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### A matter of meaning

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## Chapter 1

### **Introduction**

*Jamais nous ne nous sentons exister qu'après avoir déjà pris contact avec les autres*  
[We feel our existence only after already having been in contact with others]  
Maurice Merleau-Ponty (*Causeries*, 1948, p. 22)

## 1.1 Background of the study

Deafblindness is the term used to describe a unique condition that involves a combination of auditory and visual disabilities in various degrees (Ask Larsen & Damen, 2014; Dammeyer, 2012; Ronnberg & Borg, 2001). The number of people with deafblindness (DB) in the Netherlands is estimated between 33.000 and 38.000. It is assumed that approximately 2000 of these individuals have congenital deafblindness (CDB) (Vaal, Gussekloo, de Klerk, Frijters, Evenhuis, Van Beek, & Deeg, 2007), which means that they were born with DB or acquired this condition before the start of language development (Dammeyer, 2012). The estimated prevalence rates of DB and CDB may be an underestimation of the real prevalence. Studies have shown that service providing organisations for people with intellectual disabilities often do not recognize or acknowledge deafblindness in their clients (see Fellingner, Holzinger, Dirmhirn, Van Dijk, & Goldberg, 2009; Meuwese-Jongejeugd, Van Splunder, Vink, Stilma, Van Zanten, Verschuure, & Evenhuis, 2008).

Although many individuals with deafblindness have visual and auditory residual capabilities, they are nevertheless seen as part of the same target group. The term deafblindness is used for individuals who are totally deaf and blind as well as for individuals with residual vision and hearing to emphasize that living with a dual sensory loss is difficult. Deafblindness leads to challenges in communication, learning, getting information, orientation, and mobility (Dammeyer, 2012).

Communication challenges can have substantial consequences for the quality of people's lives. Communication is what makes human beings social. Several researchers have even defined communication as the essence of being human (e.g., Aitken & Trevarthen, 1997; Tomasello, Carpenter, Call, Behne, & Moll, 2005). According to Meininger (2011) all people including those with severe intellectual and multiple disabilities need to experience social connection with others. Communication challenges can distort these social connections, because these can have huge impact on individuals' social participation and family life (see Hilari & Botting, 2011).

In order to understand the nature of communication challenges, insight is needed in what communication is and how it is developed. Researchers have various models at their disposal with which to describe and explain communication processes between individuals. For example, communication may be conceptualized as a transfer in which communicators either send or receive information (Shannon & Weaver, 1949) or as a dialogue in which communication partners mutually co-construct meaning (Linell, 1998). The current study uses the definition of communication chosen by Janssen,

Riksen-Walraven, and Van Dijk (2003): “a form of interaction in which meaning is transmitted and shared by the use of utterances that are perceived, interpreted and negotiated by both partners” (p. 198). This definition includes the dynamic interplay between communication partners across all communication forms beyond speech and writing. This definition also emphasizes meaning making as a feature that distinguishes communication from other forms of social interaction. We have used the term ‘meaning’ to refer to products of the human mind, such as thoughts, beliefs and ideas (see Bruner, 1990).

Communication development does not start with language development. Early childhood studies have shown that communication is already present in newborns and it is therefore considered an inborn capacity (see Aitken & Trevarthen, 1997; Tomasello et al., 2005). However, it is through the interactions with other people that individuals develop this capacity and acquire language. Golinkoff (1986) showed that infants were engaged in long negotiation processes with their mothers to become understood. Through these kinds of meaningful social encounters with other people, children acquire the formal properties of signs and symbols and the relationships between them: what signs and symbols represent, and how language is used to achieve desired goals. Children also gradually learn to consider their listeners when making contributions to conversation (Eilan, Hoerl, McCormack, & Roessler, 2005) and come to understand that a single sequence of symbols may accomplish several goals at once (Sabbagh & Baldwin, 2005).

