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Speech held at the World Conference on Deafblindness. Lisbon 1999 by Jan van Dijk (Prof Dr. The Netherlands.) In co-operation with Barbara McLetchie, Cathy Nelson & Isabel Amaral

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Development through relationships.

Entering the social world

Introduction

Development Through Relationships: This is the title of the XII DBi World Conference on Deafblindness and it is with this title that the interrelationship that exists between human beings is emphasized.

It is in the origin of the human species that man lives together with other members of his species, experiences protection, and is given models for learning. As we look back into history some hundred or more, children were found who did not grow up within the group of their own species. Rather famous is the story of the wild boy of Aveyron, who was brought up by a group of wolves. Itard gave us a vivid description of how the boy failed to develop speech and stayed, despite efforts to stimulate his thinking, intellectually backward. It was very hard to teach him new skills because he was almost completely unable to adapt himself to the new situation in which he found himself. Cases such as this one demonstrate the enormous importance of living with other human beings, being protected by them and learning from them. In the many thousand years of mankind's existence, educational patterns have developed that are imprinted in the human nature. Therefore, it is a universal trait of our species that mothers have the innate skill of mothering. They are able (and it seems that this is similar in all cultures) to provide the newborn child with warmth and security. Mothers feel that the newborn child needs a safe harbour for exploration. We all know the child who ventures out of his mother's sight at a certain stage of his development, but when he encounters danger, flees back to her for comfort and security. If this secure base is not provided, the child will exhibit symptoms of stress. In this paper, I will approach the behaviour of a child who is congenitally deafblind from the findings of the neuro-biological theory of stress.

2. Neuro-biological foundation of stress

The world of a deafblind child

Recently a number of studies have been published (Nelson and Carver 1998; Rotenberger and Huther 1997; Burgess, Hartman, Faan and Clements 1995; Black 1998; Perry and Pollard 1998; Boyce, Barr and Zeltzer 1992) that demonstrate a relationship between brain formation and the ability of the child to cope with stress. These studies give great insight into the problems of development in children with multisensory impairment. Modern techniques such as MRI's and PET-scans have made visible what we theorized for many years. The purpose of this presentation is not to give you a retrospective of my work and that of my colleagues over the years. But, as a matter of fact, it has surprised me that so many ideas

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which were presented by us in a rather global manner have caught on in the educational practices of people all over the world. Although not proven, it does demonstrate that what educators of the deafblind felt through concepts such as co-active movement is an essential aspect in the relationship with the child. By doing things together with the child, following his movements carefully and touching the muscles of his limbs to discover by his muscle tone whether the child's affect was positive or if stiffening indicated a desire to retreat, the educator was able to sense the emotional status of the child. In moving-acting together, in which the sense of touch plays a dominant role, the educator acknowledged the uniqueness of the world of a human being with multi-sensory impairments. This world can be characterized as one in which "closeness" and "proximity" are the most striking features. It is only the child who can tell us through the minor changes of his body how he experiences such "togetherness" with his educator. We have emphasized that the true educator of the deafblind is a person who is able to share this world and who can set aside the world of hearing and sight in which he himself is living. It is bad practice when the educator approaches the child from his own frame of reference where he is not able to wait until the child reaches out and is not aware that the sense of touch is a sense in its own right. Such an educator does not realize that the object being touched has to be explored from all its angles and that it takes a lot of time to compare the similarities or the differences between this object and another one. (Schellingerhout, Smitsman and Van Galen 1997) From the studies on stress, we have become aware that imposing activities on a young child in such a way that he is unable to escape undermines the development of the neurological system and even destroys existing neuronal pathways.

