Beyond the eyes

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CHAPTER

6

General discussion

6.1 INTRODUCTION

Interaction and communication are an important focus of research on and support for people with congenital deafblindness because the dysfunction of the distal senses of hearing and vision has a huge impact on the process of social interaction (Hart, 2006; Rødbroe & Janssen, 2006; Vervloed, Van Dijk, Knoors, & Van Dijk, 2006). People with congenital deafblindness experience complex interaction and communication problems on a daily basis (Bruce, 2005; Hart, 2006; Janssen & Rødbroe, 2007; Rødbroe & Janssen, 2006). Their communication partners (e.g., parents, teachers, peers, caregivers) therefore often need support (Amaral, 2003; Bruce, 2005; Chen & Haney, 1995; Downing, 1993; Hart, 2006; Janssen, Riksen-Walraven, & Van Dijk, 2003; Nafstad & Rødbroe, 1999; Nelson, Van Dijk, Oster, & McDonnell, 2009, Rødbroe & Souriau, 1999) if their interaction is to promote communicative development.

Appropriate support relies on careful assessment (Huebner, Prickett, Welch, & Joffee, 1995; Vervloed et al., 2006). Several measurement instruments have been developed specifically for people with deafblindness. These have provided a good understanding of the communication skills (and other developmental skills) of these people (Boers, Janssen, Minnaert, & Ruijssenaars, submitted; Rowland, 2009), but the results are limited to a summary of the skills the person has acquired thus far, which leaves a big question mark about the person's potential communicative ability. Furthermore, problems often arise in translating the results into appropriate support (Rowland, 2009). Therefore, the potential of people with congenital deafblindness is at great risk of never being realized, thus leaving them at a lower developmental level than could have been achieved if their communication partners were aware of their ability and how to tap into it. So, we had to look beyond the eyes.

Having investigated the assessment of learning potential and how to translate the results into appropriate interventions, we decided that dynamic assessment was the answer to our goals. Consequently, the aim of the present study was to develop a dynamic assessment procedure that would address communication in people with congenital deafblindness.

This final chapter summarizes the major findings and complements them with a critical reflection. This is followed by a discussion of the implications for clinical practice and some recommendations for future research.

6.2 MAJOR FINDINGS

6.2.1 Key-elements of dynamic assessment for prelinguistic communicators

People with congenital deafblindness often rely heavily on prelinguistic communication (Bruce, 2005; Rødbroe & Janssen, 2006). As prelinguistic communication poses a real challenge to examiners wishing to develop a shared understanding with participants during assessment, it became apparent that a different approach was needed from that taken by dynamic assessment procedures developed for children who use

speech to communicate. The descriptive review (Chapter 2) revealed three key elements of dynamic assessment procedures for people who communicate at a prelinguistic level.

The first key element was that the assessment should focus on identifying contextual variables that support the person's communicative competence. In dynamic assessment procedures for people who communicate at a prelinguistic level, it is considered essential to examine the impact of the partner on the communicative behaviour of the person, as well as environmental factors (e.g. lighting, sound, the availability of motivating objects and AAC techniques) that provide clues about how to help the person develop communication skills.

The second key element of dynamic assessment procedures for people communicating at a prelinguistic level was to include communication partners in the assessment and teach them ways of positively changing their behaviour and the environment that would enhance the communicative development of the person. This is important, given that the key feature of dynamic assessment is that children perform beyond the limits of their initial ability when assisted in harmonious interaction by a more experienced adult. When communication is challenging, as it is among people with congenital deafblindness and people who function at a prelinguistic level (Downing, 1993; Grove et al., 1999; Iacono et al., 1998; Porter et al., 2001), the question arises of whether the competence of such people is constrained by their own ability to use the help and support of the communication partner or whether it is constrained by the partner's ability to provide adequate assistance. This problem can be overcome by including the communication partners in the assessment and teaching them supportive behaviour.