The development of communication and language is different for individuals with congenital deafblindness (CDB). Several studies have shown that they did not acquire basic elements of communication (Bjerkman, 1997; Bruce, 2005a). Researchers observed that individuals with CDB only communicated about objects or persons that are present in the here and now situation (Bruce, 2005a; Mar & Sall, 1994) and appeared to lack experience with exchanging thoughts (Rødbrøe & Souriau, 1999). Bruce, Godbold, and Naponelli-Gold (2004) even stated that there are no children with CDB without problems in developing communication.

An explanation for communication challenges in individuals with CDB is that culturally accepted linguistic communication means such as spoken and written language are generally not accessible to them. There are alternative means of communication for this target group though, such as manual signs and fingerspelling. It is striking that, despite these alternatives, the communication between many people with CDB and their social partners is generally of low quality: they frequently experience comprehension problems (Dalby, Hirdes, Stolee, Strong, Poss, Tjam, Bowman, & Ashworth, 2009) and communication breakdowns (Heine & Browning, 2002).

Studies thus far of social interaction between individuals with CDB and their social partners revealed low quality communication. This implicates that there is a need for an evidence based intervention that can improve the communication quality. The need

for developing a communication intervention for individuals with CDB and their partners and the need for evidence on the effectiveness of such an intervention formed the background of this study. In the following paragraphs we will describe challenges in developing high quality communication in this target group, the state of the art and gaps in current research, aim of the study and the outline of the dissertation.

## **1.2 Challenges in developing high quality communication with people with congenital deafblindness**

Low quality communication in individuals with CDB is often understood as the consequence of serious delays in their communication development. Dammeyer (2009) referred to their communication as ‘early communication’: communication that very young children display together with their parents. Bruce (2005a) and Hartmann (2012) described a lack of symbolic understanding and expression. In a 1994 study conducted by Mar and Sall, they found that 26 participants with DB (students aged two to fifteen years) exhibited non-symbolic and non-intentional forms of communication. The pre-symbolic or early symbolic communication of individuals with CDB (e.g., body language, gestures, vocalization and one- and two-word combinations in voice or sign) may be difficult for social partners to recognize (Bruce, 2003; Iacono, Carter, & Hook, 1998), leading to mutual misunderstanding (Bjerkkan, 1997). Misunderstandings are also considered to be an important factor leading to the frequently reported emotional problems and challenging behavior exhibited by people with CDB (Durand & Berotti, 1991; Janssen, Riksen-Walraven, & Van Dijk, 2004; Van Dijk, Carlin, & Hewitt, 1991).

Serious delays in the development of communication in people with CDB may be understood by the large impact dual sensory loss has on the achievement of developmental milestones, such as joint attention and object permanence. Bruce (2005a) described the difficulty individuals with CDB have in developing these milestones in relation to their unique way of being in the world. People with CDB need to develop an understanding of the world on the basis of tactile impressions, which takes much more time and effort (Bruce, 2005b). Communication delays can thus be understood as the result of the limited physical access people with CDB have to the world.

Delays in communication development may also be explained by the sparseness of meaningful social encounters with others. Several empirical studies have examined the social interactions of individuals with DB and CDB such as their interactions in the classroom (Correa-Torres, 2008), play and recreation (Lieberman & MacVicar, 2003), interactions with support staff (Prain, McVilly, Ramcharan, Currie, & Reece, 2010), interactions with a teacher (Vervloed, Van Dijk, Knoors, & Van Dijk, 2006) and interactions with siblings (Heller, Gallagher, & Fredrick, 1999). Both the quantity and quality of interactions seen in these studies were often poor for people with DB. Researchers not only reported a low incidence of interactions that occurred spontaneous

(Correa-Torres, 2008; Prain et al., 2010; Vervloed et al., 2006), but they revealed other problems as well: a lack of modifications in these interactions to make them suitable for the individual with DB (Heller et al., 1999), regular occurrence of avoiding contact by the participant with CDB (Vervloed et al., 2006), and a lack of praise by the social partner (Prain et al., 2010).

