Development of Communication in Deafblind Children

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ABSTRACT  The aim of this study was to describe the development of communication between deafblind children and their parents in real-life settings using video registrations. Longitudinal case studies of six children suffering from severe visual impairment in combination with profound hearing impairment are presented. Four of the six children also have additional functional disabilities affecting their motor and cognitive development. At the time of the first video-recording the children were between 6 months and 3 years 9 months of age. They were observed for a period of 2 years. Detailed analyses of the video-recordings showed that all of the children could communicate with their parents and the parents with their child. Even if the expressions varied and were sometimes difficult to interpret, the early development of communication followed the same patterns as that for non-disabled children, from interest in social games with the carer to interest in the physical environment and thereafter an intent to share their experiences with another person.

Children born deaf and blind belong to a risk group because of difficulties caused by their dual sensory deficit as well as difficulties experienced by their carers in daily interaction with them. Many children also suffer from other disabilities. These circumstances can result in over-dependence and learned helplessness (Marks 1998) as well as emotional and behavioural problems (Durand & Berotti 1991, Luiselli 1992). One of the most serious problems for positive development, from both the individual child’s and carer’s perspective, is to establish well-functioning communication.

Studies of the development of communication and language in deaf and severely hard of hearing children have shown that these children can develop in much the same way as hearing children, provided that they are allowed to use a language code which is easy for them to perceive as well as to produce, for example sign language (Erting, Preziosi & O’Grady Hynes 1990, Jamieson & Pedersen 1993, Koester 1994, Meadow-Orlans & Spencer 1996, Nordén et al. 1981, Preisler 1983, 1995, Robinshaw & Evans 1995). However, among such children brought up in an oral environment, where communication is
mainly based on speech, communication problems are the rule rather than the exception (Schlesinger & Meadows 1972, Vernon & Andrews 1990).

Observations of the development of communication and language in blind children indicate that during the first 4–5 months of the blind baby’s life, parents can establish a well-functioning interaction by means of face-to-face interaction, tactile contact, auditory means and physical closeness (Preisler 1991, 1995). The mothers have been shown to be able to be attentive to their children’s facial expressions, body movements and vocalizations. They can interpret these expressions as meaningful in communication and form them into a turn-taking pattern. Songs and different body plays can also be part of these interactions (Preisler 1991, 1995). But after a couple of months the parents often experience difficulties when communicating with their blind babies. Joint attention and joint actions between carer and child are considered important prerequisites for well-functioning communication (Bruner 1975). This is difficult for a sighted carer to establish with a blind child (Fraiberg 1977). The blind children’s communicative signals are often difficult to read. As they have to be highly attentive to sounds in the environment they can exhibit a stiff body posture and a blank face in situations where parents expect smiles and different body movements, resulting in a mismatch of communication (Fraiberg 1977, Landau & Gleitman 1985, Preisler 1995, Rowland 1983).

A combination of a severe hearing impairment or deafness and a visual impairment or blindness makes the situation even more complicated. Early patterns of communication are affected and this is an impairment that remains throughout life. This is described in an insightful way in an ethno-methodological study of two children who were born with rubella syndrome in the 1960s (Goode 1994).

There are few children born both deaf and blind (Andrew 1989). Within the population of young children diagnosed as deafblind, there are children with a varying degree of hearing and visual impairment, with or without additional disabilities, but also children with cortical visual and/or central auditory disabilities (Michael & Paul 1991). Most studies of these children as well as other children with multiple functional disabilities have focused on different intervention and educational programs to promote communication as well as socio-emotional development (Aitkens 2000, Chen & Haney 1995, Michael & Paul 1991, Nafstad & Rodbroe 1996, Janssen, Riksen-Walraven & van Dijk 2002, van Dijk 1986) but there are few studies focusing on the natural development of communication in deafblind children from a longitudinal perspective.

Over the last 30 years, experimental and observational studies of the development of infants and toddlers have given us new insights into the developmental process (Fogel 1993, Stern 2000, Trevarthen 2001). Studies of infant development have shown that the child is socially active from the first minutes of life and that learning takes place in interaction with others in meaningful contexts (Trevarthen 2001). Newborns can imitate expressions of the face, the hands or the voice of another person (Nadel et al. 1999). These results indicate that infants are ready to understand the motives of other
persons (Trevarthen 1988, 2001). Today there is also physiological evidence of an innate ability of understanding other person’s motives. In the cortex there are neurones that discharge when we observe an action by another individual as well as when we execute the same or a similar action. These visuo-motor neurones are called “mirror neurones” and appear to anticipate the evolution of imitations that make learning of human speech and language possible (Rizzolatti & Arbib 1998).

There are some important milestones in normal development of communication in infancy. These occur roughly at birth, 1.5, 3, 9 and 18 months of age (Trevarthen 1988). From birth, infants enter into an exchange of feelings and communicative acts with their parents. Eye contact is sought and movements of the eyes and mouth, hand gestures and vocalizations can be imitated by the infant. These observations have resulted in a new view of the infant as a competent partner in social interaction. When the infant is between 1 and 2 months old, the infant and the carer start to communicate by means of cooing, vocalizations, eye contact, smiles and body movements in dialogue-like exchanges. The carer starts to sing and to engage the infant in different body games. Stern (2000) maintains that the infant has a sense of a self from birth. During the first weeks of life this sense of self has an emergent character progressing to a sense of a core self at the age of 2–3 months. A couple of months later the interest in social interaction gradually turns into an interest in the environment. Infants start to explore the characteristics of objects and can also show intentions by pointing with eyes and hands. The infant has now evolved a sense of a subjective self (Stern 2000). For a period of time infants’ interest in social interaction seems to diminish, but returns later at the age of 8–9 months, when they show a desire to share their new-won experiences about the world with another person.

