

<p>On the road together/ Ensemble en voyage CHARGE-conference september 2018, Poitiers, France Esther Keller en Marga Leefkens, Royal Dutch Kentalis</p>
<p>Esther Keller Communication coach for persons with deafblindness, using Video Interaction Guidance</p> <p>Marga Leefkens Orthoptist and Teacher for children with deafblindness with and without CHARGE</p>
<p>The 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</p> <ul style="list-style-type: none"> -are deaf or hard of hearing -have a specific language impairment -are deafblind <p><i>Sometimes in combination with an intellectual disability, autism spectrum and/or motor difficulties.</i></p>
<p>Locations</p> <ul style="list-style-type: none"> • 38 school(units) for special education • 80 locations for care and diagnostics • 6 audiological centres
<p>Services Deafblindness</p> <ul style="list-style-type: none"> • 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.
<p>Esther: Video Interaction Guidance</p> <p>In the past fifteen years, I have met several children and youngsters with CHARGE syndrome, mostly in their residential homes with their caregivers. Working as a caregiver myself, I learned to be a trustful and interesting communication partner to persons with CHARGE syndrome. Later on I became a communication coach to support communication partners working with people with deafblindness and I received my certificate for Video Interaction Guidance.</p>
<p>Video Interaction Guidance gives me the opportunity to watch video's of communication partners and persons with complex communication needs. We watch a videofragment together, then we analyze step by step what is happening. We watch specific elements, which are important to reach successful contact.</p> <p>Every contact starts with getting attention. Do you notice me? Are you able to let me know that? How?</p> <p>To get started, we all have to be at a certain distance to be able to communicate effectively with others. To take an initiative and, on the other hand, to be able to notice the initiatives of the other person, to be able to follow.</p> <p>In the first turns, we talk about contact-opening. If we start effectively, we will be able to continue in a way both partners can join equally. And if we attune well, there will be emotional involvement (you see the curve) and we built up a narrative. We will be able to end the conversation if we both have the chance to understand there will be an ending.</p> <p>So... To get a better view on what is needed, caregivers and I analyze opening, maintenance and closing of contact. I have a video for you of a young boy –R- and myself, which can be helpful to discuss what should be added to improve the quality of interaction specifically for the persons with CHARGE.</p> <p>Contact opening: Do we have attention for each other? How do we attune? (affective, motoric, cognitive, communicative)</p>

The process of interaction:

How close do I have to be?

When is the other person able to react? How long do I have to wait?

Contact maintenance:

Observation, imitation

Breaks (wait for reaction, processing)

Turn taking

Variations, new elements

Creating rituals, routines

Evoking, sharing emotions

Involving a 3rd element

Tactile participation (Hand under Hand Exploration)

Contact closing:

Give notice of a soon end

Ending ritual

Closing clearly

(may be) staying available

Giving time for processing

Observing (BET`s?)

Accepting the ending of the db p

Questions:

We see a lot similar in other persons with deafblindness and also other people with complex communication needs, but are there more specific, unique conditions the communication partner needs to have, to benefit the person with CHARGE?

What specific characteristics of the CP are needed to come to the best conversations for persons with CHARGE? This brings us to some questions...

This is R!

He is a young boy, 5 years old.

He has problems with breathing (gets oxygen).

He has a tube for feeding.

Physically still very vulnerable. Very sensitive!! He is quickly over-stimulated!

Coloboma on the left, this has not attached the centre of the retina.

Cataract, his lenses are removed. Also nystagmus. So, he does not have clear vision.

He can see details at about 7 centimeters when we already can see them on 1 meter.

He can see objects on his right and from below.

His hearing: he reacts a little bit at 80 decibel. He is very sensitive around his ears. Therefore he doesn't want to wear his hearing-aid.

No vestibular sense.

I was wondering what specific conditions persons need who are so specifically challenged in their lives to overcome their multi-sensory problems. David Brown has learned me a lot... I used his information and asked him feedback on my ideas last year in Aalborg, Denmark...

You are so right, was what he told me! These items need our specific attention to give best opportunities to achieve good contact. Good contact voor experiencing the world, for learning, for development. But one is far most important for persons with CHARGE: position!!