The communication competence of social partners is believed to have a large impact on the quality of interactions with people with CDB (Janssen et al., 2003, 2006). Several studies have shown that social partners do not naturally adapt their communication strategies to these individuals' support needs. Social partners of children with CDB regularly stood outside the child's tactile reach (Vervloed et al., 2006) and used communication forms that are inaccessible to the child (Bruce et al., 2004). These findings imply that social partners do not easily adapt to communicating with individuals with CDB. Goode (1994) explained difficulties social partners have with communicating with individuals with CDB as difficulties with participating in a world of proximity and touch. For individuals without deafblindness this requires high levels of sensitivity, special insights, and considerable skill. Both Correa-Torres (2008) and Janssen and colleagues (2003, 2004) found that the social partners of individuals with CDB expressed a clear need for coaching and support. This need for coaching and support suggests that social partners themselves experience that they do not have sufficient skills to communicate with individuals with CDB.

In sum, low quality communication with people with CDB corresponds with problems in the social interaction between these individuals and their social partners. This is the result of interplay between the characteristics of the individual and skills of the social partner. In the search for solutions for the observed problems in interaction between individuals with CDB and their partners, the skills of the social partners will be an important target for developing interventions.

### **1.3 State of the art and gaps in current research**

The need for effective interventions to support interaction and communication between people with CDB and their social partners is obvious, based on studies of their social interactions. Unfortunately, research on DB is limited (Dammeyer, 2014) and only a few interventions have been tested for their effects in this target group (Parker, Davidson, & Banda, 2007). Yet, publications about the effects of communication interventions in individuals with CDB, although sparse, can help service providers with the selection of evidence based interventions for implementation. When aiming at getting an overview of the effectiveness of communication interventions in people with CDB, it is important to understand that researchers use different perspectives. Two main perspectives can be distinguished: an Augmentative and Alternative Communication (AAC) perspective

and a developmental perspective. We will briefly describe these perspectives and give an example of an empirical study.

Communication interventions that are developed from an AAC perspective focus on the use of adapted communication systems such as tangible objects and communication boards. An example is the study conducted by Heller, Ware, Allgood, and Castelle (1994) in which three high school students who had low vision and profound hearing loss were trained to display correct communication responses by pointing at visual symbols on a communication board. The study reported high levels of correct use of the communication device during both the intervention and follow-up phases. A limitation of AAC studies is that they often focus on the use of devices by the participant with CDB and do not necessarily provide information about the effect on their communication with others. The question is then if the AAC intervention enabled participants with CDB to share their feelings and thoughts with other people.

Studies on the effect of interventions originating from a developmental perspective have a different focus than AAC research; these studies are aimed at determining whether interventions can foster communication and language development. However, this fostering is performed in many different ways and measures and methodological approaches may be diverse, which makes it difficult to compare their outcomes. In fact, we could distinguish two approaches: a social learning approach and an interaction approach.

Researchers with a social learning approach study the effect of skills training for people with DB. An example is the 1987 study conducted by Durand and Kishi, in which five adults with DB received functional communication training. Significant reductions of challenging behavior were reported for four of the five participants. A limitation of social learning studies is that they focus on the individual with disabilities, not on the social partner or the interplay between the individual and the social partner.

Researchers with an interaction approach study the interplay between the individual and his or her social partners. These researchers focus on both the abilities of the people with CDB and the competences of their communication partners, the interaction process, and/or the broader interaction context (e.g., the activity the communication is embedded in). One intervention based on an interaction approach is the early intervention program developed by Chen, Klein, and Haney (2007). In that study, caregivers of 27 infants reported that their interaction had changed as a result of the social partner training.