During the first months of the child’s life, carers and infants mutually create sequences of reciprocal behaviours, so-called social dialogues. In these dialogues parents respond to their infants in the same modality as the infant is using – a smile from the infant is met by a smile from the parent. At approximately 9 months, according to Stern (2000), carers start to add a new dimension to their imitation-like behaviours and expand their way of communicating into a new category of behaviour that Stern calls affect attunement: the smile is not only met by a smile but also with an exaggerated facial expression, and always with vocalizations. There are, according to Stern (2000), three general features of behaviours that form the basis of attunement. These are intensity, timing and shape: the loudness of a carer’s vocalization can match the force of the infant’s arm movement; the temporal beat of the movement of the carer can match the behaviour of the infant; and finally, the form of the infant’s movement can be abstracted and rendered in a different act by the carer. This way of sharing affect is one of the most important features of intersubjective relatedness. After a period of pre-symbolic communication, the infant, at the age of approximately 18 months, can enter into a world of symbols and starts using a language code in communication. The child gradually experiences a sense of a verbal self (Stern 2000).
Intersubjectivity, a synchronized attention to and understanding of events and others’ emotions, is viewed as essential to other developing competencies such as language and social cognition (Studdert-Kennedy 1991). Intersubjective experiences begin in the first year of life and continue to be refined as children and their relationships mature and become more complex. In normally developing infants, intersubjective experience is viewed as a spontaneous development, evolving out of natural contexts of child–carer interactions. It is both the infant’s perceptual, motor, socio-emotional, and cognitive competencies and the carer’s sensitivity and responsiveness that are the basic ingredients of the experience of intersubjectivity. The sharing of meaning in joyful interactions and early mutual play with turn-taking qualities are crucial prerequisites for language development. Pre-verbal abilities in children, including the use of conventional gestures such as pointing and showing, symbolic play, imitation and the use of tools, have proven to be important predictors of later language development (Bates et al. 1979, Berglund 1999, Capirci et al. 1996, Greenspan 1997). The carers play an important role in the development of communication. Studies of parents of children with functional disabilities affecting their communicative abilities have shown that there is a tendency among these parents to use primarily a directive and adult-centred communicative style. The less the children communicate the more the adults have been observed to try to make them respond to their questions or to try to elicit contact initiatives. This, in turn, will almost always result in even less communicative behaviours by the children and can result in a negative developmental spiral.

Aim

The aim of the study is to describe the development of communication between deafblind children and their parents in real-life settings. The questions posed are: Which communicative means do the parents use when communicating with their deafblind child? Which communicative means are used by the child when communicating with the parent/s?

The aim is further to describe the children’s development of communication from a longitudinal perspective. The important milestones in normal development of communication in young children will be used as a frame of reference when describing the development of communication in deafblind children; from interest in social activities to interest in exploring the external world, followed by interest in sharing experiences and from using pre-symbolic to symbolic means of communication.

Methods

Detailed observations of children and their parents in real-life settings over a period of time have shown to be an appropriate method when the aim is to study the development of communication (Preisler 1995). In a country with 9 million inhabitants, the number of children born deafblind with or without additional functional disabilities in 1 year is very small; only a couple of
children with this diagnosis are born each year. Therefore a qualitative case study method has been chosen.

The Children

Six children and their parents participated in this study. Five of these were the children diagnosed as deafblind in Sweden at the time the study began. The sixth child was a Norwegian child, referred to the project by Anne Nafstad, psychologist at Skadalen Resource Center for the Deafblind in Oslo.

At the time of the first video-recording the children were 6 months, 13 months, 2 years 4 months, 3 years 7 months, 3 years 8 months and 3 years 9 months old. Common to all of them was that they were diagnosed as blind or severely visually impaired as well as profoundly hearing impaired. Four of the children had additional functional disabilities, such as intellectual disabilities and/or cerebral palsy. The diagnosis of each child will not be described in more detail than this, as further descriptions would enable identification of individual children. The study is not aiming at relating results to aetiology but to give a description of developmental processes from a longitudinal perspective. For each case history, individual characteristics considered important for interpreting the results will be presented in more detail.

All of the children lived with both of their parents and all of them had older siblings. In 5 of the 6 cases, a sibling was born during the time of the study. Another common denominator was that all of the children and their families had many and long experiences of hospitalization and, in several cases, of medical and surgical treatments. The children in the study were all highly sensitive to infections and therefore considered to be medically highly fragile children.

Procedure

Video-recordings and direct observations were made in the children’s homes every third or fourth month over a period of 2 years. A total of 34 video-recordings were made in as real-life settings as possible considering the fact that one or two persons were videotaping and observing the interplay. The parents were not asked to act in a particular way. Instead, the camera followed what happened during the visit and the researchers video-recorded the interplay that took place during this visit. From experience of many years of using video as a means of collecting data in the family setting, it has become obvious that if the observer directs the interaction, the interplay between parents and children can alter and the parents may become more stressed in the presence of the camera, than if the tape is allowed to run more freely (Preisler 1995).

Interviews were made with the parents about their experiences of having a deafblind child, about the social and psychological support they had received, but also about how they interpreted the child’s signals and expressions when communicating. This information became important when coding and analysing the communication between the children and their parents.
Video Analysis

A content analysis of the interactions was made in order to get an overview of the ongoing activity. This analysis involved categorizing the content in terms of feeding, nursing and play with or without objects. Thereafter a more detailed description was made by closely observing and registering the child’s facial expressions, body movements, production of speech-like utterances and their use of words and phrases. The parent’s use of speech, touch and other means of communication were also registered, as were the way the parent or the child responded to the other’s actions.