The third key element was to adapt the assessment procedure to the individual situation, rather than use a fully standardized procedure. It seems to be necessary to adapt the target abilities, target items, activities, interactions and mediation to the participant's communicative level in order to meet the person's needs and ensure the procedure has a broad reach (Missiuna & Samuels, 1989; Resing, Ruijsenaars, & Bosma, 2002).

6.2.2 Assessing communication skills

To fulfil our goal of developing a dynamic assessment procedure for people with congenital deafblindness, we needed an instrument for pretesting and retesting that could be relied on to assess a person's communication ability and the impact of the partner on the person's communicative development. As there was no state of the art review of measurement instruments addressing communication in people with deafblindness, we undertook this ourselves. In doing so, the systematic review (see Chapter 3) identified 27 instruments that have been developed for persons with deafblindness and that address aspects of communication. This review revealed three remarkable findings.

First, there was only limited focus on the assessment of partner abilities. Although the skills of the communication partner are as important as the skills of the person with deafblindness for achieving high-quality communication (Downing, 2005; Wasson, Arvidson, & Lloyd, 1997), only 37 percent of the instruments included items on partner

abilities. Furthermore, most of the instruments that did include partner abilities had fewer items on the partner than on the person with deafblindness. The partner items in these instruments focused on the communication form used by the communication partner, the function of the message communicated, social-interaction skills (initiating, responding and reciprocity) and supportive partner skills, such as whether the partner allowed adequate response time and the use of prompts and reinforcement. However, we know of partner abilities that are of value but that were not mentioned in any instrument. One such ability is the use of symbols, because people with deafblindness can only develop a lexicon if their partners use symbols (e.g. signs, pictures) fluently in their communicative exchanges (Souriau, Rødbroe, & Janssen, 2009). Another is the ability to initiate communication with a declarative function, such as communicating about activities that the person has carried out (Bates, 1976; Camaioni, 1996; Daelman, 2003; Lichtert, 2004). This indicated that the existing instruments were not comprehensive concerning the partner abilities required for high-quality communication.

The second remarkable finding revealed by our review was the lack of focus on the tactile sense in the instruments. Although the tactile sense is very important for people with congenital deafblindness (Edwards, 2012; Huebner, Prickett, Welch, & Joffee, 1995; Janssen, Nota, Eling, & Ruijssenaars, 2007; Janssen & Rødbroe, 2007; Miles, 2003; Nicholas, 2010, 2012), only a third of the instruments included items in this area, and these were usually limited to whether tactile communication modes were used, whether reactions were exhibited to touch and tactual stimuli, and the ability to use the tactile sense to attend, explore or recognize objects, animals or people. However, the use of the tactile sense can improve interaction between persons with congenital deafblindness and their communication partners if it is also mobilized for purposes such as establishing and maintaining contact, co-actively exploring objects, guiding attention to an object or person, listening to the other by feeling the signs made and confirming utterances (Janssen & Rødbroe, 2007).

The third remarkable finding was the lack of attention paid to the psychometric properties of these measurement instruments developed for persons with deafblindness. Only seven of the instruments provided information on validity or reliability, and the validity or reliability was found to be adequate for only six of these, equivalent to only 22 percent of the instruments.

As the existing instruments did not sufficiently measure the essential partner abilities and the use of the tactile sense, the systematic review led us to conclude that no existing instrument for persons with deafblindness would satisfy our purpose. We therefore developed a new measurement instrument, the Interaction and Communication Analysis List (ICAL, Boers & Janssen, 2012), to measure abilities that are necessary in both the person with congenital deafblindness and the communication partner to ensure high-quality communication. We formulated 40 major communication abilities, 18 of which focused on the person with congenital deafblindness, 18 on the communication partner and four on both (the dyad). The abilities were

drawn from a) literature on communication in the congenitally blind, deaf and deafblind, as well as on communication in the seeing and hearing, b) watching interactions on video between persons with congenital deafblindness and their communication partners and c) clinical experience. These abilities were divided into nine main categories, namely: attention, regulation of intensity, contact and confirmation, tactility, affective involvement, form and symbolization, topics and maintenance, intentional communication, and negotiation.

