Chapter 6

General Discussion
6.1 Introduction

It is very difficult for people with congenital deafblindness (CDB) to share thoughts and feelings with others. The quality of their social relationships may suffer as a result of the poorly communicated thoughts and feelings, or as a result of the low frequency of meaningful social encounters. One reason why people with CDB may have limited meaningful social encounters is that their social partners have difficulty supporting such encounters. Like everyone, people with CDB need social partners who are responsive, are able to attune their emotions and behaviors to them, and are able to engage them in a range of activities that are highly motivating while simultaneously stimulating their social and cognitive skills. Janssen, Riksen-Walraven, and Van Dijk (2003, 2006) showed that many social partners have difficulty attuning to the special needs of people with CDB and therefore have a clear need for coaching and support. There is a need for evidence-based interventions that support social partners in the development of meaningful social encounters with people with CDB. The studies reported in this dissertation were aimed to contribute to filling this void.

There have only been a few studies on the effectiveness of social partner support. However, several effect studies involving the Contact program have been carried out (Damen et al., 2011; Janssen et al., 2003b, 2006, 2011). These studies found evidence of positive intervention effects after the provision of education and video feedback to educators of children with CDB. Effects were seen in enhanced affective involvement between the communication pairs and increases in initiatives, turn taking and confirmation for the children as well as the educators. The Contact program aimed to support social partners in developing harmonious interactions with people with CDB. However, the program did not support social partners in their efforts to transmit, negotiate and share meanings. When searching for ways to support such efforts, it may be helpful to start with theories on how human beings learn to share subjective states. Trevarthen’s theory of intersubjective development, which was used in the development of the Contact program, may be a useful theoretical framework in this respect.

Trevarthen described the development of three layers of ‘intersubjectivity’ (defined as ‘the awareness receptive to subjective states of the other person’; Trevarthen & Aitken, 2001, p.4) in interpersonal communication with children between birth and 6 years of age (Bråten & Trevarthen, 2007). The first layer, observed in infants from a few months old, is characterized by their ‘other awareness’. This awareness manifests itself in the infant’s attention to the facial expressions of familiar caregivers and in dyadic activities, such as turn taking and imitation. The second layer emerges in children from the age of 9 months and is characterized by their ‘mutual awareness’. This awareness is seen in the child’s ability to share attention to objects in interaction with the social partner. The third layer is developed between the age of 2 and 6 years and is characterized by the child’s awareness of a verbal and narrative self. Behavioral manifestations of such
awareness are the use of symbolic communication and the sharing of thoughts with other people.

The effect studies on the Contact program provided evidence for the efficacy of an intersubjective developmental approach to support aspects of dyadic interaction, such as turn taking and affective mutuality between individuals with CDB and their educators. However, the studies did not test the efficacy of an intersubjective developmental approach for the support of communication, if communication is considered as we did: “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” (Janssen et al., 2003, p. 198).

This research project aimed to test if it is possible to stimulate communication at three layers of intersubjective development by means of supporting their social partners attunement and meaning making strategies. Treharthen’s descriptions of child and adult behaviors at three layers of intersubjective development (Treharthen & Aitken, 2001) were used to review the literature on interpersonal communication by children with sensory disabilities. Furthermore, the theory was used to develop an intervention that aimed to stimulate intersubjective communication: the High Quality Communication (HQC) intervention. Three experiments were planned and executed to test the effects of the intervention and, indirectly, the principles of intersubjectivity theory.

6.2. Main findings

6.2.1 Describing intersubjective development in children with sensory disabilities

We started this study by describing the intersubjective development of children with deafness, blindness and deafblindness. A systematic literature search about this development resulted in a description of the following aspects: 1) intersubjectivity measures, 2) outcomes of intersubjectivity measures, and 3) interventions and their effects.

The review of intersubjectivity measures revealed that intersubjectivity can be measured at each of the three layers of intersubjective development for children with either deafness, blindness or deafblindness. For the highest layer of intersubjectivity, which children typically acquire around the age of 6 years, we found fewer studies involving children with deafblindness than studies involving children with blindness or deafness, and they were all intervention studies. However, the studies we did find gave sufficient evidence to support the statement that children with deafblindness can reach the highest level of intersubjective development.