From these detailed qualitative registrations of behaviours, patterns of communication gradually emerged for each individual child–parent pair and these patterns will be presented in the results.

Results

The results are presented as six case studies. In order to protect the children's identity, only the most relevant information about the children is given and their names have been altered.

Mick

Mick was 13 months old at the time of our first visit. He was diagnosed as severely visually and profoundly hearing impaired, with intellectual and motor disabilities. His family comprised mother, father and an older sibling and, after a period of time, a younger sibling.

The parents told us that they could discriminate between Mick’s different expressions as signs of intentions and wishes as well as of different state of minds and feelings. Characteristic of the content of the video-recorded observations was that Mick was often lying on a carpet exploring different objects with his hands and arms. He could move around short distances by pushing with his legs or rolling. When his parents initiated contact with him he became physically active, smiling and laughing. As time passed, Mick became more stable in his body posture. He could sit and stand with support, and thus explore the environment from a new angle. He turned his face towards the faces of his parents. He was attentive to vibrations and sounds from voices and objects in his near surrounding and he imitated his parents’ sounds and movements. The parents primarily used bodily contact, actions and imitations in communication, while Mick used sounds, smiles, laughter, bodily movements and actions. There were also dialogue-like exchanges between them based on vocalizations. The parents occasionally used signs in communication with him, but they had not noticed that Mick used body signs or any conventional signs when communicating with them.

The first video observation at the age of 13 months gives an illustration to the way Mick reacted when one of the parents initiated an interaction:

Mick is lying on the floor, touches his mouth with his right hand repeatedly. The father bends over him and, when he is close, Mick becomes still.
The father touches Mick's left hand with his own hand: “Hallo”.
Mick turns his head towards his father. A grumbling sound is heard.
The father: “Are you going to say something?”
Mick turns his face to the side. He grumbles again.
The father comes even closer to Mick's face. “What?” (There is laughter in his voice).
“Are you going to say something?”
The father takes both Mick's hands, holds them in midline: “What? Hallo?”
The father laughs even more: “Hallo!”
Mick turns his head towards his father's, smiles: “Ehh hee”.
The father takes his hands in a steady grip, watches Mick closely: “Hallo”.
Mick vocalizes.
The father imitates his sounds.
(Time: 15 seconds)

The father watched and responded to each body and sound expression from Mick as part of a dialogue-like exchange. There were imitations and also affect attunement behaviours registered and Mick could show expectancy awareness in interaction.

At 16 months, there were several vocal dialogues registered between Mick and his parents. Mick was diagnosed as profoundly hearing impaired, but as the concordance of several of the dialogues was obvious it became evident that he reacted to some auditory input. Both parents constantly tried to reach face-to-face contact with him. They used affect attunement behaviours like “Uhhhh” or “Ohhhh” matching his movements in pitch and shape. Mick was responsive and active in interactions when the parents touched or cuddled him. The whole repertoire of communicative expressions parents use in interaction with young children was present; the forming of turn-taking patterns in dialogues, face-to-face interaction, imitations and affect attunement behaviours, in spite of the fact that the responses from the child were both subtle and vague.

When 19 months old, Mick had a more varied repertoire of bodily expressions than before. He explored objects by touching them with his hands, mouth and lips. He compared objects by touching them one by one. He could move around the room by rolling. He seemed to enjoy interacting with his parents, as he smiled when they initiated contact with him. It was now registered for the first time that the mother was using single signs when communicating with him.

At the age of 2 years 2 months, the parents had not yet noticed that Mick showed any interest in social interaction. Instead he preferred exploring toys. The observation showed that he was concentrating well and absorbed by exploring objects, but he also showed interest in social interaction. However, his way of expressing this was different from what is normally seen in children of his age. It was not until repeated video observations had been made, that we could see that what the parents interpreted as disinterest in fact was a way for Mick to try to share his experiences with them, as illustrated in the following example:

Mick moves around in a walking chair. The parents are seated at the kitchen table. Mick starts to move closer to them, but stops when a sunbeam hits his face. He moves back and forth and turns his face to meet the sunbeam.
Mick: “Uhh, uhh uhh”.
The father: “Yes, that was the light”.
Mick vocalizes and moves back and forth in his walking chair.
He becomes silent, but is breathing loudly.
He turns his face towards the father; he puts his right hand towards the face and starts to move his fingers.
The observer asks the father if Mick knows that the father is sitting there.
The father: “No, it is only the light that is interesting”.

(Time: 36 seconds)

Mick then looks as if he tries to find out where the father is. He bends forwards, moves his head from side to side, but both parents are silent. He moves towards his father, repeats the movements with his hands and fingers in front of the face, bends his head backwards and then forwards. He looks as if he is concentrating. Mick starts to vocalize, pauses and vocalizes again, but the father does not respond to what was coded as contact initiatives from the boy. Finally the father makes a comment that Mick cannot move any further as the kitchen table is standing in his way, and makes him move away in another direction.

Analyses of this interaction indicated that it was plausible to believe that Mick was interested in social interaction and that he wanted to share his experience with somebody. However, in this case the father was more focused on the obstacles to him moving independently.

At the age of 2 year 10 months, one interaction between Mick and his mother was engaging in different turn-taking plays by means of movements and vocalizations. The mother imitated his movements and vocalizations, which became the starting point of new games. Mick could show his intentions and desires.

The last video-recording was made when he was 3 years 3 months old. He was lying on the floor on a carpet, with both parents by his side. The interaction was primarily about turn-taking games using sounds. He was physically a large boy, but he acted more like an infant. This contradictory picture was probably one of the main reasons why the parents had difficulties in knowing how to act towards him. Each time they touched him, by caressing or kissing him, he reacted by moving parts of his body. He smiled and laughed on these occasions. His way of moving, vocalizing, by pausing and waiting for response, was interpreted as a sign that he was interested in social interaction, but these reactions and initiatives were not always noticed.