As the ICAL needed to be reliable, we examined this (see Chapter 4). The findings of this study showed the ICAL to be a reliable instrument: the overall inter-observer agreement exceeded the 80 percent criterion. The assessment of a few abilities (n = 6) proved less reliable (that is, relatively many observer pairs [35 percent or more] did not reach the same conclusion about that ability), and these will be revised to obtain higher reliability in the near future. We can conclude that reliable observation in people with congenital deafblindness is possible with the ICAL, which is a major step forwards in evaluating the efficacy of the assessment of the abilities of people with congenital deafblindness and their communication partners to ensure high-quality communication.

6.2.3 Implementation of dynamic assessment

The ICAL alone was already of great value in analyzing the strengths and weaknesses in the communication skills of people with congenital deafblindness and their communication partners. However, we took a further step into the world of hidden potential by garnering information on which support improves communication and developing a dynamic assessment procedure. This entailed adding teaching sessions to the administration of the ICAL. As dynamic assessment procedures are lacking for persons with congenital deafblindness, our study presents new information on the implementation of dynamic assessment for this target group (see Chapter 5).

The results of the pilot study, in which we evaluated the effectiveness of the dynamic assessment procedure for people with congenital deafblindness, showed that dynamic assessment made it possible to discover communication competences in the child that would otherwise not be revealed at all. These competences were the ability to increase the number of initiatives taken during interaction, the ability to enhance the use of signs to symbolize thoughts, the ability to expand the vocabulary by learning new signs, the ability to make use of a tactile communication form to transfer symbols with hand-under-hand signing, the ability to use declarative communication, and the ability to increase positive emotions and decrease challenging behaviour. The study demonstrated the learning potential of children with congenital deafblindness and the rapidity with which they can learn. Furthermore, it highlighted the dependence of the person with congenital deafblindness upon the communication partner, and the need to include the partner in the assessment, which is a rarity in the world of dynamic assessment. To improve the dynamic assessment procedure, further research is recommended.

6.3 REFLECTIONS ON THE STUDY

Reflecting on this study, we can conclude that we highly succeeded in developing an assessment procedure that was able to assess the communication potential of people with congenital deafblindness. The various studies provided us with useful information and tools to generate an appropriate assessment procedure that allowed us to show a person's potential to reach higher levels of communication. Former studies on the assessment of people with congenital deafblindness recommend performing observations in the natural environment, observing the person in interaction with a well-known communication partner, performing the observations in multiple settings and activities, revealing strengths and needs, and focusing on ongoing assessment (Downing, 1996; Engleman, Griffin, & Wheeler, 1998; Kelso, 2003; Leslie, 2001; Lunden, 1990; Mar, 2010; Miles & Riggio, 1999; Rowland, 2009; Siegel-Causey, 1996; White, Garrett, Kearns, & Grisham-Brown, 2003; Wolf-Schein, 1998). The studies also note that measurement instruments should be valid for the target group and should include important items on communication partners, and that the results of the assessment should easily be translated into Individualized Education Programs and educational goals (Downing, 2005; Miles & Riggio, 1999; Rowland, 2009; Wasson et al., 1997). The dynamic assessment procedure developed in our study responds to these recommendations and gives shape to a definite procedure that will provide guidelines to all professionals working with people who are congenitally deafblind.

In our first article, we discovered that one of the key elements in the dynamic assessment of people who are functioning at a prelinguistic level of communication is to identify contextual variables that support the person's communicative competence, and in particular, partner behaviours that have a positive influence on the person's communicative behaviour. It may have become apparent that this key element was lacking in our procedure. Our main focus was to determine the amount of change demonstrated by a person in relation to a certain communication skill in response to intervention and to reveal the person's potential level of development, relying on many dynamic assessment procedures for children who use speech to communicate. We skipped the step of identifying contextual variables, as we were familiar with interventions that have a positive influence on communication. Instead, we developed a specific protocol to guide the partner's interactions with the child. Although the effectiveness of these interventions was initially established in clinical experience, their positive effect is increasingly supported by scientific evidence (Damen, Janssen, Huisman, Ruijssenaars, & Schuengel, 2014; Janssen, et al., 2003; Martens, Janssen, Ruijssenaars, & Riksen-Walraven, 2014). This made us better able to systematically observe and record the child's responsiveness to positive changes in the approach of the communication partner (Kahn, 2000) and assess the child's learning potential.