When researchers described intersubjectivity measures in their studies, they did not systematically measure intersubjectivity in children with sensory disabilities. Most of the studies conducted naturalistic observations. However, although all the included publications referred to intersubjectivity theory as a foundation for their empirical
studies, only a limited number (e.g., Loots, Devisé, & Jacquet, 2005) explicitly used the term ‘intersubjectivity’ in their dependent measures. Therefore we had to interpret the linkages between measured concepts and layers of intersubjective development. Because of the great diversity of the concepts found, we clustered the concepts into 20 categories.

At the first layer of intersubjective development, the category ‘initiatives’ was most commonly measured and involved all target groups. At the second layer, ‘joint attention’ was measured in the largest number of studies, involving individuals with blindness as well as deafness. At the third layer, ‘symbolic communication’ was most commonly measured and involved all three target groups.

With regard to the outcomes of intersubjectivity measures, we found that delays were measured in some children with blindness and deafness as early as the age of 3 months. In children with deafblindness, intersubjective development was only studied in intervention studies that aimed to foster this development. Hence, there was a lack of data on their natural intersubjective development.

Intersubjectivity outcomes for children with deafness differed depending on whether their parents had deafness or could hear. The first group demonstrated a typical speed of intersubjective development (Jamieson, 1994) and the second group a delayed speed (Jamieson, 1994; Nowakowski, Tasker & Schmidt, 2009; Tasker & Schmidt, 2008). This difference results from the natural use of adapted communication strategies by parents with deafness that accounted for modalities accessible to the child (Jamieson, 1994).

One very commonly reported delay in children with blindness and in children with deafness who had hearing social partners, concerned a characteristic aspect of the second layer of intersubjective development: the acquisition of joint attention skills. Children with blindness have delays in acquiring joint attention that are associated with their atypical ways of showing their attention to something. Instead of pointing with their fingers, blind children use body-pointing in the form of a slight movement of their heads or upper bodies. Parents often do not recognize these behaviors as attention behaviors and thus miss opportunities to share this attention (Preisler, 1991).

Four types of interventions were found in the included studies: cochlear implants (CIs), video-feedback training, social activities and Augmentative and Alternative Communication (AAC). Several of these studies described specific partner strategies that influenced the results. In a study of the use of CIs by children with deafness, results appeared to be influenced by the social partners’ sensitivity and child-directed communication style (Markman et al., 2011). In an analysis of a music therapy intervention, Kirkebaek (2007) found that partner strategies such as taking an active part in the interaction, sharing emotions, giving processing time and bringing in novelty appeared to have mediated interpersonal communication at the first layer of intersubjective development. In a study of a game intervention, Salíes and Starosky (2008) found that partner strategies such as repetition, language scaffolding and
language input appeared to have played a mediating role for the development of third layer intersubjectivity. Finally, the AAC intervention studied by Loots and colleagues (2005) found that subjects with deafness reached the highest level of intersubjectivity when social partners’ used sign language and sequential visual interaction strategies. The important role social partner strategies played in achieving results in the reviewed effect studies confirms the importance of our interaction perspective for this study of communication with people with CDB.

6.2.2 Improving intersubjective development

Developing an intervention to improve communication with people with CDB at three layers of intersubjective development was the next aim of this study. Our High Quality Communication intervention built on the Contact program developed by Janssen et al. (2003). Similar to the Contact program, the HQC intervention aimed to support social partners in their efforts to develop affective attunement. Additionally, the HQC intervention aimed to support social partners’ efforts to transmit, negotiate and share meanings with people with CDB. These two purposes were each connected to a specific phase of the intervention: ‘attunement’ in phase one and ‘meaning making’ in phase two.

The HQC intervention was designed as training for social partners, carried out by a coach. The training consists of three components: 1) four hours of education, 2) five hours of individual video-feedback coaching and 3) three hours of group video feedback. A similar diagnostic intervention cycle, also known as the ‘regulative cycle’ (Van Strien, 1986), was used in the Contact program. The main activities within the cycle are problem definition, diagnosis, planning, intervention and evaluation. In the HQC intervention, these activities were embedded in a protocol for a coach to use with the social partners. It involves: 1) clarification of questions, 2) analysis of interaction aspects and participant characteristics, 3) education, 4) determination of targets, 5) individual video feedback, 6) group video feedback and 7) evaluation of questions and intervention targets. While the cycle was followed once in the Contact program, the HQC intervention has two cycles: one in the attunement phase and one in the meaning-making phase.

