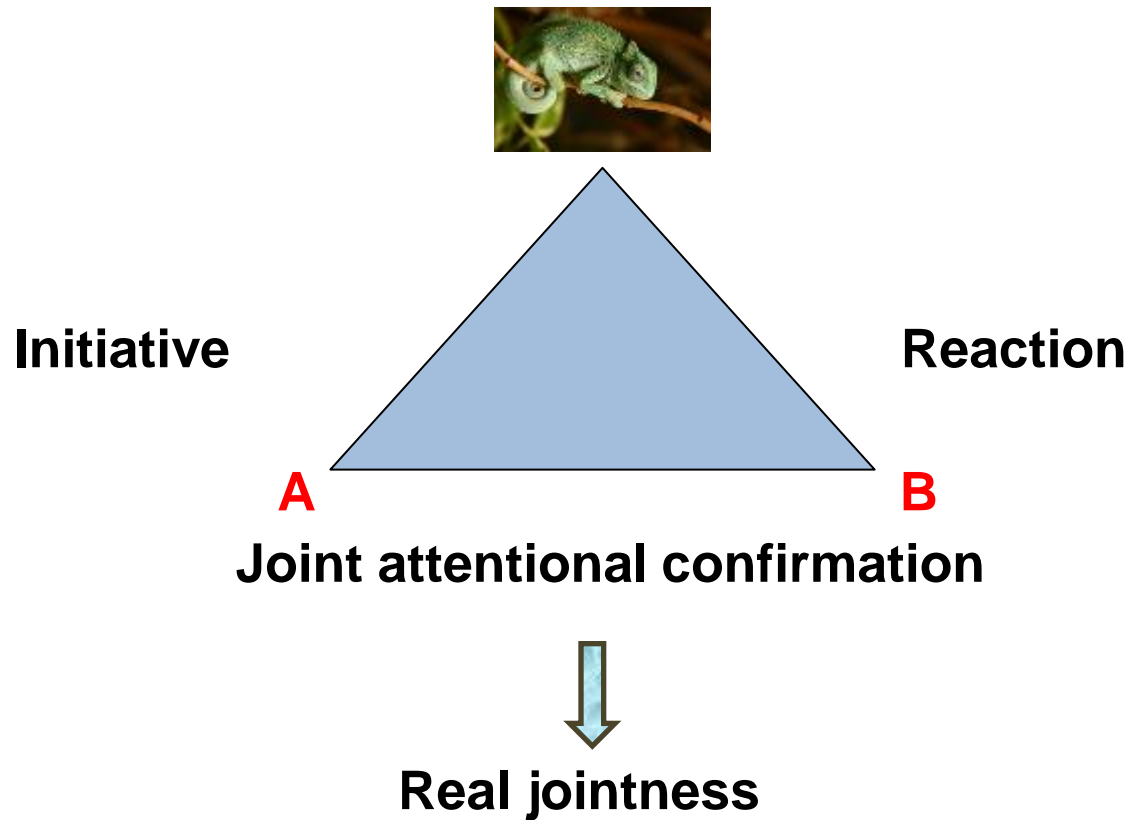
**a triadic interaction**

**show awareness to each other**

**mutual attention to the shared object or event.**



# The joint attentional engagement



Carpenter & Liebal, 2011

# The importance of joint attention

**It makes language acquisition possible**

(Carpenter, Nagell and Tomassello, 1998)

**It is fundamental to social abilities at all ages**

(Mundy and Newell, 2007)

# Dialogicality

**In a triadic interaction (ego-alter-object relation) the child and the social partner are interconnected with each other and they influence each other (Marková, 2003).**

**The communication about the object or event is co-created (Nafstad, 2009a).**

# The role of vision

**Vision is an important channel**

**➡ child is able to read the outer-directedness (Hobson, 2005).**

**Gaze alternation and pointing;**

**Distal senses seem to be important**

**(Tomasello, Carpenter & Liszkowski, 2007)**

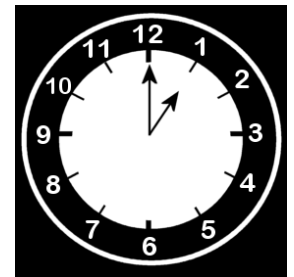
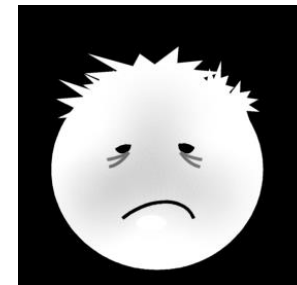
**CDB? ➡ using alternative sensory means (Nunez, 2013)**

# The role of touch (a)

**Residual vision still gives fragmented information  
and it is tiresome to use the eyes**



**therefore social partners need to give time to  
process and to explore the world around  
(Daelman, 2006; Rødbroe & Souriau, 1999).**



# The role of touch (b)

**Children with CDB**

**need tactual conversational practice**

**to become aware of the other directedness**



**Joint Attentional Engagements can arise (Nafstad, 2014)**

**Touch is the most social sense (Nicholas, 2010)**

**Touch can provide a principal source of information (Hart, 2010)**

**Touch- smell- proprioception (Brown, 2012)**

# Communication with CHARGE

**60 % of the children with CHARGE acquire symbolic language:  
spoken language, signs and/or visual symbols**



**problems to remain focused on the topic  
and  
in effective turn taking (Thelin & Swanson, 2006).**

**Early stages of intervention:  
focus on turn-taking, prosody, reciprocal imitation  
and joint attention (Trevarthen and Aitken, 2001)**