A valid point to make at this stage would be that if we were so convinced that these interventions would have a positive effect, why administer a whole assessment procedure, including test moments, instead of just teaching the communication partners

the intervention guidelines? In other words, what was the value of the comprehensive assessment procedure? First, assessment precedes appropriate intervention (Huebner, Prickett, Welch, & Joffee, 1995; Vervloed, Van Dijk, Knoors, & Van Dijk, 2006). One should always explore what is needed in a particular situation. Appropriate intervention therefore always need to start with assessing a person's current level (Rowland & Fried-Oken, 2010), or in the words of Vygotsky, assessing the zone of actual development (Vygotsky, 1978). In our case, we mean the current skills of the person with congenital deafblindness as well as the current skills of the communication partner. The ICAL revealed the strengths and needs, which is one of the prerequisites for assessing people with congenital deafblindness (Downing, 1996; Kelso, 2003; Leslie, 2001; Losardo & Syverson, 2011; Mar, 2010; Miles & Riggio, 1999; Rowland, 2009; Siegel-Causey, 1996). As learning always entails an alignment between people and their environment, the needs of the person with congenital deafblindness and of the communication partner formed the basis of the intervention phase, and we built upon this. Second, by implementing testing moments on an ongoing basis, we could monitor the learning process of the deafblind person and partner. There might be a difference between knowing how to approach a person with congenital deafblindness to create learning experiences, and really doing this. Moreover, what is learned can be diluted. Since the partner is the most important factor in the child's development, the appropriateness of the partner's approach should be guaranteed. Finally, it is important to document the learning process of the person with congenital deafblindness. This target group is often seen as severely intellectually disabled, due to their initial appearance, reinforced by the fact that most client files only report their low developmental level, often expressing it in terms of developmental age. It is well known that they often function at a much lower level than their seeing and hearing peers. However, if the communication partners of deafblind children are unaware of these children's learning potential, they are likely to treat them as if they are unable to learn, thus approaching them passively and being afraid to overestimate them. However, they are far more likely to underestimate the child, thus creating few learning experiences. Implementing dynamic assessment procedures for people who are congenitally deafblind shows us that they are able to learn and gives us an idea of what they are capable of, their learning potential. This puts a stop to thinking in terms of shortcomings and directs the focus on capabilities instead.

As with many studies on individuals with congenital deafblindness, this study faced the problem of the use of group designs and obtaining a large sample size. As the target group comprised a relatively small number of individuals, and obtaining research data was rather time-consuming, it was difficult to come up with large samples within the time frame. Either way, the many differences between persons with congenital deafblindness make it difficult to generalize the results to the entire target group or to compare subgroups. There is no such thing as norms that apply to the entire group, making group designs of less use. Therefore, in this situation descriptive analyses of individual cases do provide especially valuable and meaningful contributions. The

implementation of a multiple case study with three different cases did garner relevant information, giving us a good understanding of the effectiveness of the dynamic assessment procedure and guidelines for the implementation of dynamic assessment in people with congenital deafblindness. Nonetheless, the great heterogeneity of the target group and the influence of individual differences on the assessment, make it strongly recommended that the dynamic assessment procedure be implemented using more cases in future research in order to describe a procedure that works for all possible participants.

The results of our study may also be of significance to the assessment of individuals with profound intellectual and multiple disabilities (PIMD). This target group also contains people with visual and/or hearing disabilities, who often function at a prelinguistic level of communication. While information about the learning potential of people with PIMD is limited (Munde, 2011), the dynamic assessment procedure could help gather information on their communication potential.

