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DbI's Network on Communication and Congenitally Deafblind Persons

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Report
International Course
on
Communication and Congenital Deafblindness

Vilnius May 25-28, 2000
Lithuanian Centre for the Blind

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1. PROGRAM

OPENING CEREMONY

This session was opened by the Vice-Minister of Education, in presence of the Head of Special Education Department of the Education Ministry. It was an opportunity to focus on the problems of children with multiple impairment and on their needs. The format for training teachers in Special Education in Lithuania was described.

The two directors, Mr LERCH from the CNEFEI and Mrs DAUJOTIENE from The Lithuanian Centre for the blind, presented their centres and their collaboration in this project. Mrs KAKLAUSKIENE from Socrates Agency in Lithuania presented all the European actions in Lithuania about education, and the new programs. A journalist, from the special press for the blind, was present and posted a press release in his periodical.

AWARENESS LECTURES

These lectures were offered to the 20 participants of the Socrates Comenius Program (8 countries) and to 29 persons from Lithuania. The texts of these two lectures are included in this report:

- « Introduction to Deafblindness » by Jacques SOURIAU
- « Co-creating communication with persons with congenital Deafblindness" by Anne NAFSTAD and Inger RØDBROE.

SEMINAR

20 participants from Estonia, Poland, Russia, Hungary, Czech Republic, Romania, Slovakia, and Lithuania.

Three sessions of video analysis led by Anne NAFSTAD and Jacques SOURIAU helped reach three aims:

1. Improvement of knowledge about communication with congenitally deafblind children (CDB).
2. Development of a method for video-analysis to observe interactions with congenitally Deafblind persons and to improve communication skills of the professionals.
3. Establishing a network in Eastern and Central Europe in order to collaborate with other networks working on the same topic in other parts of Europe.

2. Report on the contents addressed during the Seminar

The contents of this Seminar are based:

1. *-on the lectures presented by the two co-leaders of the Seminar,*
2. *-on the results of the video-analysis sessions. All the participants brought video-clips illustrating aspects of their work with the CDB in their organisation. These video-clips reflect what is actually done by the participants in their daily practice.*

The main aspects which were addressed during the session are summarised in the following text which was co-written by the members of the DbI Communication Network:

> **Communication is a pre-requisite**
> **for learning,**
> **for developing,**
> **and for being a human being.**

Interactions as sustained exchanges

The taped sequences that the participants brought to the seminar were all portraying a child with congenital deafblindness involved in ritualised but playful interactions with a teacher. The group agreed that interaction was sustained throughout the focused sequences in all the cases. The fact that these interactions were sustained was considered a key point and led to investigating two questions:

1- Why is it important for an interaction to be sustained?
- Because it prevents loneliness.
- Because it gives access to other people's world
- Because it takes time for an interaction to become coherent.

2- What are the conditions for an interaction to be sustained?

2.1 -Tuning.

It is important for the adult to adapt to the child's rhythm, tempo, focus of attention, emotions and movements. At this level, the adult does not look for meaning or interpretation. The purpose is to connect oneself with the dynamics of the child's action.

2.2 -Availability.

The adult has to react to the child's movements by following the child's initiatives or challenging them and by playing with closeness and distancing. It means imitating or complementing the child's

movements and intervening only when the child is losing his attention. The opposite of availability would be intrusiveness. Availability prevents the child from withdrawing.

2.3 -Establishing predictability (and surprise).

Imitating the child, being contingent, repeating with small variations the responses to the child's initiatives, provide him with a sense of predictability. The child feels that the partner's reactions can be somehow anticipated, so that he can go trying on playing. Predictability brings a sense of coherence, and to a certain extent, a first hint of "meaning". This predictability can also be experienced through more complicated games offered by the adult on the basis of the repertory of games proposed by the culture and previously experienced by the adult when he was a child. Predictability implies variations (improvisation), but also "surprise". When the rules of a game are well established, the child can enjoy very much to be challenged with a bit of unexpected reactions of the adult (for instance, delaying a movement, or changing a location). These "surprises", as long as they are embedded in a predictable pattern, not only do not break the interaction, but also provide the child with more playful emotions and a better understanding of the rules of the game (by contrasting the expected with the unexpected).

2.4 -Offering a cultural pattern for communicative development.

Through the games based on bodily experiences, some aspects of the communicative patterns are developed: turn taking, sustaining attention on a topic, taking initiatives to trigger the partner's reactions.

Dyadic vs. Triadic interactions

So far, when considering how an interaction can be sustained, we have mainly thought of situations when the interaction is based only on the two partners' bodies. Introducing an object in the interaction can be the occasion for transforming a dyadic relationship into a triadic one… This triadic exchange involves three elements: the child, her/his partner and something they communicate about. This element is external to the strictly here and now dyadic interaction. It can be an object, a part of the body, a gesture or the memory of a previously shared experience. Of course, this third element could be an object which is used by both partners to maintain the attention towards each other to go on playing. But it is not always an object, and using an object does mean that the interaction is triadic since it could be only parallel.

In the videos that were analysed during the seminar, most of the rituals were organised as joint interactions with an object, whereas a few were "face to face" interactions, that is when the participants relate to each other directly. However, when the interactional routine involves an object, it is difficult to discover if there is joint involvement in the interaction with the object, or whether this is a parallel involvement.