Thank you for your attention and feedback!!

Marga: The role of vision and touch in joint attention and congenital deafblindness

This handout is without the stillframes and video's

The main topic in my Master study at the University of Groningen is joint attention
So I first like to explain what joint attention is
Why it is important and what dialogicality has to do about it
then I will tell what the role of vision and touch is in the joint attentional engagements
After that, we will watch the video material of my case study of D,
A boy with congenital deafblindness due to the Charge syndrome
I will give you questions in mind and we can have a discussion about the answers
Then I will present the results of my case study

Joint attention can emerge in a triadic interaction
if the child with CDB and his social partner both show awareness to each other
about having a mutual attention to the shared object or event.
To perceive the awareness and mutual attention,
analysis of the EXPRESSIONS will lead to recognize episodes of joint attentional engagement

In this figure the joint attentional engagement is shown: you see, person A and B and a chameleon (the object)
Person A takes an initiative to person B about the chameleon and person B reacts
Hereafter they share their attention and they become aware of each other's subjective attention
Carpenter and Lieball describe this sharing look as bidirectional
and this is where the joint attention truly emerge.
Hobson states that joint attention entails more than merely recognizing another person's attitude.
The real jointness means *feeling connected with the other person* and this contains the most communicative enjoyment

Joint attention is important because
IT make language acquisition possible (Carpenter, Nagell and Tomasello (1998)
((By creating a shared referential framework in which the children may experientially perceive the language used by adults.
For example when a child points to a little thing in the pond his parent can explain what the child sees and so the child learns that that little thing in the pond is a duck which can swim))
Joint attention is fundamental to social abilities at all ages

In the light of the dialogicality theory Markova describes that 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).
And Nafstad describes that the communication about the object or event is co-created (Nafstad, 2009a).

The role of vision: According to Hobson vision is most important channel by which the child is able to read the outer-directedness. (Hobson, 2005 p 201/ 202)
Gaze alternation and pointing are fundamental abilities upon which the joint attention behaviour develops (Tomasello, Carpenter & Liszkowski, 2007).
Children who have good vision and good hearing can follow the gaze of their social partners and at the same time listen to the comments about the third elements. So for the emergence of joint attention the role of the distal senses seem to be important.
Therefore it might be assumed that deafblindness effects the development of joint attention
Results of a recent study of Nunez (2013) showed children with congenital deafblindness spontaneously engage in joint attention by using alternative sensory means. Because multisensory experiences in interaction can generate a better understanding of children with CDB

The role of touch (a): In case of total blindness the visual perception of the other's intention is absent.
If the child has residual vision this 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): Nafstad explains that Children with congenital deafblindness need tactual conversational practice to become aware of the other directedness and so joint attentional engagements can arise (Nafstad, 2014)

Nicholas showed that touch is the most social sense, and it provides us with fundamental means of contact with the external world.

In the regulation of our emotional wellbeing interpersonal touch is fundamental. Therefore in this study we focus on the role of touch. Since children, like any other human being, use their hands to manipulate objects, it is often assumed that these hands are the main source of information, however all things we do, whether it is something simple as sitting down or feeling cold, rely on touch (Nicholas, 2013).

Hart recommends that social partners should look for the possibilities where touch can provide a principal source of information about the world around people with congenital deafblindness.

(instead of considering CDB as a negative state, where the lack of vision and hearing only hinders (Hart, 2010)).

Brown adds that, besides the sense of touch, also smell and proprioception play an important role in the world of deafblindness (Brown, 2012), although these two might (partly) be disturbed in case of the CHARGE syndrome.

Communication with Charge: About 60% of children with CHARGE syndrome acquire symbolic language and communication with spoken language, signs, and/or visual symbols. The children who use symbolic forms often have problems to remain focused on the topic and in effective turn-taking (Thelin & Swanson, 2006).

Trevarthen and Aitken (2001) state that explicit focus on for instance turn-taking and joint attention might prove particularly effective, at least in early stages of intervention

D.: In my case study analysis have been made of the interaction between D. and me, as his social partner, during a real life event. (p 29)

D. is a boy with congenital deafblindness due to the CHARGE syndrome (caused by CHD7 genetic disorder)

He is deaf and has a moderate to severe low vision (with glasses).