The instrument produced (the ICAL) in this study does not incorporate a developmental perspective. The advantage of assessments with a developmental perspective is that one knows where the person's present skills fit in the continuum of skills in each area assessed (Miles & Riggio, 1999). Such a perspective provides an understanding of what the person has already mastered and what the next challenges are. There are two main reasons that the ICAL does not have such a perspective. First, it is not certain if the developmental sequence of people with congenital deafblindness is the same as for hearing and seeing persons. The communicative development of hearing and seeing children largely progresses via successive steps (Adamson, 1996). We are unsure whether this is true for people with congenital deafblindness. Second, this assessment is not suited to such a perspective. We included the skills needed for high-quality communication, skills that together are important in communication, so it is not a matter of the progressive mastery of skills. However, if future dynamic assessment procedures are to be developed, for example on cognition, one could consider documenting skills in their natural developmental sequence. Knowledge of the developmental sequence of children with congenital deafblindness would help us avoid the frustration of trying to teach children something when they have not yet mastered the prerequisite skill. It will also help us understand how sensorimotor, cognitive and communication skills are often interrelated and build on each other.

6.4 CLINICAL IMPLICATIONS OF THE STUDY

The project provides a checklist, in the form of the ICAL, to determine whether the communication skills that are important for high-quality communication have been mastered by both the person with deafblindness and the communication partner. But above all, the project resulted in a dynamic assessment procedure to measure the communicative abilities of people with congenital deafblindness. This procedure, which includes the ICAL and interventional tasks and guidelines, expands upon the

possibilities of measuring the learning potential of children and adults with congenital deafblindness and improves interventional planning. As dynamic assessment has been shown to unfold abilities that are not otherwise demonstrated, it is especially important for diagnosticians to take this kind of assessment into account when studying children or adults with congenital deafblindness. In addition, the assessment results can be used to tailor instructions and adapt activities to the person's individual needs. It is of high clinical value as it stimulates development and improves communication, thus resulting in improved well-being, not only in the person with congenital deafblindness but also in the communication partner.

The examiner must possess the expertise to adjust the assessment to the individual. Individuals with congenital deafblindness are not a homogenous group. As there are differences between them, a standardized procedure would not fit everyone's needs. Activities and partner behaviours have to be adapted to the person's level of functioning and interests, as well as to the person's vision and hearing. For example, if a child is unfamiliar with signs, it is better to choose a song that implies just a few signs in the assessment. Furthermore, if the individual does not exhibit any development in response to the initial procedure, the examiner should expand upon this by making adjustments. This study demonstrates which adjustments can be made to create an assessment that has the maximum likelihood of assessing the potential of any person on the prescribed interaction and communication abilities. However, the examiner does need to choose which of the possible adjustments are relevant to the particular situation. This dynamic assessment procedure does reach a higher level of standardization than the majority of procedures for people who communicate at a prelinguistic level that we explored in this study. It thus gives the examiner as much direction and guidance as possible. Still, we do strongly recommend that examiners receive training before implementing the dynamic assessment procedure, to perform an adequate assessment and a reliable analysis of communicative behaviours.

The communication partner has a major role in our dynamic assessment procedure as the mediator who helps the person with deafblindness learn. Whereas most dynamic assessment procedures include only a child and an often unfamiliar examiner (e.g. Bain & Olswang, 1995; Feuerstein et al., 1979; Gutiérrez-Clellen & Peña, 2001; Hamers, Sijtsma, & Ruijssenaars, 1993; Haywood & Lidz, 2007; Van der Aalsvoort, Resing, & Ruijssenaars, 2002; Tiekstra, Hessels, & Minnaert, 2009), this procedure includes a third person: a mature, familiar communication partner who is taught appropriate communicative behaviour. In turn, the communication partner provides the person with congenital deafblindness learning experiences, giving possibilities to learn new communicative skills. This not only requires motivation and dedication from the partner, but also a home situation or workplace that facilitates the participation of the partner in the assessment. This can entail time and money because it can mean a co-worker taking responsibility for a student who normally is under the supervision of the participating communication partner, or a parent returning home from work early to take care of the other children so that the participating parent is not disturbed.