In the first case, the partners will be sharing the experience of the interaction, the focus is then on the experience of sharing and not on the object related action. In the last case, the focus is on the object more than on the social interaction as such. When the two partners are directly responding to each other, without contemplation (which means without thinking about acting) or acts of interpretation (i.e. commenting), the interaction is dyadic. It involves only the two persons. Dyadic interaction (i.e. mutual responsivity and sensitivity) was most easily observed when there was no object involved.

The integration of the object related action into the shared interactive space is difficult as there is a risk of parallel and not joined involvement. However, in several sequences, we were able to see an emerging triadic pattern of interaction (i.e. where the child directed the attention of the adult to a particular location outside the dyadic space, indicating the motivation to share some aspects of his experience having to do with that location (i.e. the location of eating movements in the banana sequence). And there were instances where the child was able to join the adult in sharing her attention to a particular location of an event inside the dyadic space. So we can distinguish between three different exchange patterns:

1- Dyadic mutual exchanges (improvisation: no object, no interpretation). The sequences are sustained by improvisation for both partners.

2- Parallel exchanges involving objects. Parallel exchanges are not negative, but their function is not to sustain interpersonal involvement, but to sustain proximity. E.g. giving massage with an object can be a sequence of playful triadic interaction. But it can also be a way to be together, a way to sustain proximity and to explore experience. So it is important not to see sequences as good or bad, but to identify their functional patterns. Sometimes, patterns that are organised as social interactive play function as such. Sometimes, they function as co-regulation of proximity, distance and exploration.

3- Triadic exchanges. They do not necessarily involve an object. A third element can also be a gesture, (an emotional expression) that takes on the function of a communicative and contemplative sign, i.e. it is separated from the cause of external interaction. In fact, the third element is not an aspect of the external world, it is a mental unit, an image, an idea. To begin with, it is an enthusiasm that is shared.

We saw the formation of the third element, an idea, represented by a gesture in one of the sequences. The girl was FORMING the image, the bodily experience of eating a banana. The gesture indicated that the idea was not on the banana as an object of possible consumption, or on eating as consumption, but on the experience of chewing and swallowing the banana, a kind of pride, so the child was acting as if she wanted to share with the teacher the pride in discovering her eating of the banana, her enthusiasm in relation to a bodily event.

We have observed this tendency before. When congenitally deafblind children attract the attention of the other to herself, and subsequently to a third location outside dyadic space, that space tends to be their primary experiential space, i.e. the bodily space. Certainly, CDB can become very attentive to what is happening, not only on their skin, but also inside the body.

In most of the taped sequences, we cannot observe that the child was forming gestures indicating that the experience of the interaction was rich enough to trigger image formation in the form of reminiscences and expectations.

The gestures were mimetic in the sense that they emerged directly out of the interactional experience characterising some emotionally charged motions and locational aspects.

The gestures that were identified in very many sequences represent a potential for co-creating shared meanings and shared vocabularies. This potential was only to a small degree utilised.

The group discussed how one could proceed to turn these gestures into communicative and interpretative symbols, i.e.: semiotic (but not linguistic) signs.

The tendency of adults not to see the gestures is not an indication of a lack of sensitivity, but an indication of how culture shapes the selectivity of the perception. In other words, we see what we look for. So, what we need to do, is to change our perception, from being adapted to recognise cultural similarities, to recognise gestures that we usually do not recognise. In order to do that, we need the video and adequate theory. Sensitivity does not solve the problem.

So, what we have to do first, is to discover the mimetic gestures. Next, we have to decide what function to provide them with. Since they typically do not have a socially directed function, we can decide what function to provide them with. We can turn them into signals. Or, we can turn them into symbols. The first is simple. It means that we interpret the gesture as a request signal for an object, or an object related action, i.e. if the child hits his head, and this is the opening phase of a "song", we may act in one of two ways: we may interpret the gesture as a request signal, as an opening phase in a fixed sequence, and we may then start to sing the song contingent upon the touch gesture.

In order to turn it into a symbol, we do the opposite. We refrain from acting and fill the empty space with "talking" (hopefully also thinking). Very often this is based on mutual imitation. To begin with, these empty spaces cannot be too long, they are like parentheses within sequences of interaction. Of course, communicative interaction can also be ritualised like a pattern, a kind of game. The child can learn the patterns of the game as he learns other games.

The video, which is published in addition to this text, will illustrate the concepts addressed here.

3. Lecture 1: Introduction to Deafblindness

by Jacques SOURIAU[1]

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History

Deafblind education started during the second part of the XIXth century, with the exception of Victorine Morisseau who was a student of the Paris school for the deaf at the end of the XVIIIth century (Collins, M.T., Zambone, A.M. undated). In these times, deafblind children were known as kind of individual heroes as well as their teachers. Among them we can mention: Germaine Cambon and Marie Heurtin (Arnoult, L. 1948) in France, Helen Keller in U.S.A., Ragnhild Kåta in Norway, and Olga Skhorokodova in the former Soviet Union. These first experiences of educating deafblind children usually took place in schools for the deaf or for the blind and were very much inspired by the philosophies and methods of these institutions. Besides, only «educable» children were entitled to benefit from these first successful attempts of education.

A big change happened forty years ago when, in the so called developed countries, many children were born with congenital rubella. Most of these children were not any more «educable» than the ones before. They displayed learning difficulties and challenging behaviors which prevented them from benefiting from the methods of education which were used before. New approaches were developed which were partly inspired from the education of the deaf or of the blind children and also from the discoveries emerging from the developmental psychology field.