Pat

Pat was 3 years 8 months old at the time of our first visit. She was a fragile little girl who was both visually and hearing impaired with intellectual and motor disabilities. She had some residual vision and she reacted with smiles when she heard her parents’ voices close to her. Pat lived with her mother, father and an older sibling. A younger sibling was born several months after we met Pat.
During the 2 years of observation, we registered a change in patterns of communication between Pat and her parents. It started with dialogue-like exchanges in which each took their turn, and during which the parents responded to almost every expression or movement of the face or the body of their daughter as a meaningful part of communication, towards the first indications of symbolic communication. During the last video-recording, Pat could express herself spontaneously using the sign for "MORE." (Note: throughout this paper, spoken language is indicated by "lower case" letters in speech marks, sign language alone is indicated by CAPITAL letters, and spoken language accompanied by signs or elements of sign language is indicated by "**bold** lower case" letters in speech marks.)

At the first video-recording, Pat was 3 years 8 months old. When the parents started to communicate with her, they lowered their voices and talked quietly. Pat responded with body- and head movements, lip- and mouth movements and vocalizations. The parents interpreted Pat's expressions as meaningful parts of a dialogue-like exchange.

The parents used imitations and affect attunement behaviours. Both the parents and Pat initiated vocal dialogues and imitations. The parents occasionally used tactile signs. At the age of 4 years, the parents told us that Pat had been prescribed a pair of glasses. They hoped that she now would be able to detect more visual cues. As previously, we could register how Pat and her parents could take part in dialogue-like exchanges where each had an active role and where the initiative changed back and forth. The parents were sensitive to her expressions and every change in body or head posture was interpreted as intentional and meaningful forms of communication. When vocal contact failed, the parents started to blow or touch her face. Pat's responses were primarily by means of smiles, vocalizations, but also occasional laughter. The parents used tactile signs in communication with Pat a couple of times.

When Pat was almost 4 years 5 months old, she was visited once more. She had grown since the last visit and showed better head stability. The patterns of interaction between Pat and her parents were much the same as last time, with one difference. Pat could now initiate contact to a higher extent than before and her expressions seemed more conscious and intentional.

When Pat was visited at 5 years 2 months old she was lying on a carpet. When her father approached her and asked if she wanted "...to come to Daddy?" she vocalized, moved her body and smiled, and the father placed her in his lap. This became the start of a long dialogue-like interaction between the father and Pat that lasted for several minutes. The father asked questions like: "Do you want to be with Daddy for a while?" "What have you been doing today?" "Do you want to sit on the sofa?" Pat answered with vocalizations and smiles.

Towards the end of the recording, the father was feeding Pat. After a while they took a pause and Pat laid her head on her father's chest:

The father said: "Pat, would you like to have some more?"

Pat opened her mouth, moved rapidly backwards and moved her left arm, as in the sign...
for MORE.
“Oh, how clever you are?”
The father bends forwards in order to be able to take more food from the plate to give to Pat.
“Would you like some more?”
Pat: “Hmmm”.
Pat bends her body backwards and vocalizes. She moves her left arm upwards.
She puts it down and touches her father (intentionally?).
The father gives her some more food: “Would you like some more?
Pat looks at her father and vocalizes.
The father rubs the tip of his nose on hers and says something to her.
(It is not possible to distinguish what he says).
Pat: Vocalizes.
The father: “Hmm”.

(Time: 59 seconds)

This was the first time we had registered that Pat used a body sign to communicate intention. Some time later, she repeated the sign and once again she was given something to eat.

Gus

Gus was 2 years 4 months old when we first visited him. His was first diagnosed as severely visually and profoundly hearing impaired. He was suspected to have brain damage, as he had both motor and intellectual disabilities. As he grew older, it was found that his hearing loss was not as profound as first assessed. His visual abilities had been more difficult to diagnose, but his vision apparently improved when he was prescribed a pair of glasses. His cognitive functioning had also been difficult to assess as he had difficulties both with his fine and gross motor control as well as difficulties in making himself understood. However, observations showed that he probably had a cognitive ability that had been underestimated. Gus lived with his father, mother and two younger siblings.

Play was the general theme during each of the video-recordings made. He particularly enjoyed plays with big movements, for example when his mother made him turn around in his walking chair in a rapid pace, or when she let him throw himself backwards quickly. When a well-known game was to be repeated it was clearly shown in his happy expression how he was anticipating the next part of the play. Gus initiated contact with the others by moving towards them and by using speech or speech-like words as well as gestures and some signs. The parents had started to use single signs with him when he was diagnosed as profoundly hard of hearing, but as they found that he could hear more than expected, they started to rely solely on speech in communication. Gus liked to listen to music. He could interact with his mother by means of vocalizations, eye gazes and body movements. He had started to utter single words, and occasionally used signs.

At the age of 2 years 4 months, when visited for the first time, he was engaged in listening to an audio tape-recorder. He had an audio-tape with nursery rhymes that he enjoyed listening to. One of the songs was about a boy
called Gus, which he particularly liked. Each time his name was mentioned, he smiled. Gus had a vast repertoire of facial expressions for joy, surprise, play, wonder, anger and irritation. According to the way the mother responded to his reactions as well as her comments to the observer, she interpreted and understood many of his thoughts. He seldom used vocalizations or other sounds. He showed his intentions by repeated body- and/or arm movements, indicating, for example, “One more time”. The mother responded to all his movements and expressions.

The mother’s utterances to Gus were primarily rhetorical questions such as “Are you a naughty boy?” or “Do you want to play now?” She also made several comments about how clever he was. She places the sign CLEVER on his upper forehead a couple of times, i.e. where the sign is located in sign language.