We carried out the first application of the HQC intervention using a single-subject experimental design. We tested the effect of the intervention on Vincent, a 19-year-old man with CDB, and three of his professional caregivers. This study also demonstrated the feasibility of measuring manifestations of intersubjectivity in the interpersonal communication between Vincent and his social partners at three layers of intersubjective development. A coding system was developed for this measurement and it proved to have sufficient inter-rater reliability.

The interpersonal communication between Vincent and his social partners at the first layer of intersubjectivity appeared to be most strongly affected by the HQC intervention. The intervention had large and medium-sized effects on both the dyadic
interaction between Vincent and his social partners and on the sharing of his emotions. Medium-sized effects (referential communication, shared meaning) and small effects (meaning negotiation) were found for the categories at the second layer of intersubjective development. The intervention also corresponded to a medium-sized change at the third layer in the category ‘declarative communication’ and a small change in the category ‘shared past experience.’

We did not find the expected patterns of improvement in first layer categories in the attunement phase and second layer categories in the meaning-making phase. Five categories that we expected to increase in the second phase had already improved in the first phase. Two second layer categories decreased in the second intervention phase. However, both third layer categories increased in the second intervention phase and one of them was not observed before the start of this phase. On the basis of these findings, we argued that stimulating these categories requires a different focus than for the first and second layer categories: less on being together and more on meaning making. This was implemented in multiple experiments that subsequently followed the single case-experiment.

In this single-case experiment, increases in communication at the third layer of intersubjective development were not accompanied by greater use of conventional communication forms. We concluded that there was a difference between the effect of the intervention on the number of communicative acts and on the complexity of these acts. On the basis of this difference, we proposed that testing the effect of communication interventions should not only rely on measuring the quantity of the communication, such as counting the number of communicative acts, but also on analyzing the quality of interpersonal communication. We proposed that measuring communication at three layers of intersubjective development is a way to detect qualitative changes in communication between people with CDB and their social partners.

### 6.2.3 Testing the High Quality Communication intervention for people with deafblindness across social partners

In order to replicate the positive effects of the HQC intervention on manifestations of intersubjectivity that we found in the single-case experiment and to implement the recommendations based on the first experiment, we applied the intervention to 5 new participants with congenital deafblindness and 22 social partners. The participants with CDB were one female and four males, with an age range of 13 to 49 years. The social partners were 20 professional caregivers and 2 teachers. The intervention was carried out by five coaches who worked in the organizations that provided services to the participants.

Results indicated that the HQC intervention was effective in enhancing intersubjective behaviors in the five participants with CDB across social partners (see Table 1 for an overview of the results of all the case experiments in the research project). All participants
showed significant improvements at the first and second layers of intersubjective development. Three of the five participants also showed significant improvements at the third layer of intersubjective development. The most strongly affected category was meaning negotiation. This second layer category was operationalized as ‘efforts of the partner to obtain more information about the meaning and purpose of the participant’s communicative act and efforts of the participant to provide such information.’

The lower number of participants with positive intervention effects at the third layer of intersubjective development was explained by the complexity of interpersonal communication at this layer in relation to the participants’ developmental ages. The majority of participants had a developmental age below or around 2 years, an age at which children who develop typically have not yet or are only beginning to reach the highest layer of intersubjective development.

Analysis of each participant’s communication patterns across social partners showed that there was a high variability between the measures within each phase. Overall, the majority of effects were measured in the second part of the intervention, in which social partners were supported in their efforts to transmit and share meanings with the participant. On the basis of the different results in the two intervention phases, it was concluded that adding support of meaning making to the attunement support that was provided in the first phase is more effective than having a single focus on attunement support, as was used in the Contact program on which the HQC intervention was based.