So, from 1860 up to 2000, a lot of changes occurred in the way deafblind children education was thought of and implemented; besides, each of the various schools or institutions dealing with this specific handicap developed their own approaches, with a lot of things in common, but also with their own excellent or weak points. But, before going on with commenting this evolution and describing the state of the arts, it is necessary to explain who are the deafblind people.

Definition and categorisation

In 1990, during the IAEDB conference (International Association for Education of the Deafblind, since renamed Deafblind International: DbI), a resolution was unanimously passed, stating that the spelling of deaf-blind would be changed to a single word: deafblind. This decision was meant to stress the fact that deafblindness is a unique handicap which is more than the addition of deafness and blindness. It is an ongoing concern for deafblind people, families and professionals to ensure that deafblindness is

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recognised as a separate disability and that it requires specific approaches and services. This recognition has to be expressed in laws or administrative rules, but also in the actual way provisions and education are organised. Most of the definitions state that deafblindness does not necessarily imply that the person is totally deaf and blind. Usually, being deafblind means:
- both visual and hearing impairment,
- which generates functional consequences
- that necessitates specific approaches which cannot be reduced to the methods usually used for the deaf or for the blind.

Nowadays, a lot of attention is given in developed countries to low incidence diseases or handicaps. This does not mean that the uniqueness of deafblindness is due to the low incidence itself, but to the fact that this separate disability requires specific provisions. For example, in France, deafblindness has been recognised as a specific handicap because it meets two criteria: low incidence and specific methods.

The fact that deafblindness is a separate disability does not mean that it is not heterogeneous. Usually, we describe four main categories:
- People born deaf and blind
- People born deaf becoming blind
- People born blind becoming deaf
- People becoming deaf and blind.

This kind of categorisation accounts for the time of occurrence of deafblindness. Other parameters could be used: degree of hearing loss and visual loss, existence of additional disabilities, causes of Deafblindness (for example: prematurity, Rubella, CHARGE Syndrome, Usher Syndrome, CMV and...unknown) etc. This creates a variety of situations which necessitates a lot of individual planning.

Nevertheless, deafblind people have in common a high risk of lack of communication and social contact, and, as regards communication, a big difference is observed between congenital and acquired deafblindness.

Acquired deafblindness vs. congenital deafblindness

There is a very big difference between people who were born with a double sensory impairment and those who acquired it later on, that is after mastering the use of language for communicating and thinking. All people with acquired deafblindness have an experience of communication, and more precisely, of communication through language. When losing their vision, or their hearing, or both, they experience the deterioration of the conditions through which communication could be experienced normally. They also experience how simple aspects of their daily life become more and more difficult. This new situation triggers both depressive reactions and attempts to overcome all these difficulties.

I will illustrate the situation of people with acquired deafblindness using the example of people with Usher Syndrome, one of the most common causes for acquired deafblindness. People with Usher syndrome are

usually born with deafness and lose their vision progressively due to retinitis pigmentosa. In the type 1 form, they experience first a narrowing of their visual field and a total blindness in poorly lighted contexts. Their daily life is affected by the fact that they have to stop activities like driving, which reduces a lot their autonomy, and have to learn new mobility skills. Sometimes, they cannot go on with their hobbies or sports, and have to develop new ones which are more adapted to their declining vision (for instance, football is no longer possible, while swimming or tandem are). Keeping one's job can also be difficult and requires a lot of energy, not only for implementing the tasks required by this job, but also for travelling to the working place and participating in the professional social life.

They also have to change drastically their communication habits. When they still see, but through a very narrow visual field, they have to ensure that the people they talk with are located at the right distance (so that they can see all the signing or lip-reading space) and in the right lighting. In poorly lighted contexts, they may have to rely on tactile sign language (and tactile guidance) in order to understand what they are told. All these adaptations mean a totally new life and an ongoing fight for maintaining social contacts in spite of the difficulties in sharing activities with others and communicating with them.

Communication is of course, for them, a major issue. Changing from visual sign language to the tactile one is not technically difficult, learning Braille is more demanding. But the problem is less practical than psychological. Using tactile methods or a cane for mobility is felt as a move to the world of the blind, that is a change of identity, which can be very painful. It is necessary to respect the specific way each person with Usher Syndrome will adapt psychologically to his/her new situation and accept that sometimes, the use of new methods for communicating or of technical aids are differed, although they could help a lot, from a professional point of view.

It is important to stress the fact that people who become deafblind tend to go on using the method of communication they are familiar with. Blind people becoming deaf will often try to use Braille, a system they know well, for new purposes, for instance to have conversations. And deaf people becoming blind will use sign language, but in a tactile way.

Among the people with acquired deafblindness, it is necessary to mention the case of the elderly. Actually, it can be an aspect of getting old to lose progressively vision and hearing. These people can be considerably helped by better lighting, technical aids for hearing and staff and family members mastering better communication skills. Deafblindness in old age concerns many people, but their specific problems very often go unnoticed. Obviously, people with acquired deafblindness have to face an extremely challenging situation as far as communication and social life are concerned.

Nevertheless, congenital deafblindness is even more challenging, because the development of the more basic processes require very specific skills from the families and the carers.

Evolution of concepts and methods in deafblind education

- Before Rubella -

As I mentioned before, the aims and methods of education changed over time since the XIXth century. This evolution reflects changes in the specificity of the deafblind enrolled in the programs and in the scientific knowledge and paradigms that developed in the field of researches concerning communication and language development. In order to illustrate these changes and to picture more precisely what is going on nowadays in our field, I will try to present an overview of the history of deafblind education.