During this first visit it could be registered that Gus was in an intensive period of experimentation and exploration of the environment. He was also interested in social interaction. However, he could not yet interact socially and explore the world simultaneously. At the age of 2 years 10 months the play between the mother and Gus had developed. It now involved well-known moments, pauses, repetitions as well as close physical contact. They often engaged in well-known children’s games and the mother elaborated the games to fit his special needs and abilities. The mother was now observed to be more skilled in visual–manual communication. She made sure that she had established mutual eye contact before signing. She also signed with Gus’ hands. The mother had also started to introduce new aspects to their interplay. She let him touch her nose at the same time as she touched his. She introduced different songs and body plays. He showed clearly and loudly which part he liked and which he disliked. He produced a lot of vocalizations and it was possible to distinguish between different emotional states, such as joy and discontent, from the sound of his voice.

When visited at the age of 3 years 2 months his father was at home with his son. Again, mutual play was characteristic of the interplay between Gus and his parent. Peek a-boo, turn taking and expectancy play were occurring frequently. According to Gus’ reactions, it was obvious that this was the type of interaction he preferred. He laughed heartily and intensively in these instances.

At the age of 3 years 6 months Gus was watching and listening to a television program when we arrived. One of his favourite programs was broadcast: a dramatization of the Finnish author Tove Janson’s *The Moomin Troll*. However, the mother wanted to play with Gus and get him to practice moving around. Detailed analysis of the 25 minute video-recorded interaction illustrated how the mother and Gus each had different wishes at that time. Finally, they found a solution and towards the end of the recording they sat close together, watching the television program. It was an interaction mostly in line with Gus’ intentions.

At the last visit to Gus’ home, when he was 4 years 1 month old, he was laughing loudly during most of the interaction and for prolonged periods of time. Play was again the most frequent activity. This time, the play had
become wilder, more exaggerated and advanced. Gus invited his mother to take part in his play and he varied theme and content. The mother followed him in his play activities and reciprocity and joy was once more characteristic of the interaction. Gus both vocalized and started to form the sounds of the consonant “b”.

Sue

Sue was 3 years 7 months old when we first visited her. She had been a premature baby, and required intensive care during her first months of life. Sue lived with her parents and two siblings, one older and one younger. During her first year of life, the parents did not find it possible to establish contact with her. They described the situation as “she was just lying there”. It was later found that Sue had a hearing loss and a moderate visual impairment. She had recently started to wear a hearing aid. The parents and her siblings used speech in communication with Sue.

At the first visit it could be registered that Sue spoke in multi-word sentences, even if the articulation made it difficult for an outside observer to discriminate all of the words she used. Sue visited a speech pathologist regularly. But for a while she had not been able to see Sue and the mother thought this was the reason why Sue’s speech had deteriorated.

At the first visit to the home at the age of 3 years 7 months, three children and the mother played in the children’s bedroom. The mother played peek-a-boo with the two younger children, while the older child played by herself. Towards the end of the video-recording, Sue initiated a role-play.

From Sue’s point of view this whole interplay must have been difficult to take part in. The room was small and the children and the mother were talking to each other most of the time from different parts of the room. Sue showed some understanding of the content of the dialogues, as she looked in the direction of a certain object mentioned. She initiated contact several times with her mother, but it was difficult for her to gain her mother’s attention, as the mother could not understand what she was saying. Sue wanted to sit close by her mother. This seemed to be the most effective way for her to get the mother’s full attention and to be able to start a dialogue. In these contexts several dialogues could be recorded. The content of the dialogues was about the toys they played with or the object they were looking at. The mother often posed questions to Sue, such as “How old are you?” “What is your name”, questions children are seldom interested in answering, as the information is already well known. A couple of times Sue initiated peek-a-boo and pretend play with her mother. These initiatives were responded to in a positive way by both the mother and the siblings.

Three months later, when Sue was 3 years 10 months old, she was visited again. The video-recording was made during a mealtime. Sue was now observed to use a couple of signs upon request and she could finger spell her name. The mother posing questions and Sue answering them by nodding her head or responding with signs. Sue frequently initiated contact with her
mother but the mother also had to attend to her other children and Sue soon lost interest, and started exploring her toys.

Sue could not be visited again until she was 4 years 10 months old. When communicating, Sue and her mother used speech, although Sue was observed to use signs occasionally. Her speech development had now improved, both in terms of the length of sentences and the content of the conversation, but also with respect to articulation. As an observer, it was much easier to understand what she talked about this time, compared with the year before.

During the video-recorded interaction, the mother, the older sibling and Sue were sitting close to each other looking at the pictures in a book. There were several pictures of different objects on each page. At first, the children had difficulty in sharing each other’s attention, but finally the mother decided that they should take turns in to name the objects. This turn taking order worked, and for 25 minutes, the children were looking at the pictures, naming them one by one. The mother had to leave the room for a couple of minutes and the older sibling took the role of the interrogator and Sue the responder, and then they changed roles. Sue could answer most of the questions the sister posed. Occasionally she could not remember the name of the object, but answered in terms of its function. When the mother and Sue started to discuss other topics than the here and now present, for example, what Sue had been doing or experiencing, she became more expressive and talked in complete sentences.

When last visited, Sue was 5 years 11 months old. She looked like a young school child who liked to count and write. She had started to wear glasses. She seemed more self-conscious, maybe even somewhat embarrassed in the presence of the camera. The mother wanted her to talk and to tell us about certain topics, but Sue showed no interest. Our interpretation was that she was so absorbed by her books, both by looking at pictures and reading the text that she did not have time or interest in answering her mother’s questions. The mother interpreted this somewhat avoiding behaviour as due to problems with her hearing aid. But in the beginning of the video-recording, we observed that Sue answered a question the mother posed from a distance, when at the same time an electric food processor was being used. Therefore, her behaviour was probably due more to lack of interest, than to the hearing loss. But it was obvious that she could share her thoughts and actions with others, if there were opportunities to do so.