2. Educational failures

I have been wondering, why, during all the years of intensive work with deafblind children and adults so much went wrong in the development of these human beings. We lack solid statistics in our field, but it is estimated that about 60-80% of the congenitally deafblind children have moderate to severe intellectual impairments. It is coming more to the forefront of our field that many persons with deafblindness exhibit abnormal behavioural patterns and some of these are merely sociably unacceptable, but others may be life threatening, such as is seen in self-abuse. Deafblindness was closely associated with autism less than two decades ago. The diagnoses of autism were established based on a number of symptoms, but particularly on stereotypical behaviours and aloofness. At this time, it is becoming rapidly clear that autism is a genetic disorder that should be distinguished from symptoms derived from social or sensory deprivation (Szatmari, Jones, Zwaigenbaum & MacLean 1998). When the educator of deafblind individuals lacks the insight and skill to understand the world of the deafblind child, one can observe how the individual retreats into himself, avoids touching objects, and attempts to cope with his "unbalanced organism" by exhibiting stereotypic behaviour. The question of how this scenario can be prevented or remediated arises. A neurological predisposition often plays a role, but this is not the complete explanation. The role of the environment must be considered as well. Do the persons in the environment of a human being who is bereft of hearing and sight provide the most appropriate conditions? Do our educators have the right attitudes and skills to follow the specific roads of development of the deafblind child? In her research study, Marleen Janssen from the Netherlands, has analyzed teachers' behaviour through the application of microanalyses. It has become clear that often the teacher misses out on the child, and by doing so, continuously destroys the formation of concepts by giving confusing suggestions to the child. This creates in the child a feeling of loss of control of the situation (Janssen, RiksenWalraven & Van Dijk in press). It is this confusion or chaos that can be considered one of the reasons why so many congenitally deafblind children have weak memories and learn so slowly. The studies quoted above demonstrate that in young children, as well as other mammals, the structures of the hippocampus are only well formed when there is a great regularity in the individual's life.

3. Routines

As we have stated earlier in our work (Van Dijk 1986 and 1991), routines are very important in deafblind

education. Modern neuro-biological findings show that when the neurological system is faced again and again with the same sequence of events and is therefore able to anticipate the next one, the condition is favourable for the growth of the neural pathways. When it comes to the establishment of a solid bond between mother/ principal caregiver and the child, this memory process plays an important role as well. In order for the mother to become a safe harbour, the child must have established a clear working model of this person in his mind. In this case "the mind" can be called hippocampus which is part of the limbic system (our emotional and motivational system). The working model can only be stored firmly in the subcortical structures of this part of the brain when there is enough repetition and when the child undergoes a positive feeling as he experiences the security she provides. Herewith, the basis for the motivational system is laid. This means that the child is willing to incorporate another person in his life. It should be noted here that we have still insufficient information as to how to enhance the formation of a working model into the child's mind when he is deafblind. Is it based upon the scent of the principal caretaker, on her/his way of moving and the routines of activities? Most likely, it is a combination of all of the above factors. It is obvious that when a child, whose emotional balance is easily disturbed, is provided with many different caregivers, it is hard, if not impossible, for the foundation of security to be laid. Recently this had been affirmed by a study of Romanian orphans. It appeared that in those youngsters who had received scant mothering, the levels of cortisol were established in such a way that they did not serve the neurobiological system dealing with stress. It is very interesting to report that when a very specific educational program based upon routines and security was offered during one year, success could be measured by more favourable cortisol levels. In this regard, the studies of rats provide us with very significant information. It has been shown that molecular changes in the hippocampus can be achieved by caressing the young rat's skin twice per day. It appears that a brush moved over the rat's fur two times per day for five minutes as the rat matured was sufficient to help the animal to cope with stressful events and to improve his social adaptation. It appears that the period that is the most effective for the molecular change occurs early in life. In deafblind education we have stressed the fact that stimulation of the skin enhances the development of a strong relationship between mother and child. I am aware that so-called massage programs have entered our field. As it is true for all educational measurements, such a program must have a sound base and fit into the total approach for the child. It is unclear until what age such programs have experienced success. It has been argued for quite some time that there is a critical period for establishing an effective bond between the child and the principle caregiver. In normal development, it is a generally accepted fact that the most sensitive period is between 9 and 18 months of age. However the follow- up studies of the Romanian children show that this period might be quite longer. (Meaney, Carlson, Smith & De Kloet 1998)