The descriptions of Helen Keller's education implicitly support the idea that communication started in her life when she understood for the first time that the word "water" fingerspelt in her hand by her teacher Ann Sullivan was related to the water running on her hands. This event was a breakthrough in her life since from that time, her language developed rapidly as well as her knowledge of the world. This way of describing the development of communication in Helen Keller has been criticised by M. Mesheryakov in his book "Awakening to life" (1979). First of all, Helen Keller was not deaf and blind from birth, but from 18 months of age because of ... This has been seen as very early, since deafblindness occurred before the acquisition of language. However, we know now that during the first one year and a half of life, a lot of communicative competencies are developed (for instance: turn taking, joint attention). Besides, Helen Keller education by Anne Sullivan started only when she was eight. Before that she was partly a difficult child because she missed a lot of information about the world and she could not make herself understood by other people, with the exception of Martha Washington, the cook's daughter who was her playmate. The two little girls were able to play and communicate, inventing a sign language of their own. Helen Keller mentions that she felt that other people moved their lips, but she could not make out what it meant. So, during the first months of her life (before becoming deafblind) and through her experience with Martha, Helen Keller had probably acquired all the skills for communicating (the dialogic competency), except the language of her country. What Helen Keller learnt with Ann Sullivan is that the English language can be used for communication.

The example of Helen Keller illustrates the fact that we often think of communication as the capacity to use language. We even tend to reduce the concept of communication to acquisition of a vocabulary. This way of thinking has often been implicitly used in deafblind education by the families and the professionals. It reflects the fact that in our culture, language is so pervasive and dominant, that it is very difficult to imagine that communication could be implemented in other ways.

Another example, belonging to the story of another deafblind child, born in France, will illustrate another restrictive conception of communication. Marie Heurtin was a little girl born totally deaf and blind. Her education started in the Institute of Larnay in 1895. Her teacher noticed that she liked very much to play

with a little knife. She used to tease her by taking the knife away from her, and then she formed with her hand the word «knife» in sign language before giving it back. When for the first time Marie produced by herself the sign «knife» for asking for it, it was seen as her first communicative act. By the same token, many teachers or family members tend to see communication as a capacity for requesting. Of course, requesting is one of the functions of communication, but it is very far from being the only one, or the first one, or even the most important one.

These two examples illustrate a tendency, not only in laymen, but also in professionals or scientists, to reduce communication to using language for requesting. This conception (although incomplete) did not hinder the development of Helen Keller or Marie Heurtin, since they acquired through other ways, the other skills that are necessary for communicating with other people. New problems emerged when new challenges arose with new kinds of children.

- After Rubella -

When the education of rubella children started around 1970, professionals discovered that these children, although very often they were not totally deaf and blind, had many difficulties in learning how to communicate. Most of them had to go through heavy medical and surgical treatments during the first months of their lives, they had a low birth weight, and had difficulties with fine and gross motor activities. They were also known for displaying a lot of stereotyped behaviours like light gazing, eye poking, hand waving before the eye, rocking, etc. Because of these behaviours, professionals and families had the impression that these children lacked attention, motivation for the activities proposed by the carers, and interest for sustaining communicative interactions. In order to overcome these problems, professionals tried to find methods allowing these children to be more involved in other activities than stereotyped behaviours, to form symbols and to use them for communicating. The Rafael department in the Sint-Michielsgestel School for the Deaf (the Netherlands) was, at that time, very active in experimenting with new approaches and an example for many institutions in western countries. Among many aspects of these new approaches, I will mention a few ones. First, it was seen of the utmost importance to ensure that events should be carefully organised in space and time so that children can have an overview of their own life and anticipate activities and people's presence. Anticipation was a master word. This structuration of space and time of activities was also expressed through symbolic tools like calendars representing the various elements of the children programs. Various symbolic tools were used: objects of reference, visual or tactile pictograms, gestures and fingerspelling. These tools were used in connection with the activities so that they could progressively signify them or elements of them. Another important idea was that children can build representations on the basis of movements. So, motor activities (and very often gross motor ones) accounted for a large part of the programs. They could be natural ones (e.g. swimming) or more artificial (e.g. chained movements performed in strict order in a special room). These activities based on movements help the children to categorise events, to anticipate them and to connect them with symbolic tools.

Conditioning and learning theories were also very much used to design the teaching procedures. Children were felt as lacking motivation and professionals were looking for possibilities to make children engage in activities and learning. The use of reinforcement and the analysis and division of tasks and behaviours actually gave a basis for presenting the children with tasks they could actually learn. These tasks could concern autonomy, communication and knowledge of the world. This approach was very much in line with the concepts which were dominant at that time in the field of scientific psychology. Of course, these principles were not applied with the same level of intensity or flexibility in the different schools, but they constituted a very important aspect of the lingua franca used in the deafblind field. It is also necessary to stress the fact that the way hands on professionals used the educational methods in reality with the children could be very different from the way leaders and researchers designed and analysed them. It was often for the better, and fortunately, teachers and educators are able to bring their own creativity to compensate for the unavoidable limitations of scientific theories. Their emotional involvement probably accounts for a big part of the success of many methods.