### 6.2.4 Testing the HQC intervention in communication dyads and analyzing their communication patterns

The next aim of the study was to test the effects of the HQC intervention on intersubjective behaviors in communication dyads, each involving one individual with CDB and one social partner. We carried out a second multiple-case experiment, which involved nine communication dyads. The participants were two children and three adults with CDB; two of them had been diagnosed with a profound cognitive delay, two with a moderate delay and one with a severe cognitive delay. Social partners were parents, professional caregivers and teachers. Three coaches carried out the intervention; they worked at the organizations that provided services to the participants with CDB.

Results of the comparison of the intervention phases with non-intervention phases produced similar results as in the first multiple-case experiment (see 6.2.2): significant effects on intersubjective behaviors at both the first and second layers of intersubjective development were seen in all dyads. An effect was also found at the third layer of intersubjective development for five of the nine dyads. These dyads involved the two individuals with the highest cognitive abilities and the only participant who used speech. Table 1 presents an overview of the result for all the case-experiments in the research project.
Table 1
Overview of participant characteristics and intervention effects for each participant

<table>
<thead>
<tr>
<th>Nr</th>
<th>Fictive name</th>
<th>Gender</th>
<th>Age</th>
<th>Etiology</th>
<th>Visual disability</th>
<th>Hearing loss</th>
<th>Cognitive delay</th>
<th>Communication system</th>
<th>Categories that significantly improved by the HQC intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Vincent</td>
<td>Male</td>
<td>19</td>
<td>Goldenhar syndrome</td>
<td>Blind</td>
<td>Severe</td>
<td>Severe</td>
<td>Sign language, tactile symbols</td>
<td>Dyadic interaction, Shared emotion, Referential communication, Shared meaning, Declarative communication</td>
</tr>
<tr>
<td>2</td>
<td>Judy</td>
<td>Female</td>
<td>38</td>
<td>Congenital Rubella Syndrome</td>
<td>Partially sighted</td>
<td>Profound</td>
<td>Severe</td>
<td>Gestures and single signs</td>
<td>Dyadic interaction, Shared emotion, Referential communication, Meaning negotiation, Shared meaning, (proto-)Declarative communication</td>
</tr>
<tr>
<td>3</td>
<td>Frits</td>
<td>Male</td>
<td>19</td>
<td>Prematurity</td>
<td>Blind</td>
<td>Severe</td>
<td>Severe</td>
<td>Speech, single signs, tangible objects</td>
<td>Shared emotion, Meaning negotiation, Shared meaning, Declarative communication</td>
</tr>
<tr>
<td>4</td>
<td>Mehmet</td>
<td>Male</td>
<td>13</td>
<td>Congenital Rubella Syndrome</td>
<td>Partially sighted</td>
<td>Profound</td>
<td>Profound</td>
<td>Gestures, drawings</td>
<td>Shared emotion, Referential communication, Meaning negotiation, Shared meaning, (proto-)Declarative communication</td>
</tr>
<tr>
<td>5</td>
<td>Paul</td>
<td>Male</td>
<td>37</td>
<td>Congenital Rubella Syndrome</td>
<td>Blind</td>
<td>Profound</td>
<td>Moderate</td>
<td>Sign language, tactile symbols</td>
<td>Dyadic interaction, Shared emotion, Referential communication, Meaning negotiation</td>
</tr>
<tr>
<td>6</td>
<td>Keith</td>
<td>Male</td>
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<td>Prematurity</td>
<td>Blind</td>
<td>Severe</td>
<td>Severe</td>
<td>Gestures, single signs, tangible objects</td>
<td>Dyadic interaction, meaning negotiation</td>
</tr>
<tr>
<td>7</td>
<td>Mark</td>
<td>Male</td>
<td>26</td>
<td>Unknown</td>
<td>Blind</td>
<td>Profound</td>
<td>Profound</td>
<td>Gestures, tangible objects, single signs</td>
<td>Dyadic interaction, Shared emotion, Referential communication, Meaning negotiation, Shared meaning</td>
</tr>
<tr>
<td>Nr</td>
<td>Fictive name</td>
<td>Gender</td>
<td>Age</td>
<td>Etiology</td>
<td>Visual disability</td>
<td>Hearing loss</td>
<td>Cognitive delay</td>
<td>Communication system</td>
<td>Categories that significantly improved by the HQC intervention</td>
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<tr>
<td>8</td>
<td>Nathan</td>
<td>Male</td>
<td>6</td>
<td>CHARGE</td>
<td>Partially sighted</td>
<td>Profound</td>
<td>Moderate</td>
<td>Sign language, Pictograms</td>
<td>Dyadic interaction, Shared emotion, Referential communication, Meaning negotiation, Shared meaning, Declarative communication</td>
</tr>
<tr>
<td>9</td>
<td>Lisa</td>
<td>Female</td>
<td>13</td>
<td>CHARGE</td>
<td>Partially sighted</td>
<td>Profound</td>
<td>Moderate</td>
<td>Sign language, pictograms, drawings</td>
<td>Shared emotion, Shared meaning, Declarative communication</td>
</tr>
<tr>
<td>10</td>
<td>Jane</td>
<td>Female</td>
<td>48</td>
<td>Congenital Rubella Syndrome</td>
<td>Blind</td>
<td>Profound</td>
<td>Profound</td>
<td>Gestures and single signs</td>
<td>Dyadic interaction, Shared emotion, Referential communication, Meaning negotiation, Shared meaning</td>
</tr>
<tr>
<td>11</td>
<td>Don</td>
<td>Male</td>
<td>38</td>
<td>Prematurity</td>
<td>Blind</td>
<td>Severe</td>
<td>Severe</td>
<td>Speech, single signs</td>
<td>Dyadic interaction, Shared emotion, Referential communication, Meaning negotiation, Declarative communication</td>
</tr>
</tbody>
</table>