According to Rødbroe and Souriau (1999), interaction approaches became more popular because practitioners experienced that approaches that purely focused on skills training or the use of adapted communication systems were insufficient to help children with CDB achieve high quality communication. Practitioners therefore sought a solution in describing strategies social partners could apply in order to develop meaningful social encounters with an individual with CDB. Theoretical grounding for this approach

was found in early child studies, such as those on early attachment development (see Ainsworth, Blehar, Waters, & Wall, 1978).

Studies on social partner support with the Contact program indicate that the provision of interaction support to social partners positively influenced social interactions with people with CDB. The Contact program was developed and tested by Janssen and her colleagues (2003). The program aimed to foster harmonious interactions between children with CDB and their educators by enhancing the educators' interaction competences. They were given instruction and video interaction guidance by trained interaction coaches. Several single-case experiments found that the program improved the quality of social interactions between the children and their educators (Janssen et al., 2006; Janssen, Riksen-Walraven, Van Dijk, Huisman, & Ruijsenaars, 2011, 2012). One effect study showed that the intervention was also effective for 12 children and adults with visual and intellectual disabilities and their 72 professional caregivers (Damen, Kef, Worm, Janssen, & Schuengel, 2011).

The Contact studies revealed that interactions can be positively influenced by supporting social partners in adapting their interaction strategies to the individual needs of people with CDB. The developmental-interaction approach that was used in these studies seems to be the most efficacious approach for the support of individuals with CDB. A question is, however, to what extent such an approach can also enable people with CDB develop higher complex forms of interpersonal communication. In the Contact studies there was no systematic investigation of the efficacy of interaction support of social partners on the transmitting, negotiation and sharing of meanings, such as thoughts, experiences and ideas, with individuals with CDB.

## **1.4 Aims of the study**

This study uses a developmental-interaction framework for the analysis and treatment of communication needs in individuals with CDB. The development of communication in typical children will be the starting point of our research. We are specifically interested in the extent to which, as in typical child development, higher complex interpersonal communication in individuals with CDB can be stimulated through meaningful social interaction. Because of the substantial evidence of the importance of social partners' interaction competences for the quality of social interactions of individuals with CDB, our study will focus on the effect of supporting interaction skills of social partners on interpersonal communication.

The theoretical foundation chosen for this study is Trevarthen's theory of innate intersubjectivity (Trevarthen, 1979, 1980, 2001; Trevarthen & Hubley, 1978). The term 'intersubjectivity' is widely used to refer to the ability to share subjective states between two or more individuals, but also refers to the manifestations of this ability in interpersonal communication. Trevarthen (1979, 1980, 2001) and Stern (1985) have



studied the interplay between young children and their mothers and found that the ability to share subjective states becomes increasingly elaborate as children grow older. More basic forms of attunement between infants and their parents form the foundation for developing communication and learning. Other authors, such as Leadbeater (1989) and Linell (1991), have described intersubjectivity between adults, emphasizing the importance of negotiation and co-creation between both partners in order to develop shared meanings. Trevarthen's theory was chosen as the theoretical framework for this research project because it describes the development of basic and advanced forms of interpersonal communication in several developmental stages: the three layers of intersubjective development. For individuals with CDB it may be relevant to analyze their communication with these three layers in mind, to be better able to detect and foster emerging forms of higher complex communication.

Trevarthen's theory of innate intersubjectivity has a clear empirical basis founded on micro-analytic observations of the communication between mothers and their children between birth and six years of age (Bråten & Trevarthen, 2007). There is overlap between Trevarthen's theory of intersubjective development and other theories, such as those developed by Stern (1985) and, more recently, Loots and colleagues (Loots & Devisé, 2003; Loots, Devisé, & Sermijn, 2003). However, Trevarthen is considered to be the most explicit in his premise that communication competence is more fundamental than language (see Beebe, Rustin, Soter, & Knoblauch, 2003). This premise is of fundamental importance for the study of a target group that is usually without any language.