It was also felt that learning and conditioning theories, in spite of their efficiency in obtaining some results were far from explaining why some children were anxious and little motivated for learning, exploring the world and engaging in communication. The attachment theory (Bowlby 1969) brought some light on these problems and helped to think differently of education and relationships. During the first months of their lives all human beings (like all animals) develop a strong attachment to other human beings (and usually, first of all, their mothers). Observations of apes showed that the basis for establishing this bond was more tactile contact than feeding. For human babies, the lack of human contact or of sensitivity from the adults results in delayed development, high anxiety and sometimes autism. The better the quality of attachment is, the more the children spend energy in exploring the world, playing and learning. The feeling of security leaves more energy and resources for orienting attention and activities towards the outer world. In the case of deafblind children, many conditions create a risk of developing anxiety, and consequently difficulties in developing harmonious relationships and exploring the world. In the beginning of their lives, many of them have to go through painful medical treatments which often separate them from their mothers. The lack of vision and hearing as well as the motor difficulties generate a difficulty for them to organise and predict events and people's attitudes and for their close carers (parents, family members and professionals) to read and react to their feelings and utterances. A careful observation of the children (in daily life or using more organised procedures like the Ainsworth «strange situation») gives a possibility to evaluate the quality of attachment of the children in order to take this aspect in planning their education. The theory of attachment, putting forward the necessity for the staff to develop sensitivity to the children's expressions, not only helped to decrease the level of anxiety of these children, but also prepared new ideas concerning communicative development.

Communication and dialogue

Some of the children educated with these methods became social, managed with daily self-help skills, learned crafts and made good conversation partners. But many other ones, when getting older, although

mastering many things they were taught, like reading pictograms, understanding signs, expressing signs, taking part in daily activities, were, as regards communication, rather passive, taking little initiative, taking part in conversations only in rather formalised and adult dependant ways, like through the reading of calendars or answering stereotyped questions. This lack of expressivity, initiative and flexibility in communication became a question for some professionals and program leaders. There was the feeling that something was missing in the way these children were educated. The last developments of the research concerning the first months of life helped them finding explanations and new ways of approaching congenitally deafblind children. The main aspects of this new approach are:

Before speaking, children experience sustained and playful interactions with partners. Through this experience, they acquire skills for monitoring exchanges (turn taking, sustaining a focus of attention) taking the form of body dialogues. These dialogues are based on the mutual capacity of the two partners to express their own intentions and to read and react to each other. Then, the structure of these interactions is made more complex with the introduction of external elements and language. Interaction is progressively transformed in communication about "something" (an object, an event, a thought etc.) Language must not be seen as providing the capacity to communicate, but rather as an outcome of the complexification of the communication processes.

Mimetic and narrative aspects of communication

In modern societies, relationships, communication, knowledge transmission, and social rules are very much seen as carried out and expressed through language. This view is very much influenced by the specific characters of European and American cultures as well as by an adult-centred vision of development. Children born in cultures with less technology learn a lot through direct body contact and visual observation. Besides, when education is based on language, it takes the form of narratives which provides explanations about how the world is organised and how to behave socially. Merlin Donald (Donald, M. 1991) calls «mimetic» the behaviours which rely on direct body expressions for communicating and thinking, and «mythic» the narrative and language based forms of knowledge transmission. These two aspects of social communication and thinking are easy to observe in young children.

Before they can actually speak, children are able to produce utterances using what is sometimes called body language. They point to things, they re-play passed experiences, they make visible their feelings through face expressions or body attitudes, they tune up rhythmically with other people. All these body movements make it possible for children to communicate their intentions or their thoughts to others, and more specifically to provide them with the feedback they need to sustain their attention and communicative activity. It is of the utmost importance that the children carers are able to read this body language and to react in an appropriate way. Children need to feel that they are felt and understood in order to keep on taking initiatives of communication and sustaining their attention. This is all the more true for deafblind children, although it is more difficult to read their behaviours. For instance, face expressions or pointing

movements are more difficult for them to express. Or, more exactly, the functions that we are used to read on the face or through pointing are expressed through other expressions like clapping hands to express joy, or touching a part of the body or an object to manifest the focus of attention. But it is not enough to be able to interpret these expressions, it is also necessary to react in such a way that the deafblind are able to feel and make sense of these reactions. Of course, using the tactile sense is very necessary. But the meaningness of these utterances is also dependant on the structure of the interaction itself. Communication does not work as a questions-answers sequence, but as an ongoing exchange of intentional movements whose purpose is to develop a here and now experience of play and communication, but also to share the memory of previously shared experiences. Re-playing together a past experience is not only a topic for communicating but also a way to build up representations that can be a basis for symbol formation. Another aspect of re-play is the fact that children (including the deafblind ones) are very sensitive to being imitated. This type of mutual/immediate imitation is observed between mother and young babies, but also between children (especially when aged from 2 to 3)(Nadel J. & Camaioni L.; 1993). Parents very often imitate their seeing and hearing children, which elicits interest and new utterances from them. Deafblind children react the same when they are imitated. Obviously, for deafblind people at their first steps of development, playing together is the best way to create the conditions for sustaining a lively dialogue. This approach is extremely child-directed and far from «adult teaching». Rhythm, body contact, mutual imitation, and re-play provide good entrances for co-creating communicative episodes. And all these aspects can be carried out through direct body contact.