*for this participant it appeared that there were emerging forms of and not fully developed declarative communication
We were now specifically interested in seeing whether, as in the first multiple-case experiment, the majority of effects would be seen in the second intervention phase. In that phase, social partners were supported in their attempts to transmit, negotiate and share meanings with the participants with CDB, following the attunement support they had received in the first intervention phase. It appeared that the second phase once again produced the most effects for the communication dyads, but there was a difference between behaviors at the first layer and behaviors at the second or third layers. Effects on first layer categories were either mostly seen in the first phase (dyadic interaction) or in similar amounts in both phases (shared emotion). For all second and third layer categories, the second intervention phase produced more effects than the first intervention phase. In contrast to the other second and third layer categories, the second layer category ‘meaning negotiation’ already showed significant increases in the attunement phase for five of the nine dyads.

Some dyads were exceptions to these overall patterns of change: they showed late improvements in first layer behaviors or early improvements in second or third layer behaviors. For most of these dyads, this could be related to how much they already showed these behaviors before the intervention. Late results were understood as time needed for communication dyads to develop new communication behaviors. Early results were explained as social partners’ ability to stimulate higher complex intersubjective behaviors in the attunement phase, for those participants who already had these behaviors in their interaction repertoire. This last proposition is in line with findings in the first single-case experiment with the HQC intervention, in which several second layer categories already improved in the first intervention phase (see 6.2.2).

In order to see if there was a correspondence between the level and type of intersubjective behaviors exhibited by the two communication partners, we analyzed a specific sequential communication pattern: intersubjective behavior of the social partner and the subsequent intersubjective behavior of the participant with CDB. A strong correspondence between the two behaviors was considered to support the main assumption behind the HQC intervention: that social partners can stimulate intersubjective behaviors in people with CDB.

A correspondence between intersubjective behaviors was indeed found. There was not only a highly significant correspondence between the levels of communicative behaviors in all the observed two-event sequences, but there also appeared to be a correspondence between the types of behavior. Almost all the participants’ second and third layer behaviors were preceded by the exact same types of behaviors by the social partners and not by other behaviors. For example, a participant’s declarative communication was preceded by a social partner’s declarative communication. This finding seems to support the importance of social partners’ use of higher layer intersubjective behaviors to elicit these behaviors in people with CDB. This finding, as well as the fact that there were some significant occurrences of behavior combinations
in which the social partner communicated at a higher intersubjective layer than the participant with CDB, reflects the presence of a ‘scaffolding’ mechanism. This mechanism is described in competent partners who aim to facilitate learners’ acquisition of skills at their proximal zone of development (see Stone, 1998; Vygotsky, 1978). The learner is supported in such a way that he or she is able to reach a higher skill level.