Our research is not the first attempt to test the efficacy of an intersubjective developmental approach for the study of interpersonal communication in individuals with CDB. Trevarthen's theory was used for the development of the Contact program (see Janssen et al., 2003). This program only focused on the first layer of intersubjective development. Until now there has been no scientific evidence that the provision of interaction support to social partners can also stimulate higher layers of intersubjective development in individuals with CDB. Our study aims to take away this uncertainty, not only by testing the effect of social partner interaction support on the communication of individuals with CDB at three layers of intersubjective development, but also by testing the main assumption behind the use of this theory in our practice based research. Our assumption is that intersubjective behaviors of the social partner can elicit these behaviors in individuals with CDB. We are specifically interested to see if intersubjective mediating behaviors that are observed in parents of children with a normative development at different layers of intersubjective development can be used for individuals with CDB to increase behaviors at these layers. Two types of behaviors will be tested: 1) behaviors that foster attunement to the emotions and behaviors of the individual with CDB and are associated with the first layer of intersubjective development, and 2) behaviors that foster meaning making with these individuals and that are associated with the second and third layers of intersubjective development. Because attunement was also the focus

of the Contact program, testing the additional value of meaning making is also a way of testing the effect of our newly developed intervention relative to the Contact program.

This research project has four main objectives:

1. To develop a social partner-oriented intervention based on Trevarthen's three layers of intersubjective development and the Contact program;
2. To test the effect of the new intervention on communication with people with CDB at the three layers of intersubjective development;
3. To test the effect of supporting social partners in their attunement versus the support of social partners in meaning making additional to attunement, on three layers of intersubjective development;
4. To test the correspondence in levels of intersubjective communication between people with CDB and their social partners.

## **1.5 Outline of the dissertation**

The structure of this dissertation is based on the aims of the research project. It consists of this introductory chapter (Chapter 1) and four chapters based on manuscripts for international peer-reviewed journals. The last chapter gives a concluding discussion of the research project.

Chapter 2 presents a review of the literature on intersubjective development. The aim of this review was to describe intersubjective development in children with sensory disabilities. It first presents relevant aspects of Trevarthen's theory of intersubjective development and then describes 1) how intersubjectivity is measured in children with sensory disabilities; 2) what levels of intersubjective development are measured in these children; 3) interventions that are specifically related to intersubjective development in these children; and 4) achievements of interventions with respect to both intersubjectivity and communication.

The knowledge gathered in the literature review was used to develop an intervention aimed at stimulating communication at three layers of intersubjective development with people with CDB. Chapter 3 describes this new intervention, called the High Quality Communication (HQC) intervention. Furthermore, it presents a single-case experiment in which the intervention was first tested. The chapter describes: 1) the feasibility of measuring intersubjective behaviors at three layers of intersubjective development in a young adult with congenital deafblindness; 2) the amount to which the participant's intersubjective behaviors increased when his social partners received support in using adapted strategies for interpersonal communication; 3) differences found in the participant's intersubjective behaviors between situations in which his partners received support in using strategies for meaning making in addition to strategies for attunement and situations in which his partners only received support in using attunement strategies;

4) the relationship between increases in the participant's intersubjective behaviors and increases in his use of conventional communication; and 5) his social partners' opinions of the HQC intervention.

The experiences in the first experiment led to the design of a larger experiment. Chapter 4 presents a multiple-case experiment in which the HQC intervention was tested in five individuals with deafblindness and 22 of their social partners, including teachers and professional caregivers. The aim of the experiment was twofold: 1) to see whether, similar to the single-case experiment, supporting social partners would foster interpersonal communication at the first layer; and 2) whether it would foster communication at the second and third layers of intersubjective development. Chapter 4 describes: 1) the effectiveness of the HQC intervention in improving communication with participants with CDB at three layers of intersubjective development across social partners; 2) the correspondence of increases in communication at the first layer of intersubjective development with the start of the first intervention phase in which social partners' attunement strategies were supported; 3) the correspondence of increases in communication at the second layer of intersubjective development with the start of the second intervention phase in which social partners' meaning-making strategies were supported; and 4) the correspondence of increases in communication at the third layer of intersubjective development with the start of the second intervention phase, in which social partners' meaning-making strategies were supported.