But they can also be based on a shared use of objects (toys, daily life tools like spoons, towels etc. or symbolic items like objects of reference or pictograms). This is a real challenge for children with congenital deafblindness. Daily life implies the use of «things» when being in contact with deafblind children. Besides, teachers or family members expect them to learn competences through the use of these «things», for instance: learning how to use a spoon for eating or to build a tower with a set of cubes. «Things» are very much used in education and «educational» things or games exist which are designed to help the children develop their autonomy, their knowledge of the world and their symbolic activity. Unfortunately, we feel sometimes frustrated because deafblind children reject these objects or use them in a very self-centred and a less communicative way. In order to understand this phenomenon, it is necessary to refer to how seeing/hearing children develop as regards the use of objects, and which specific challenges deafblind children have to face. During the first part of the first year of their lives, seeing/hearing children experience communication through direct body contact. They are not able to process simultaneously attention to their human partners and to an object. It is only during the second part of their first year that they are able to interact with somebody without losing contact with an object used as a topic for communicating (for instance a toy used for hide and seek games). This is made possible by the growing capacity of the brain to process various sources of information and by the fact that auditory stimulation can be expressed simultaneously with visual or tactile sources of information (the child can pay attention to a sentence like «look at the big ball» while looking at and touching this big

ball). In the case of deafblind children, processing sensory information is more demanding because of the sensory impairment; neurological deprivation can also hinder the capacity to process various sources of information; and most of all, in many cases, each piece of information has to be processed through the same channel, the tactile one.

So, we should not be surprised when a child grasps a little plastic ball, takes it to its mouth, licks it and/or bites it, and throws it away. It may be that this little ball does not call for exploration, and, above all, provides very little cues for the child to feel the expressions of the human being behind the ball. By contrast, if you use a very big ball, on which the child can lie or sit, there are many more opportunities to facilitate that the child can both feel the ball and the partner, which creates possibilities to play games and sustain interactive episodes, in the same lively way as experienced through direct body contact. Not all the things have the same power to elicit games and human interactions. Obviously, big things allowing a wide tactile contact and/or allowing dynamic and rhythmical experiences are good candidates for these first attempts to play «with somebody here, with something there». This capacity is too often wrongly taken for granted in deafblind children, which can result in frustrations in both partners when they try to use things for playing. This capacity named «secondary intersubjectivity» by Colwyn Trevarthen is the next step after the «primary intersubjectivity» period, when the child is only able to feel the other «subject» intentions and emotions through direct body contact (Trevarthen, C., AND Hubley, P. 1978).

During this seminar, based mainly on video analysis, we will see how these aspects of development can be implemented with congenitally deafblind persons.

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4. Lecture 2: Co-creating Communication with Persons with Congenital Deafblindness

By Anne Nafstad[2] & Inger Rødbroe[3]

Interactional prerequisites for communicative interaction

Persons with congenital deafblindness are at high risk of being excluded from participation in basic interpersonal communicative relationships. During the years that we have investigated prerequisites for participation, the focus has been on the adaptation of the sighted and hearing adult (the partner). The use of video analysis has helped us identify how the partner may adjust her interactive and communicative attitude so that it fits the conditions of deafblind persons and liberates the resources of the particular child.

Video-replay of different sequences of interaction makes it possible to study how the child and the partner adjust themselves to each other on a moment-to-moment basis. We may frequently discover on the video-replay of the sequence that the rhythmicity of these reciprocal exchanges tends to be distorted. It can be that the spontaneous activity of the child is subtle and difficult for the adult to relate to without first becoming aware of it on the video-replay. It can be that his activity is different from what the adult expects. The child can for instance appear to be passive and withdrawn when he is actually thinking. Maybe he initiates contact with his foot instead of his eyes or hands.

Maybe his explorative activity takes a long time and looks strange. All in all, the spontaneous activities of persons with congenital deafblindness tend to be different from what we expect on the basis of our linguistic culture and our sighted and hearing perspectives. To detect these behaviours we need some distance and reflection. When we detect them, we are not used to relating to them and understanding them. So we need to explore how we can do that in a way that makes the interactive sequences fluent and sustained. This fluency is co-created on the level of micro-exchanges, as moment-to-moment adjustments.

It is fortunate for us and the deafblind children that we use video-recordings and video-replay as a professional tool. In this way the professional work can be more specific than it was in the past, and we can more easily discuss and share with each other. There is a new level to our work: There is the relation between the adult and the child as before, but there is also the continuous analysis and readjustment of the interactivity. This is done to facilitate the participation of the child.

It is important to keep in mind that the video-analysis should not be used in a technical way. We need to

remember that it is very difficult for everybody to interact and communicate with persons with congenital deafblindness. Once we accept that it is very difficult, the difficulty can be an inspiring challenge rather than a problem. Even experts need to adjust themselves continually and take on an explorative, inquiring and playful attitude, while still being serious and specific.

During the years that we tried to work out a position for our work, we attended to co-regulative and co-creative micro-exchanges within four fundamental patterns of interaction.

I   Co-regulation of proximity and distance within co-created greeting-rituals

II   Co-regulation of explorative ventures and explorative sequences

III   Co-regulation of motion and emotion in co-created rituals of social interactive play

IV   Co-creation of shared vocabularies and shared meaning in co-regulated communicative sequences

The purpose of this focus was to identify the adjusted interactional conditions under which the deafblind child may develop as an affectionate, playful, explorative, and communicative person in relation to his environment.