John

John was 3 years 5 months old when first visited. When he was 1 year old it was stated that he was totally deaf in one ear, but reacted to some sounds in the other. He was wearing a hearing aid. He was totally blind. There were no other functional disabilities diagnosed. His family comprised parents and a younger and an older sibling. The parents had also started to learn sign language.

At the first visit, when John was 3 years 5 months old, we observed that John could be intensely occupied with exploring the surrounding world with
his hands and other parts of his body. He also took an active part in social interaction with his mother. The mother used speech and signs when communicating with him, as well as touch. A couple of months later the communication was concentrated around play. John could now show his intentions more clearly than before. At 4 years 8 months of age the play had become more advanced in content and form and mother and son started to share references. At the age of 5 years 6 months communication was primarily by verbal means, i.e. tactile signs, and the content was about the here and now present.

At the first video-recording, John was lying on the kitchen floor with his mother by his side. He explored his hands very carefully. The mother observed him and she reacted to every expression or movement, which could be interpreted as a sign of interest in contact. The mother used vocal affect attunement behaviours to attract and, later, to keep his attention. She lowered her tone of voice when she was turning her attention to him. Their contact was also by bodily means. John used body movements, head turns towards or away from the mother, hand- and foot movements, sounds and a couple of signs when communicating with his mother.

He spent considerable time in exploring his surrounding world. He put objects into his mouth; he felt them with hands, mouth and tongue and by turning and twisting them. His interest in the physical world was occasionally interpreted by the mother as disinterest in her or in any social contact. Many similar interactions have been observed between parents and blind children (e.g. Preisler 1991, 1995).

The mother tried to initiate vocal contact with John several times, but he did not show interest in interaction. One question raised when analysing the sequences was whether he was aware of that she wanted to interact with him. He could probably feel her presence, her warmth, and the way she smelled as she touched him every now and then. But it was obvious that the mother and the boy had difficulties in sharing a focus of attention.

On several occasions during this video-recording, John was guiding or showing his mother the way he wanted her to act. He showed with facial expressions, posture and body movements how he wanted her to rock him back and forth, both with respect to direction and pace. In most of these instances the mother seemed to understand his intentions as he reacted with a smile on his lips. But there were also instances when he tried to express an intention by using signs, which the mother initially did not notice or even misinterpreted, as in the next example:

John and his mother have been playing a give-and-take game with a brush. But then John lies down on the floor, somewhat away from the mother, and he holds his hands over his face and eyes. He looks a bit tired.

The mother: “Don’t you want to play any longer?”
She takes the brush and caresses his right hand twice, with a short pause.
John is quiet.
The mother stops caressing him. She watches him.
She initiates contact by “knocking” with the brush on his hand.
John waves both hands in circular movements in front of his face: MILK.
The mother leans forward: “Shall we get something new to you?”
John vocalizes. He makes a new movement with his hands: the one hand’s finger over the other hand’s palm.

(Time: 10 seconds)

In this situation, the mother did not understand that John wanted to have something to drink, but that he might want to play with something else.

The mother lifts him in a standing position. She walks with him to a drawer where the brush is to be placed. They put the brush into the drawer. John starts to search for other objects with his hand, picks a fork and explores it with his mouth. He then throws the fork on the floor:

He makes an up and down movement with his right hand. He vocalizes and sits down on the floor. He repeats the movements: MILK.

The mother takes his hand, moves it up towards the drawer and gives him a new object to explore. The mother talks to him and comments what he is doing and how he is doing it.

John makes a movement with his right hand.

The mother: “Do you want to drink? No, not while you are sitting here”.

John repeats the movement. The mother takes his hand:

“If you want to drink then we will take a glass of milk”.

She raises him to a standing position, takes his hand and makes the sign for MILK.

(Time: 3 minutes 2 seconds)

They walk together towards his chair by the kitchen table and she gives him a glass of milk.

When John was 3 years 10 months old the mother had started to use tactile signs with him. When she initiated contact with the boy she carefully put her hands under his and started to sign. John often smiled in these situations, and we interpreted this as a sign of shared meanings. During a couple of occasions during this video-recorded interaction, he made the sign for DRINK. But when the mother showed him a glass, he did not show any interest. The mother made a comment that John often used this sign not as a request, but rather as a way of expressing different wishes or just as a mode of establishing and maintaining contact with the outer world.

Characteristic of the interaction at 4 years 1 month of age was that the John and his mother were occupied with different give-and-take and expectancy plays. At the age of 4 years 4 months, John knew several signs. He also showed interest in exploring his environment, actively and systematically, by means of hands, mouth and body as well as interest in other people. He recognized the different members of his family and, according to the mother, showed special interest in his younger sibling. He wanted to touch other people’s fingers and hands, and she believed that this was his way of recognizing different people.

When visited at the age of 4 years 8 months the mother made frequent comments to John about what she intended to do, by signing with his hands. At the age of 5 years 1 month he explored his mother’s hands and fingers carefully, particularly her rings that she had not worn for sometime. He touched his own body several times; particularly the ears were thoroughly
investigated. John repeatedly initiated plays with the mother. The theme was primarily to take one’s turn or to give and take objects. The play became more complicated and advanced. At the same time the play became more wild and courageous. John did not only want to move in a certain way, he was not content until the mother was performing similar movements. There was a lot of physical intimacy initiated by John. They were imitating each other’s sounds. The imitations could also be the mother knocking on the floor and John answering by waving his arms. The mother often held her hands close to John and offered them to him occasionally in order to make him able to communicate with her. On one occasion he started to touch and explore a ball. At regular intervals John searched for his mother’s hand and showed her not only that he wanted her to touch the ball but also how she should handle it. Thus they could share a focus of reference and mutual interest in an object in a way that had not been registered in the earlier video-recordings.