On the basis of the findings in the first multiple-case experiment, a new multiple-case experiment was carried out. Chapter 5 presents a second multiple-case experiment with nine communication dyads, each of which consisted of one participant with DB and one social partner (i.e., parents, teachers and professional caregivers). The aim of this experiment was to test the effect of the HQC intervention on intersubjective communication between each dyad. Furthermore, we aimed to test the main assumption of the HQC: that social partners can elicit higher layer intersubjective communication. Chapter 5 describes 1) the effects of the HQC intervention on communication in the dyads at three layers of intersubjective development; and 2) the correspondence between the social partner's type and level of intersubjective behavior and the type and level of intersubjective behavior displayed by the person with DB.

Chapter 6 provides an overview of the study's major findings and presents some critical reflections. An overview of the study's organization and the focus of each chapter is given in Figure 1.

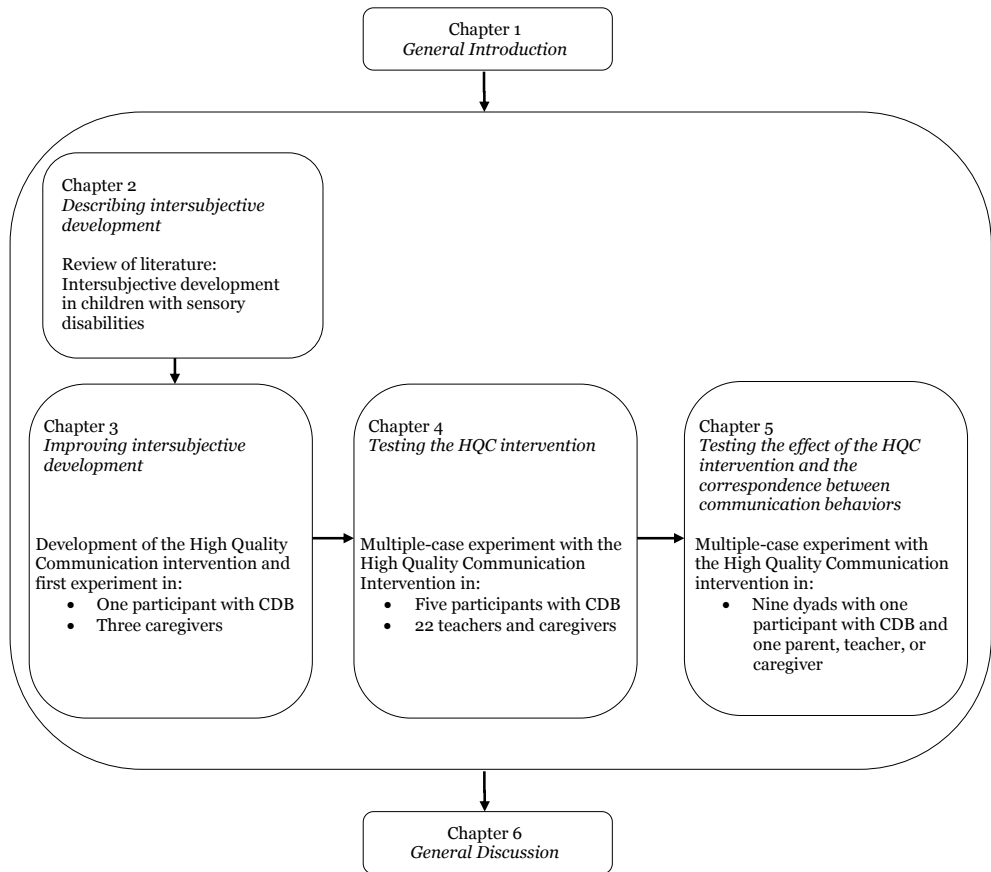


Figure 1. Overview of the organization of the study

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