The discovery of a correspondence in level and type of intersubjective behaviors in communication patterns involving one participant with CDB and one social partner made the second multiple-case experiment more than a replication study. The fact that most of the participants were involved in two communication dyads also revealed variations in communication between different dyads that involved the same individual with CDB.

6.3 Strenghts and limitations of the study

A characteristic of our study is that we did not alternate the two treatment phases (attunement and meaning making). The fact that the meaning-making phase followed the attunement phase in each case experiment implies that we have no information about the single effect of supporting social partners’ efforts to transmit, negotiate and share meaning on intersubjective communication. However, we purposefully chose the standard succession of the two treatment phases. Trevarthen’s theory of innate intersubjectivity states that attunement of behaviors and emotions forms the foundation for meaning-making processes. We assumed that if we alternated the two phases, we would have given some of our participants an insufficient basis for developing higher intersubjective behaviors. This meant that they would receive a less effective or perhaps even an ineffective intervention, which conflicted with our ethical standards.

Another limitation is the generalizability of our results. In total, 11 participants with CDB and 34 of their social partners participated in the study. Our design enabled us to compare the effects of different conditions on performance (Kazdin, 2003) for each single participant. However, evidence of effects in a single case are not automatically sufficient for developing expectations about such effects in other participants, especially when they have different individual characteristics (e.g. age, abilities) and circumstances (e.g. educational setting). Yet, a group study would not have provided such information either; that type of study provides evidence about average effects in a sample and do not clarify how interventions affect individual cases. Especially for populations that are so diverse in relevant aspects such as people with deafblindness, information on average effects may not be very meaningful unless samples are so large that effects may be differentiated according specific configurations of individual characteristics.

A solution for the generalization problem is to replicate case experiments (Barlow, Nock & Hersen, 2009), such as we did, involving participants with various individual characteristics. Our study included men and women, children and adults, and
individuals with different developmental ages, different severities of sensory disabilities and different communication systems. Furthermore, the social partners and settings were different (see Table 1). For other researchers it may be relevant to select other types of participants, partners or situations to see if results can be replicated for these cases.

The repeated observations in each case experiment gave us the opportunity to examine changes in behavioral patterns over time. Our first multiple-case study was the best example in this respect, because there were many data points in this experiment. The four conditions in both our multiple-case experiments (a baseline condition, two treatment conditions and a follow-up condition) allowed us to test whether the intersubjective behaviors continued in the predicted pattern or changed as the conditions were altered (see Kazdin, 2003).

A limitation of our study is that behavioral patterns of individuals with CDB were measured across social partners in both the single-case experiment and the first multiple-case experiment. Therefore it became more complicated to interpret variations from one data point to another. The number of data points and the fact that all social partners were distributed across the phases were means of controlling the influence of partner characteristics on differences between conditions.

A strength of the study is that we used different baseline lengths for each participant in the two multiple-case experiments, which meant that they started the intervention at different moments. The baseline however, started around the same time in each multiple-case experiment. The between-subjects replication of changes in behavior patterns after the start of each intervention phase gave us a more solid basis for linking these changes to the actual intervention.

Another strength is that observations were performed in a naturalistic situation: the group home, school, daily care or work setting of the participant with CDB. Although the camera may have had some effect on social partner behaviors, situations were not specifically created for the research project and this makes it more likely that we observed spontaneous communication behaviors.

This study is a practice-based research project with a clear theoretical foundation. Trevarthen's theory of innate intersubjectivity not only guided the intervention, it was also a guide for the selection of dependent variables and the methodology used to measure them. The study therefore not only shed light on the effectiveness of our intervention, but also enabled us to draw conclusions about the efficacy of our theoretical framework for the understanding and solving of practice-based problems: how to support social partners in developing shared meanings with individuals with CDB. Moreover, the study contributes to understanding the sharing of subjective states between human beings.