4. Assessment

Only through careful assessment can it be established whether or not an effective bond is growing between the child and his/her caregiver. It is possible to observe this when the child encounters stressful situations such as when he is hurt. Does he seek out his caregiver for consolation or does he simply find the nearest lap to climb upon? In a rather informal assessment method, I always ask the mother to leave the room for a few moments after having said good-bye to the child. Upon reunion, I observe whether the child shows signs of comfort as opposed to anxiety or anger. When the latter is the case, the child might have already formed a working model of the caregiver as a person he cannot trust. Through the technique of the Strange Situation, it has become clear that 35% of children all over the world have already build up such a negative model of insecure attachment. It can be assumed that this percentage is far higher when it comes to children with impairments. Broesterhuizen estimates that no more than 25% of deafblind children have a secure bond with their mother. There is hope that in the future, increasing numbers of deafblind children will have a more favourable start in their lives as educators are becoming aware of the uniqueness of the world of the deafblind.

Thus far, we have emphasized the importance of mothering. In essence, this means sensitivity to the needs

of the child. That so many parents of deafblind children, despite tremendous efforts, "miss-out" on their child can be attributed to factors relative to the child's temperament. In some children, (e.g. the child born prematurely), the level of arousal is so high that even the smallest changes in the environment, including mother's behaviour, might set off periods of crying and fussing that might give the principal caregiver a feeling of incompetence. She might try harder to comfort the child which only adds to the stress for both. A recent study has shown that intervention strategies focused on the improvement of mother-infant interactions have been rather successful. The irritable children, whose mothers had 6 months of training, were, at the end of this period, more sociable, self soothing, explorative and cried less than the control-children (Van den Boom 1994). Another type of child who is vulnerable to receiving inadequate mothering is the infant with facial-deformities. In the "new deafblind population" we see quite a number of these children (e. g. children with Goldenhar , Charge syndrome or children with Treacher-Collins syndrome). It is suggested that since the face is the primary tool of human communication, it may play a crucial role in bonding and attachment (Perry, Czyzewski, Spiller and Treadwell-Deering 1998). Early facial repair, if possible, is advised. In my experience, training parents and staff to pay attention to the total physical appearance and positive behavioural traits of the child rather than focusing on the face alone might help to establish more normal interactions with the child.

The work of Bowlby and Ainsworth that laid the basis for attachment theory some 50 years ago has had tremendous impact on the theory and practice of child development and child pathology. Initially there was pessimism as to whether or not a bond could be established with a child after the critical period had passed, but recently, there are indications that even when the start of life has been very difficult, "attachment-systems" stay open for quite a prolonged period of time. It is generally agreed that the neurobiological systems upon which attachment is based are "locked" quite early in life, but that as the maturation of the child continues, other avenues of learning are becoming available. It has been shown that some deafblind children are quite motivated to adapt their social behaviour when a peer models appropriate behaviour or provides reinforcement (Lancioni, Oliva, Andreoni & Pirani 1995). It had also been observed that in deprived monkeys who lacked social skills, a younger monkey could act as a "therapist" by contributing actively to the rehabilitation process. Although the deficiency in social competence persisted, the acceptance of the deprived monkey within the group improved through social learning. We need further research on the effects of inclusion and intervenor programs on the behavior and social learning of deafblind youngsters and the underlying foundations of them. Perhaps the improvement in the neurobiological factors that influence the lowering of stress may play a role here.

5. Entering the social world

It can be stated that the brain systems regulate the capacity to cope with the changing social environment (Kraemer 1992). These systems, which are the same as the ones that mediate attachment, are organized hierarchically. It is a challenge to discuss this neuro-biological organization relative to deafblindness. It shows how important assessment is in determining what the most favourable conditions for the child to build these systems are.

1. First of all, the child must give attention to the (social) stimuli and determine its significance. This can be illustrated by the following example: The child must be able to perceive a person approaching him and then remember that this is the person who provides comfort. The process of determining whether or not a stimulus is a significant one is called gating. The turning of the head in the direction of that person, tracking his movements visually, hearing the sounds of footsteps becoming louder and louder (doppler effect) increases cortical synaptic density. Immediately, it strikes us how a deafblind child is at a disadvantage in such a situation. For a long time, we were even unable to determine whether the child had the capabilities to perceive the stimulus. Since the last decade, tests have been developed that can give us information as to the degree of hearing and visual loss. These findings have explained the variance in the population of children we call "deafblind". It is through