The last video-recording was made when John was 5 years 6 months old. He was lying on the floor playing with his hands. As soon as the mother approached him, he became active and started to communicate.

He makes his mother take his hand and signs COFFEE TIME.
The mother: “Do you want to have . . .? You have to wait for a while.”

(Time: 29 seconds)

John started to grumble, but when the mother helped him to stand up and started to interact with him, he looked pleased again. As soon as he was standing up, his whole appearance changed: from that of a baby when lying on the floor, to a pre-school child. He now had good body posture and he could stand straight and steady in front of the mother. In addition, his body movements seemed more deliberate and intentional than before. Auditory input now seemed more meaningful to him. He started to produce sounds with different toys. He banged them towards the table while he imitated the sounds. He blew into holes in toys, and thereby produced new sounds. He could occupy himself with toys for a period of time, carefully investigating and trying out their functions. As soon as the mother approached him, he took her hand and put it, for example, on a toy where he was spinning a wheel. This was repeated several times. We interpreted this as a way of showing that he wanted to share his experiences and activities with her. Actions became both the form and the content of the communication.

During this video-recorded interaction, John and his mother rarely used signs, but both seemed inclined to use it when necessary. John was constantly holding his hand close to his mother’s as if he wanted to have a channel available for communication. When they used verbal communication, the content was mostly about food, drinking and having biscuits. On several occasions we observed that John was smiling and even laughing, which had seldom occurred earlier. He could communicate with his mother and she with him, even if the communication was mostly about concrete objects and about the here and now present.
Nick

Nick was diagnosed as blind at the age of 4 years. When he was 1 year old, the parents started to suspect that he also had a hearing loss. He was later diagnosed as deaf. The aetiology of his deafblindness is not known. Nick lived at home with his both parents and an older sibling.

There were several video-recordings of Nick, as the parents started to make video-recordings of him when he was 6 months old. During a period of almost 7 years, it was possible to register how his communication development followed the same path as that of a sighted and hearing child. It started from early patterns of interaction with dialogue-like exchanges and joyful playful interactions, to interest in the surrounding world with explorative behaviours, to intentions to share his interest and attention to the external world with others. Towards the end of the observation period, he started to use single signs in communication.

At the age of 6 months, the interaction between Nick and his mother did not differ from how mothers and babies interact at this age. The mother was talking to her child in “motherese” and she told him what she intended to do to him, how he seemed to like what she was doing to him, and she also started to get him to join in dialogue-like exchanges. She touched and caressed him constantly. Her comments to him were, for example: “How clever you are”. “Could you do that as well”, i.e. she seemed to realize that he was a competent and alert baby. In the dialogue-like exchanges, the baby used sounds, laughter and vocalizations while the mother used speech, body plays and songs. The mother moved a lot when she talked and sang to him, which probably facilitated his understanding of what she was expressing. At this age he had not yet been diagnosed as hearing impaired and it is difficult to judge from this video-recording that this would be the case. The mother treated him as a hearing child, but she supported her actions with bodily contact as well.

The next video-recording that was analysed was taken when Nick was 1 years 6 months old. The most characteristic of the interactions analysed was the vocal dialogues between mother and child. It was not until repeated registrations had been made, we found that there was a slight mismatch in these dialogues. However, the mother quickly adapted her way of talking and vocalizing to her son's reactions, as if she wanted to form a well-functioning turn-taking pattern. Nick showed manual interest in some toys that he was presented with, but others did not evoke his interest to the same extent. These toys were only very quickly investigated and then left. Closer observation showed that he needed time to investigate a certain object before he was prepared to explore another one.

When Nick was 3 years old, he had become tall but very thin. His head- and body postures did not seem as steady as before. His sounds were weak and reminiscent of a younger child’s vocalizations. He could take a few steps with support. He was poking his fingers into his eyes. There was a dramatic change in his whole appearance at this age. The diagnoses of deafblindness had now been made and Nick and his parents had had
their first contact with a team of specialists of deafblindness. The emotional situation for the family had changed dramatically, which could also explain his way of reacting and expressing himself. The family was still in shock.

At the age of 7 years we registered a well-functioning interaction between Nick and his mother. Sign language had been introduced in the family and we could observe in the same way as in the case of John, how the hands of Nick and his mother were alert in a way that had not been observed before. They were now an important means of communication. Nick seemed very eager to have his mother’s hands close to him so that he could use them for communication when he wished. The communication became based more on verbal means both from the child and the mother.

The following excerpt from the last video-recording is presented as an illustration if this.

It is time to eat. Nick takes a seat at the table. He moves his hand over the edge of the table. His mother gives him a plate with food and he starts to eat by himself with both hands. Then he takes his left hand and starts to make searching movements. Is somebody there? The mother stands behind him, and then sits down at his side. Nick puts his left hand on his mother’s arm. He looks satisfied. Voices can be heard in the background. He opens his mouth and then closes it. He moves his hand towards his mother’s hand, and their hands meet. Their movements are almost in synchrony. Then Nick and his mother signs: I (YOU) EAT

(Time: 14 seconds)

The sign I (YOU) is placed on Nick’s body while the sign for EAT is placed on his mother’s mouth, albeit it is Nick who is eating. It is difficult to judge whether it was Nick initiating the conversation or the mother. Having watched this video excerpt closely we interpreted as if it was Nick has started the conversation. There are other persons in the room and one of them makes a comment:

“Nick, are you eating?”
Nick smiles and vocalizes.
“Are you having food?”
Nick pokes one of his eyes, turns his head towards his mother. (Is he becoming embarrassed?) The mother makes a comment on what the person said.
Nick takes his hand from his eye and makes the sign: FOOD/EAT (it is a similar sign for both words. The mother reaches out her hand, Nick takes it: “YOU ARE EATING”.
Nick smiles and laughs softly.
(Time: 22 seconds)

We interpreted his expression as a clear indication of mutual understanding. The video-recordings showed that at the age of 7 years Nick had started to communicate about the here and now present.
Discussion

All of the children in the study could communicate with their parents and the parents with their child. The parents primarily used speech, but also some signs and vocalizations. They used haptic means and body movements. The children used facial expressions, arm- and hand-movements, body movements and vocalizations and some signs when communicating with the parent. Even if the children’s expressions varied and were sometimes difficult to interpret, detailed analyses showed that the development of communication followed the same path as that of a non-disabled child. It started with interest in social games with the carer, developed into interest in the physical environment, and thereafter intention to share their experiences with somebody else.

The social games observed most frequently were different turn-taking and body movement games. Movements, sounds and touch were important communicative expressions in these playful activities. Thereafter the children started to show interest in and pay attention to the environment. They started to feel, taste, smell and, in other ways, test qualities and functions of objects. The children further showed that they wanted to share attention and actions with their carer. In some cases they had to guide their parents, showing them how they wanted a game or an action to be performed. All of the children in this heterogeneous group could share their experiences to some extent with their parents. Their way of expressing themselves differed, as did the content of the communication. But they all seemed to strive to establish and sustain meaningful and joyful interactions. In time, several of the children were able to take part in verbal communication.

For the two children first described, Mick and Pat, the communication was primarily on a pre-symbolic level. They could show intentions by means of body movements. They could also start to show that they wanted to share their experiences with their parents. Towards the end of the observations, Pat started to use single signs. The way Mick and Pat acted and reacted during the first observations was characteristic of children of between approximately 2 and 6 months of age, when they are experiencing a sense of a core self according to Stern (2000). Gradually they started to show intention to share experiences with another person. The way the children reacted to their carers, more clearly so with Pat than with Mick, when they were close to them physically as well as psychologically, confirms that this is a possible interpretation.

Gus and his parents could share meaning particularly in playful interactions, which are characteristic of experiences of a subjective self. In this period, the infant can clearly show communicative intent. Other characteristics are interest in exploring and experimenting with the physical environment. This means that there might be temporary difficulties in sharing experiences with somebody else. But gradually the infant will be able to share its experience and interest with the carer. Towards the end of observation period, Gus and his carer could share experiences by verbal means.

Sue was a child who could hear a lot and who also could use her vision to an extent that the other children could not. Sue and her mother could
communicate by verbal means. Sue lived in a large family where she had to share both the physical as well as the psychological space with siblings who were only slightly younger and older than her. It could be difficult for her to be able to perceive all that was said or all actions that took place at the same time. Her need for very close physical contact with her mother during the first recordings could probably be interpreted as a need for security and tenderness, but also a more concrete need for being close to somebody in order better to perceive what the mother said and to use the mother as an interpreter of the visual and the hearing world. When Sue was alone with her mother or when only one sibling took part in the interaction, Sue’s needs could be satisfied in a more adequate way and the communication was more or less without misunderstandings. Towards the end of the study, Sue could take her first steps towards an experience of a narrative self, i.e. to perceive and to interpret human activities in terms of a story (Stern 2000).

Both John and Nick were deaf and blind without any other known functional disabilities. Towards the end of the study, they started to communicate by using single signs. As the parents started to use tactile signs in communication, the children received a tool to be used in communication. John started to use one and the same sign for several activities. It was not always a way of asking for something or telling about something, it could also be used as a way of attracting the carer’s attention. Even if the number of signs or the variation of the signs used was limited, it could be registered how important the hands were as a means of communication – both the child’s and the carer’s hands. Initially the parents grasped the children’s hands and formed them into a sign. But in these instances there was a risk of stopping the child using their hands freely and keeping them open for dialogue. When the parents instead started to offer their hands to their children, the dialogue became more extended. The ways John and Nick acted and reacted indicate that they were entering a period of experiencing a sense of a verbal self.

The results of this study confirm those of other mother–infant interaction studies; that infants’ perceptions seem to be tuned in to human and social stimuli and that all children have a congenitally, hereditary ability to communicate with the social environment (Trevarthen 2001). Despite severe functional disabilities in several cases, the children could take part in communication and share meaning. But the results also point to the difficulties the deafblind child has in interpersonal encounters. As they cannot see the communication partner, they cannot imitate the actions of others. Research on mirror neurone systems has pointed out the importance of imitation of visuo-motor actions of others for language and communication (Rizzolatti & Arbib 1998). As they cannot hear what the other says they have to rely on their other senses, such as touch, smell and movement. Thus, the input of information is very restricted for a deafblind child, especially for a child who has additional functional disabilities.

Neurological research shows that early emotional experience has on impact on the development of the young brain. Interactive experiences may therefore result in a reinforcement of neural-pathways, while lack of such stimulation may be damaging for the child’s development (Greenspan 1997). Every step
on the developmental path takes considerable time for the deafblind children to achieve. They are, more than most other children, dependent on their parents or main carers for positive early development. It is therefore an important task for habilitation services to give these parents emotional support, to encourage them to communicate with their child by all possible means in order to find a way to meet the needs of their child. It is of importance to encourage them to initiate joyful, playful and above all, meaningful interactions with their child. This seems to be the best nourishment for positive development in deafblind children.

References