The statistical data analysis method used in our case experiments, the Non-Overlapping of All Pairs technique, proved to be feasible for analyzing differences between the conditions in the study. The technique did not require the usual prerequisites for
the analysis of variance, such as a normal population distribution or equal amounts of data in each phase. Our study also combined different ways of analyzing intersubjective behaviors and therefore provided more in-depth information about this type of behavior than most studies on the communication of people with CDB. For example, all our case experiments revealed that participants with CDB exhibited significant changes in intersubjective behaviors that were associated with the intervention phases. However, the study of the communication dyads revealed that there were substantial differences between dyads involving the same participant with CDB.

6.4 Reflections

One contribution of this research is the empirical study of intersubjectivity, defined as the ability to share subjective states, between people with congenital deafblindness (CDB) and their social partners. There has not been a systematic analysis of intersubjectivity in this target group before, which made it uncertain if it was possible to detect manifestations of intersubjectivity in their interpersonal communication. In observing the interpersonal communication of individuals with CDB we saw the different levels of complexity in intersubjectivity as described by Teyrathen, namely the three layers of intersubjective development. We argue that analyzing three layers of intersubjectivity is a means to evaluate the quality of communication between individuals with CDB and their social partners. We propose that looking at communication from the perspective of intersubjective development may also be valuable for other target groups, such as for individuals with intellectual disability with or without sensory or motor disabilities.

Differences between dyads with the same participant with CDB and the changes in intersubjective behaviors after training their social partners revealed that the social partners’ competencies influenced the quality of the communication. This finding was also supported by the strong correspondence between levels and types of communication behaviors displayed by the social partner and the levels and types of behaviors subsequently displayed by the participant with CDB.

The influence of social partner competencies on interpersonal communication is in line with studies on social interaction between people with intellectual disabilities (ID) and their professional caregivers. In their review of the literature, Hostyn and Maes (2009) concluded that partners’ interactive strategies, knowledge, and perceptions influence their social interactions with individuals with profound intellectual and multiple disabilities. Variations in the attachment behavior of individuals with ID towards different professional caregivers were partly related to differences between caregivers (see Schuengel, De Schipper, Sterkenburg, & Kef, 2013). A study by Schuengel, Kef, Damen, and Worm (2010) showed that variation in social interactions between individuals with visual and intellectual disabilities could be understood by looking at differences in the caregivers’ mental representation of their own childhood attachment.
experiences. Willems, Embregts, Bosman, and Hendriks (2013) found that the attitude of professional caregivers towards social interaction had a significant influence on their interactive behavior towards individuals with challenging behavior and ID. Our study provides additional insights into how characteristics of the social partner influence the quality of the social interactions of individuals with disabilities. In our study, communication measured in a single dyad or at a single moment in time was not necessarily a good representation of the communication competence of the participant with CDB. This is an important finding for people involved with the assessment of communication skills in people with deafblindness, and probably also in assessing people with other disabilities. In a study on the development of an instrument to assess the complexity of communication in people with severe intellectual and developmental disabilities, (see Brady, Fleming, Thiemann-Bourque, Olswang, Dowden, Saunders, and Marquis, 2012) it was stated that assessors should take into account that communication of these individuals can show variation in different social contexts. We propose that the assessment of communication in individuals with communication support needs should always take into account the extent to which the social partner attunes to the individual’s behaviors and emotions and supports the transmission, negotiation and sharing of meanings with the individual. In dyads in which social partners’ attunement and meaning-making strategies are not optimal for an individual with CDB, the partner needs to receive support before any valid evaluation of the individual’s communicative potentials is possible (Boers, Janssen, Minnaert, Damen & Ruijssenaars, 2014). Improvements in intersubjective behavior as a result of adapted partner strategies could then be considered an indication of the adequacy of these strategies and also allow a better perspective on the individual’s communication competences and needs. We recommend that professionals involved with communication assessment and support practices ensure that assessment and support go hand in hand in an ongoing dynamic process.