the process of assessment that we can determine, in which situations and contexts, hearing aids and corrective lenses will be the most useful in enhancing the orientation and gating process. In virtually all studies on this subject, the senses of touch and vibration have been overlooked. One may only speculate whether these senses influence the increase of cortical synaptic density in a similar manner as do hearing and vision. Since we have come across totally deafblind children who are able to organize their world appropriately, one may draw the conclusion that the remaining senses of touch, vibration and smell have similar influences on brain development. It is our feeling that the process of stimulating the deafblind child to use the near senses must be very carefully guided. Vibrations that are too intense might lead to avoidance behaviour. Too rough of textures to tactile defensiveness, smells that are too intense to withdrawal. By carefully manipulating these stimuli, the assessor is able to find out what the most favourable condition for learning is, what the most favourable input channel is, and in what rhythm the stimuli should be presented. The latter is often very much dependent upon the child's temperament.

2. A second mechanism that is fundamental to the regulation of a child's relationship with the world in which he lives is his ability to determine the effect of the stimuli; whether it is rewarding, or if it should be ignored. If a child responds and there is a positive consequence, it is likely that both stimuli will be connected and stored in the brain. This connection occurs within seconds. In children who see and hear normally, the connections happen continuously, often without any intervention on the part of the educator. Perhaps the most devastating effect of deafblindness is that this type of incidental learning can hardly take place. In the assessment process, it should be determined how this type of contingent-learning occurs, what the best reinforcers are, and last, but not least, how often the stimuli should be repeated until the connection between the stimuli and consequence takes place. Only if this is properly planned can an organized system of knowledge develop in the child's brain.
3. A third mechanism to help the human being cope with the demands of his physical and social world is the pattern of arousal and relaxation, including sleep. In periods of high vigilance, gating and conditional learning are built up; during sleep, these behaviours are integrated at the gating level so that in the next occurrence of an identical situation, the problem will be treated as routine. This rhythm seems to be essential in providing the human being with sufficient adaptive capacity. We can observe that in people who succumb to stress, this mechanism is malfunctioning. One can only speculate as to whether the poor sleeping patterns which are often reported to exist in deafblind children can also be explained by the failure of this arousal-sleep mechanism. From a neuro-biological point of view, it appears that the daily life of an individual with deafblindness should be carefully organized in such a way that periods of intensive learning are followed by periods of relaxation in which routines have a prominent place and then by periods of sleep.
4. A fourth mechanism is the organizational plasticity. In order to adapt to the changing demands and challenges from the environment, our coping mechanism should be fine-tuned and readily available. One can observe that severe problems at this level occur in virtually all people who are congenitally deafblind. As soon as the social environment demands quick adaptation, it appears that the neuro-biological systems are inadequate. Clear stress phenomena can be observed that may lead to refusal, self-abuse and inappropriate social behavior. Often this behavior can be explained because the previous hierarchical stages, as discussed above, did not have a distinct place in the educational approach. However, sometimes the demands from the "hearing and seeing" world put upon a person with deafblindness are just too great. People come and go, touch, smell, talk, shout, request, demand, push and pull, all within a matter of seconds. Persons who are unable to communicate with a deafblind child or adult or lack the ability to read a deafblind person's body language may approach the individual who is deafblind rather unexpectedly. These "encounters" may have occurred over many years without the deafblind person having been taught an appropriate way to say "no."

Many efforts in the past to develop better educational programs for the deafblind have been successful. Some principles have received strong support from sciences such as neuro-biology. It is now time to adopt

a more total, holistic approach with strong emphasis on the environment and ecology. By environment, we mean the physical environment. We know how all- important good adaptation of space, light and sound is for an individual who is deafblind. The term, ecology, includes the hearing and seeing persons who share their lives with a deafblind individual. The attitude, the willingness to creep under the skin of a deafblind person, the willingness to listen to him, is the foundation upon which a true relationship between people can grow and flourish. It is our task , together with the individual who is deafblind, to pursue this theme in the next millennium so that we really can say that by DEVELOPING RELATIONSHIPS the individual may enter the SOCIAL WORLD.

Note: *This paper was illustrated by a CD-Rom produced by Jan van Dijk & Arno de Kort.*

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