Furthermore, this transformation of parental, caring and classroom practices, results in an intervention programme that delineates specific teaching strategies. It is most important to facilitate a professionalization programme for the communication partner and all other familiar communication partners to ensure that the recommended intervention is continued by all communication partners. Only then will the person with congenital deafblindness be given the opportunity for optimal development. Investing in professionalization is the cornerstone of development.

Since communication partners need professional support to learn how to implement new approaches, and examiners how to collect, interpret and use assessment data, the implementation of this assessment model does require time and effort, as does any new programme (Losardo & Syverson, 2011). Furthermore, dynamic assessment takes more time to administer than a single test due to the interactive nature of the procedure, which involves three phases. Nevertheless, when using this dynamic assessment procedure in daily practice rather than for the purpose of research, as was the case with this study, two testing moments – pretest and posttest – suffice for most communication abilities, rather than the seven in this study. For the three cases in this study, the outcome of the two pretests did not differ much, and the last posttest seemed to be a good indicator of the extent to which children benefit from the intervention. An extra pretest or posttest is recommended if the interaction on a particular day appears different from normal, for example due to sickness in the person with congenital deafblindness or communication partner. This is sometimes, but not always, discernible in the person with congenital deafblindness if, for example, the person does not want to interact anymore or is tired. A decline in results may also be explained if the person becomes visibly sick within a few days after testing. If this is the case, it is always recommended that another pretest or posttest be performed. A further recommendation based on our research, is to test the categories 'positive emotions' and 'challenging behaviour' on two different days per testing phase, with at least one week in between (pre/posttesting) rather than at one test moment, and the symbols expressed every session, as these behaviours are more at variance. The low number of test moments and the clear procedure make this assessment practical for daily, real-life application.

6.5 RECOMMENDATIONS FOR FUTURE RESEARCH

The results of the current thesis are promising and show that if the assessment is implemented in a dynamic way, information becomes available on the person's communicative learning potential. However, if the person does not show any progress, they will require additional attention. Although the total intervention package of five sessions over six to seven weeks showed remarkable results for the two girls, it did not for the boy. We presume that the main reason for a person not showing any communicative improvement is not lack of potential in the person but rather that the procedure does not reflect the person's needs. We therefore want to study the effect of certain adaptations, such as spreading the sessions over a longer period of time, coaching the

partner before resuming the posttests as soon as any problem areas are indicated in the partner's performance, and including objects or activities that are of more interest to the person. Furthermore, for some abilities (symbolizing emotions and expressing declarative intentions) the time span of the intervention was too short. Further research should determine the time required to achieve results on these abilities. Future research should also focus on the impact of environmental factors such as lighting and sound, and the availability of motivating objects, as these are also preconditions for optimal communication (Snell, 2002).

Further studies on dynamic assessment should not only include more participants but also children and adults who are physically disabled. In the pilot study in this thesis, we focused on the use of signs for symbolization. However, not all people with congenital deafblindness are able to make signs, due to physical disabilities. Since language development consists of adding vocabulary in whatever form it is understandable to and performable by the child (Miles & Riggio, 1999), other forms should be included in the assessment in such cases.

Another important point to consider in future research is the predictive validity of this assessment. A number, such as IQ, should preferably be used to represent expected future performance, but that is not possible in this case. Still, the way a child's learning rate is reflected in future performance can and should be examined. For example, is the speed of learning to use new symbols in communication an indicator of learning performance later in life? With dynamic assessment we do reveal children's abilities and how much they change in a set time. An interesting question would be whether these are valid predictors of future success.

Last but not least, future research might also supplement our findings explore whether the partner continues to follow the recommended intervention guidelines even once the coaching has stopped. As the person with congenital deafblindness is only given the opportunity for further development when the partner maintains the appropriate intervention.