The newly developed High Quality Communication intervention expanded on the Contact intervention (see Janssen et al., 2003). The HQC had a similar effectiveness as the Contact intervention on basic aspects of communication such as dyadic interaction, as well as on more complex communication behaviors such as the use of communication to refer to something or someone. This is an important contribution for a target group for whom the quality of interpersonal communication is a serious problem. It is interesting that in several case experiments, we observed intersubjective behaviors in the intervention phases that were not observed during the baseline phase. However, we are uncertain whether those behaviors were ever part of the participants’ prior interpersonal communication. Therefore, we can conclude that the HQC intervention fostered intersubjectivity in our participants with CDB, but we do not know if it caused intersubjective development.
It is important to note that the relationship between the quality of the communication in individuals with CDB and their social partners’ competencies does not mean that we should blame social partners for low quality communication. The quality of the communication should instead be understood as a complex interplay between the unique characteristics of the individual with CDB (such as the bodily-tactile being in the world and his need of more processing time) and the spontaneous communication strategies of the social partner (see Goode, 1990; Hart, 2010). Our study also revealed that individuals with CDB have different communication competencies and needs that can vary from one observation to another and are often only or more clearly visible when analyzing them frame-by-frame on a video. This can explain why our social partners—although often educated in and experienced with the support of people with deafblindness—needed individual video-feedback coaching to be able to attune their communication strategies.

The discovered importance of social partners’ competences for the quality of the communication of individuals with CDB has implications for practice. For organisations that provide services to individuals with CDB this means that they should focus on the support of social partners in order to help them develop communication competences that match the needs of individuals with CDB. Our findings also support the importance of scaffolding communication at the proximal zone of development (see Vygotsky, 1978). The study revealed evidence for the importance of social partners’ communication at the second and third layers of intersubjective development in eliciting communication at this layer from people with CDB. We also showed that attunement of behaviors or emotions can serve as a basis for this scaffolding. This means that the support of social partners should first focus on optimizing their attunement to the behaviors and emotions of the individual with CDB and then on the scaffolding of higher complex interpersonal communication.

The studies in this dissertation show that an intersubjective developmental perspective is a valuable perspective for understanding how partner strategies can enable people with CDB to show and develop their communication competences. We believe that our research also revealed some of the dynamics of intersubjectivity. Apparently, intersubjective behaviors can be stimulated and perhaps even further developed by practicing them in social interaction with adults and children with complex disabilities such as dual sensory loss and severe cognitive disabilities. However, intersubjective behaviors often did not increase in the exact order of the three layers of intersubjective development: first and second layer categories especially did not always increase one after another. This suggests that less complex ways of sharing subjective states do not necessarily precede more complex ways. Perhaps the development of intersubjectivity in general is a process that does not necessarily follow a strict sequential pathway.

We recommend further study of the development of intersubjectivity in individuals with CDB. Monitoring this development in individuals with CDB, preferably from...
birth, in relation to the use of adapted strategies by their parents, could provide more information about ways to prevent communication delays and to support full language development.

6.5 A matter of meaning?

Communication is a matter of meaning. Low quality communication is a serious problem for people with congenital deafblindness (CDB) and their social partners. There are, however, hardly any scientific studies about the effect of communication interventions in this target group. The question is also if available interventions have the proper focus. Several communication interventions focus on the use of communication systems that can be used as an alternative for speech and writing and do not consider the communicative interplay of individuals with CDB. Effect studies that focus on the interplay between an individual with CDB and his or her social partners focus on how partners influence each other’s behaviors and emotions. There appear to be no other effect studies that pay specific attention to how individuals with CDB and their social partners transmit, negotiate and share meanings in their interactions.

This research project used an interaction approach to measure and support social partners in meaning making with participants with CDB. Because our intervention had an attunement phase and an additional meaning-making phase, we were able to evaluate the value of additional meaning-making support for interpersonal communication with people with CDB. This value became visible when comparing the amount of effects for all the case experiments measured in the meaning-making phase with the attunement phase. In all the case experiments, combining meaning-making support with attunement support produced more effects than attunement alone. It also produced higher layer intersubjective behaviors, such as communication to refer to something or someone, the sharing of meanings and the sharing of thoughts. These are all very relevant behaviors that enable individuals with CDB to express themselves and show who they are. We can therefore not only conclude that it is necessary to support both meaning making and attunement in social partners in order to foster high quality communication with people with CDB, but also that this can have an important meaning for them and their social partners. Hence, the support of social partners’s communication competences is a matter of meaning!
References


Chapter 6