In order to identify the adaptations from the adult that have a positive effect on co-regulation and co-creativity, we have used exemplary video illustrations: We collected several tapes of e.g. affectionate mother-child interaction, and picked out the sequences where the patterns we looked for were most clearly portrayed. Then we tried to adapt the interactive and communicative environment in similar ways in other cases, and observed if the effect of the adaptation was going in the same direction as in the example. A selection of the clearest video examples we found are collected in the two videos of The DbI Working Group on Communication (CNEFEI 1996 and 1999)

In what follows, we shall look briefly at how the partner may contribute to bring forward the active participation of the congenitally deafblind person within each of the basic patterns. Thereafter, we shall look at how the patterns fit into a coherent model of communication intervention. In the end we shall sum up some key concepts that are useful when we apply video replay more specifically in communication intervention.

Co- regulation of proximity and distance

The first video of the DbI Working Group on Communication contains two different cases in which the child and the mother are involved in the co-regulation of distance and proximity within co-created greeting-rituals. These rituals are charged with positive affection, so that the exchanges are finely tuned and intense, which explains why they are clear. We may observe that the co-regulation of proximity and

distance between the partners is structured like a kind of game with repetitive episodes, where the child, with encouragement from the mother, ventures out beyond reach of the mother and is called back again (by the mother's tenderly blowing in the direction of the child). The venturing out beyond reach and being called back or returning back; the penduling motion along the path of distance and proximity is the rule of the game. In the good examples, we notice that the mothers never grasp their children, never clutch or hold them, are never intrusive or forcing themselves upon them. They stay available and encouraging, and scaffold the game, but they let the child lead the co-regulation. Only in this way is the child able to build up a sense of coherence between the feeling of freedom and belonging. During the formative process, we see that flexibility of bodily motion in space and embodied emotion are totally blended.

Already when we attend to this pattern we can see that it is very fortunate when persons with congenital deafblindness have a good bodily feeling for organisation of movement in space (and many have), and later we shall see that it is fortunate that social interactive play based on synchronised motion and emotion can be so rich in the case of congenital deafblindness. All the fundamental components that go into the patterning of a dialogue (social, emotional, and cognitive components) are basically organised bodily-emotional motion in space (like a kind of expressive dance). Actually, this bodily spatial dimension is more clear in the case of congenital deafblindness than in the case of sighted and/or hearing children. Children with congenital deafblindness contribute to clarify this basic dimension, which otherwise is masked by functional distant modalities and cultural linguistic practice.

We have sometimes observed that it is not necessarily fortunate to have residual vision for deafblind persons. Sometimes this disturbs the bodily organisation of experience. We have observed several cases where deafblind children loose their residual vision and switch to a much better functioning and more holistic bodily organisation, obviously providing them with an embodied sense of coherence which some appear to have lost because of residual vision. We shall first briefly look at co-regulation of explorative ventures and sequences.

Co-regulation of explorative ventures and sequences

The most critical adaptation of the adult during explorative ventures and sequences is to be available by contract, but refrain from disturbing the child. This can be a big challenge, in particular if the child is in the project of building up an image of your face, including for example the inside of your mouth. During explorative sequences and ventures, the congenitally deafblind child is not only discovering the world, he is first building up images of what he subsequently discovers. Or more correctly; he creates the image of what he discovers while discovering it. To intrude is to intrude into a creative cognitive process; the process of image formation.

There is a risk that we stop the exploration of the child because we think it lasts too long or looks repetitive. This is the same as not giving time and space for image formation. To try to make the child explore in

more culture-similar ways, or not at all because it looks strange and repetitive, is of course not what we really want to do. To show him the world by directing his touch is the same as directing somebody's visual perception. This is not what we want. We do it when we are not aware of the way he explores. The child first has to discover the world in his own way, the task is to make some important aspects of the world available for exploration and discovery. Important aspects are for instance the persons (and animals) in his family; these are much more important to discover than any other "object".

Co-regulation of movements and emotion in sequences of social- interactive play (intersubjectivity)

The contemporary study of early interaction and early communication has put a lot of attention to so called face-to-face interactions, usually involving mother and child. It is believed that sequences of playful bodily emotional interaction give the partners a basic bodily-emotional feeling of connectedness, togetherness or "inter-subjectivity". By this inter-connectedness the child changes from being a biological organism to becoming a social being. The capacity for bodily-emotional inter-subjective communion is detectable from birth. In interactive sequences of co-ordinated movements and emotional states, there is a good match between the behaviour of the two partners.

In the case of congenital deafblindness, it helps to know that the partner has to match his own interactive behaviour to that of the child, so that the child can recognise his own behaviour in the behaviour of the adult. If the behaviours look very different, or feel very different, the child cannot feel that the adult recognises his spontaneous expressions as his own.

Psychologically this has to do with the feeling of being accepted for what you are, of experiencing how you are experienced by the other. Our image of ourselves is the image that is mediated by the other. Concretely it means that adults have to act very much like the deafblind child during these social interactive encounters. Only then can he be a participant in the exchange. The social interactive play has to be based on behaviour that is automatic for him. He cannot learn new behaviours and interact at the same time.

The more fundamental form of interpersonal togetherness has a kind of musical quality. Rituals of playful interpersonal togetherness may set the stage for true dialogical interaction, for understanding, and for acquisition of cultural knowledge and practice by way of identification with the other.

There are several sequences illustrating the musical quality of social-interactive play in the first video of the DbI Working Group on Communication (1996). There is a rhythmical organisation of synchronised movements, the building up of repetitions of themes, like stanzas, and a melodious organisation of glides within expressive emotional states. Such playful sequences can be somewhat similar to jam-sessions, or

improvisations over well-known songs and nursery-rhymes. It is important however, that the culturalized music is adapted to the co-created bodily-emotional music, and not vice versa.