# Case study

**Participant: D., a boy (9.5 years)**

**CDB due to the CHARGE syndrome**

**(CHD 7- genetic disorder)**

**deaf and moderate to severe low vision**

**uses the Dutch Sign Language**



# CHARGE syndrome

**D has also:**

**Facial palsy right side**

**His right eye has the best vision**

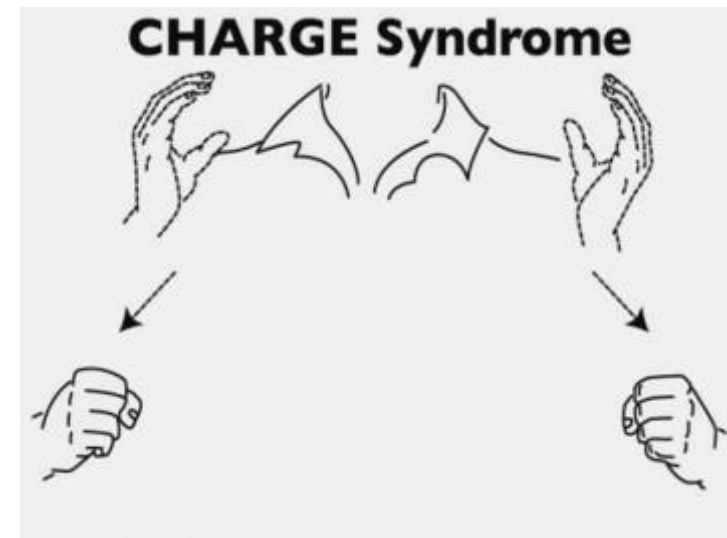
**Nystagmus**

**Low muscle tone/ balance problems**

**Touch can show hyperreactions on some kind of structures**

**Most likely smell is disturbed**

**First year of life operations**



# The purpose of the case study

**The purpose was to find out to what extent this boy will benefit from the tactile modality in a Dutch sign language conversation with his social partner.**



# Video 10

**Title: Can the chameleon grow in the future?**

# Video 18

**Title: The big spider**

# Results of the case study



**CDB effects the possibilities to share the attention in the joint attentional engagements**

**Analysis shows that the use of touch is needed**

# Results of the case study

## The tactile modality contributes to the joint attention episode

- **Use of the tactile modality leads to more climaxes and more emotion**
- **Increase of real jointness**
- **More meaning**

# Discussions and conclusions

**The joint attention episode can be deepened**



**Analysis shows that the use of touch**

**is needed to maintain the topic**

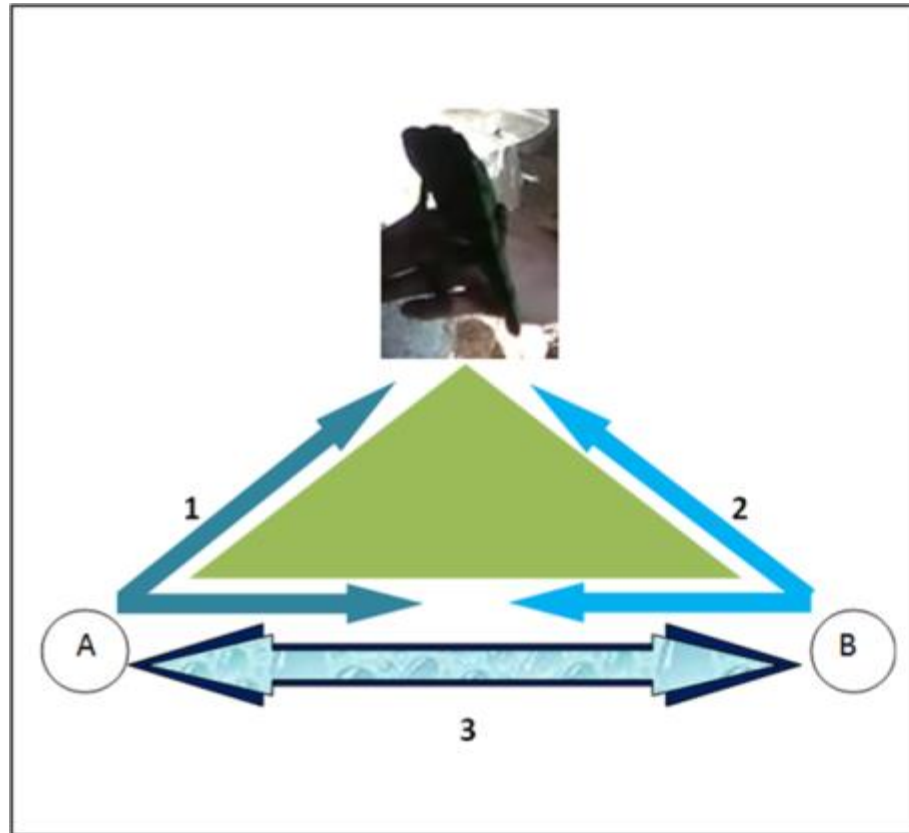
**and**

**create balance**

**in conversational turn-taking**

**Recommendations for further research**

# Results of the master study



Picture of Carpenter & Liebal, 2011, adjusted by M. Leefkens, 2015





*'A joy that is shared is a joy made double'  
 'A shared sorrow is half a sorrow'*

To effectively communicate, we must realize that we are all different in the way we perceive the world and use this understanding as a guide to our communication with others.

Tony Robbins

quote fancy



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# Thank you for your attention

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