For communication he uses the Dutch sign language (with pictograms for augmentative support).

He visits the Royal Dutch Kentalis Guyotschool

Happy boy, full of energy and interested in the world around him and eager to learn
can't stay on a topic for a long time and taking turns is difficult

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

D. and me went for a visit to a ZOO and the tour guide Tim showed us all kind of animals.

A cameraman made video recordings of the sign language conversations.

It was specially planned to use the tactile modality complementary to the Dutch sign language.

Of all the video material 8 video sequences were transcribed and analyzed and the focus has been on the dialogical framework.

To perceive the awareness and mutual attention in the joint attentional engagements

Analysis of ALL the expressions had been made.

Not only visual and vocal behaviour but also

<p>Sign language, body movements, touch and facial expressions has been analyzed. The purpose in this case study 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. Today I like to analyze the videos together with you and discuss what can be influenced by the CHARGE syndrome</p>
<p>In the first one the joint attentional engagement is about the question: Can the chameleon grow in the future? First I will show you the video and here after we will look to some of the still frames I would like to show you the other video. And the joint attentional engagement is about the question: The big spider In the video first the real spider walks on the hand of D. and me, Hereafter we communicate about this experience</p>
<p>Results: In all Analysed 8 sequences the Joint attentional confirmation is created; The boy and social partner show the awareness to each other and have mutual attention to the shared object/ event The strengths of the boy as well as the strategies of the social partner both contribute in establishing these joint attentional confirmations Because the boy needs more expressions to explain what he wants to know when he takes the initiative or when he reacts it can be assumed that his low vision and deafness effects his possibilities to share the attention Analysis of the functional use of vision and touch in the visual sign language conversations shows that touch is needed when the complexity of the conversation increases.</p>
<p>It can be assumed that due to the deafness of D. it is impossible for him to take note of the object/ animal and at the same time to register the sign language of the social partner. Also as a result of his visual impairment he fails to see visual information when the complexity of situations increase. So his congenital deafblindness, as well as the CHARGE syndrome, should be taking into account during the joint attentional engagements. Narratives and the use of the tactile strategies contribute importantly to the emergence and maintenance of joint attention in communication. Moreover the use of the tactile modality leads to more climaxes and more emotions in the joint attentional confirmation, which might be called a deeper joint attention. The real jointness can be observed in the 'Yes, yes, yippee moments' during these joint attentional engagements.</p>
<p>Analysis shows that the use of touch is needed to maintain the topic and create balance in conversational turn-taking. →Coming back to my main research question: The use of narratives and the tactile modality was helpful for maintaining the topic in the joint attentional engagements. This is also supported by the literature study and the outcomes of these analyzes underline the importance of the use of the tactile modality in combination with the Dutch sign language</p> <p>This case study points at the importance of further research on this topic and it is recommended to organize a tactile sign language course with focus on communicative connectedness for the social partners of this boy. Despite and or due to the charge syndrome: The use of the tactile modality clearly contributes to deepen the joint attentional engagements.</p>
<p>Analyses of the data shows that the joint attentional confirmation is created in all eight sequences: the child as well as the social partner show awareness to each other and have mutual attention to the shared object/ animal or event. However, always more than two turns were necessary before the joint attention confirmation</p>

could emerge.

This is why the picture of Carpenter and Liball is adjusted

Person A can initiate the attention (1) to the object and/or to the other person. Person B can either react (2) to the object or to the other person. The two arrowheads at the arrows 1 and 2 indicate that the person with CDB during his initiative or reaction needs time to 'switch' between the object and his social partner, because *as has been shown in the results of the case study* the boy with CDB needs more turns and uses more total expressions.

In the joint attentional confirmation (3) the two arrows relate to the fact that both persons can either have the same reaction or they add their own response and this can lead to a kind of flow in the joint attentional engagement as discussed in the results. More climaxes can emerge and more emotion has been seen in case the tactile modality was involved.

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