We can typically observe in these sequences that the congenitally deafblind person seems to be recognising himself in the expressions of the other. Simply because the partner acts very much like himself, only perhaps adding clarity of expressions and a narrative contour to the sequence.

Sequences of social interactive play are very important psychologically. When these sequences are well-regulated and sustained, they bring out the best in both partners. And we can often see that children initiate exploration and affectionate proximity during these sequences. We also often see that they create gestures during, and on the basis of these events.

The emergence of a language from the body

During and on the basis of ritualised well-regulated and co-creative exchanges, congenitally deafblind persons will typically start to form bodily images out of the salient reminiscences and expectations of interactional experience. This is indicated by a bodily and emotional gesture, called a mimetic gesture. These gestures are often a combination of a characteristic motion with bodily-locational touch (e.g. touching the place on the throat where the child feels that she is eating a banana). The adequate interpretation of such gestures is SOMETHING FELT LIKE THAT THERE/HERE. If we translate these gestures into linguistic expressions, we miss the point that these gestures emerge from the bodily experience of the interaction, and not from object-related action or culture. Analysing videos helps us notice these gestures. As these gestures do not initially tend to be addressed to the adult, it is very difficult to discover them during the actual encounter. It is even more difficult to be able to react upon them in an adequate way immediately. But the task is rather clear: Since these gestures are not initially communicative, we have to act so that they are provided with, and progressively take on a communicative function. The good thing about these gestures is that they are already contemplative. We do not have to worry about whether the child has any reference to these gestures. These gestures emerge from a source of experience, they are bodily and contemplative and charged with emotions all at once. We just have to add the intentional communicative and dialogical function. The child is perhaps starting to blend the present with the past and the future, and this marks the very beginning of a mental space. We have to share his experiential space, however, in order to share his mental space. Meaning is something that is socially co-created. While the child is performing the mimetic gesture, he is partly in proximal space, partly in distal space. It can be something in the here-and-now that triggers his image of something in distal space. A feeling of something soft and tender may trigger the image of mummy. We have to follow his motions in and out of these experiential spaces in order to join him in the co-creation of a shared mental space. We have to know his experiential world, and as far as possible, share it in actuality and imagination. This, in turn, is a prerequisite for joining him in the negotiation of shared meaning in emerging dialogues.

Co-creating shared vocabularies and shared meaning.

So far, the types of interactional patterns that we have attended to are dyadic. Communicative interaction requires that the interaction is triadic, meaning that the gesture takes on the function of a third element; is provided with its own status, as a potential symbol (sometimes called proto-symbol). This third element, the gesture in this case, is presented to us by the child. It is something to us, but we do not know what. It is a potential symbol, it is something that can come to mean something for both of us, it has a potential communicative function and a potential negotiated shared meaning. So we have to act accordingly. We have to tell the child, in a bodily manual gestural way " I see what you say, you say something LIKE THIS". In fact, what we do, with the tactile dialogical positioning of hands, marking the dialogical game, we imitate his gesture on ourselves, eventually also on his face or body (wherever he himself localised it). In this way, he will progressively expect that his gesture, in this positioning of hands, will be reflected by the other. In this case he will know that his gesture is perceived by the other, and it is acknowledged as a social and shared gesture; a potential sign. He is able to communicate, share whatever is on his mind by that gesture. But what is on his mind? How can we know what it means? We do not have to know, and we do not have to guess. We can just follow the rules of the game. The game is negotiation. The meaning of a gesture changes the gesture into a sign. It is not the same as the gesture. The gesture sets the stage for the sign, but is not the sign. The sign is what is negotiated, the shared meaning that emerges out of sequences of negotiations. We do not really know if shared meanings are really shared, what we know is that we follow the rules of the game.

So we have to know the rules of the dialogical game. Part of that game of negotiation is illustrated in the second video of the DBI working group on communication. The major thing to remember is while we negotiate shared meaning and shared vocabularies, we do not act with objects in the external world. We are acting in a shared communicative space, a world of much imagination. You imagine what is in the bodily mind of the other person, and you share what is in yours. The sharing of the gesture is the first indication, and in the beginning sharing is blended with imitation. Probably when the child feels that you act like him on yourself, he probably believes that the gesture for you is embedded in the same imaginary space as it is for him, i.e. that you do not only do the same, but feel and think the same.

To simplify this matter, it makes sense to distinguish between declarative and instrumental sequences. It is important to give priority to the formation of declarative sequences, where we indicate to the other person the willingness to share what is on his mind, and negotiate his gesture into a communicative and potentially meaningful sign.

In instrumental sequences, the child uses the gesture as a part of a tool, which the other person is also a part of. Instrumental sequences are leading up to object-related action in the external world, and they are not related to the negotiation of shared meaning or shared vocabularies. It is very easy to provide the gesture of the child with the function of a signal, in this way, instead of a symbol. In that case the child

with congenital deafblindness will, most often unnecessarily, develop autistic like problems. We have experienced that it is avoidable when we are able to control that reciprocal interaction is sustained.

Applied documentary literature:

The IAEDB Working Group on Communication and Congenital Deafblindness: Documentary videos
" The Emergence of Communication Part I"
"The Emergence of Communication Part II"
Address: CNEFEI 58-60 Avenue Des Landes. 92150 - Surenes, France

Nafstad, A. and Rødbroe, I (1999) *Co- Creating Communication*, Dronninglund: Nord-Press
Address: NUD Slotsgade 8 - 9330 Dronninglund, Denmark

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