Meaningful modalities

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Chapter 1

Introduction and Outline

Communication partners of people with congenital deafblindness (CDB) face the challenging task of creating opportunities for them to achieve their interactive and communicative potentials. In order to achieve these potentials, communication partners should be able to recognize the social behaviors of people with CDB. This implies that communication partners need to become aware of which interactive and communicative skills are necessary to access the world of touch and proximity in which people with CDB operate (Goode, 1994). Moreover, communication partners need to find ways to adjust to the interactive and communicative possibilities of a particular person with CDB, since these possibilities substantially differ between individuals. Therefore communication partners are confronted with questions about how to adapt their interactive and communicative behaviors in everyday situations.

The dual-sensory disabilities that characterize congenital deafblindness cause several fundamental problems (Janssen, Riksen-Walraven, & Van Dijk, 2002, 2003a): a) people with CDB perceive and process information in a fragmentary way (Daelman, Nafstad, Rødbroe, Souriau, & Visser, 1999; Janssen & Rødbroe, 2007) and b) people with CDB appear to function on a transition level of pre-linguistic to linguistic communication (normally reached between 0-2 years of age) (Bruce, 2005; Janssen et al., 2002, 2003a; Nafstad & Vonen, 2000). Moreover, research has indicated that dual-sensory impairments also affect processes related to cognitive and social development, orientation and mobility that lead to serious interactive and communicative problems for individuals with CDB and their communication partners (Chen & Downing, 2006).These problems are likely to contribute to a lack of adequate input from the environment,

resulting in stagnation related to communicative development and creating harmonious interactions (Janssen et al., 2002, 2003a).

The above-mentioned problems with regard to interactive, communicative, and linguistic development can be explained by taking a closer look at the restricted access that people with CDB have to one of the conventional communicative modalities (e.g., the oral-auditory modality or the visual-gestural modality) and any associated languages (spoken and signed, respectively), since this restricted access severely affects processes of interaction and communication (Bruce, 2005; Rødbroe & Janssen, 2006; Rødbroe & Souriau, 1999). In order to optimize processes of interactive and communicative development, communication partners need to attune to a communicative modality they are not familiar with: the tactile-bodily communicative modality. Creating opportunities for people with CDB to achieve their interactive and communicative potentials implies that it is necessary to use alternative non-linguistic communicative acts that underlie the tactile-bodily communicative modality (i.e., tactile gestures, body postures, bodily movements, muscle tension, natural gestures, and tactile cues) (Aitken, 2000; Bruce, 2005; Chen & Downing, 2006; Janssen & Rødbroe, 2007; Mesch, 2001; Rødbroe & Janssen, 2006; Rødbroe & Souriau, 1999). Moreover, they ultimately need to learn a language that lends itself to being used in the tactile modality: a sign language.

For the purpose of this thesis, the dependence on alternative communicative acts is referred to as the '*communicative modality mismatch*': the mismatch between the immediate interactive and communicative behavior repertoires of people with CDB and their communication partners. This mismatch is demonstrated, for example, in

the interactive and communicative behaviors of communication partners that are not attuned to the behaviors of people with CDB (Chen & Downing, 2006; Daelman, Janssen, Larsen, Nafstad, Rødbroe, Souriau, & Visser, 2004; Nafstad & Rødbroe, 1999).

Researchers and communication partners agree upon the importance of intervention programs for training communication partners to optimize interaction and communication with people with CDB. According to this thesis, minimizing the negative effects of the communicative modality mismatch forms the starting point for intervention: training communication partners to use the tactile-bodily communicative modality in an adequate way during interaction and communication.

Although several intervention models and strategies aimed at persons (adults and children) with CDB and their communication partners have been developed and carried out in the past (Chen & Downing 2006; Durand & Berotti, 1991; Janssen et al., 2002, 2003a; Janssen, Riksen-Walraven, & Van Dijk, 2003b; Rødbroe & Souriau, 1999; Sigafoos, Didden, Schlosser, Green, O'Reilly, & Lancioni, 2008), none of these interventions explicitly focused on the role of the communicative modality mismatch within the intervention process. Therefore a new intervention model has been developed: the Intervention Model for Tactile Communication (IMTC). This intervention model focuses on optimizing the use of both tactile-bodily interactive skills (e.g., taking initiatives) and tactile-bodily communicative skills (e.g., using tactile-bodily signs). It serves as a basis for the intervention program on tactile communication. Since the IMTC defines interaction as an essential prerequisite for communication, the use of interactive tactile-bodily behaviors precedes the use of communicative

tactile-bodily behaviors during the intervention. With regard to interaction, the IMTC trains communication partners to use tactile-bodily interactive behaviors to create mutual attunement of behaviors and emotions. With regard to communication, the IMTC trains communication partners to use tactile-bodily communicative behaviors for creating meaning and sharing experiences.

1.1 The Target Group: People with CDB

Deafblindness can be generally defined as the combination of significant auditory and visual impairments (Aitken, 2000; Balder, Bosman, Van Dijk, Roets, Schermer, & Stiekema, 2000; Mesch, 2001). The sensory losses that are caused by deafblindness vary in onset and severity from individual to individual. Therefore, the term 'deafblindness' does not necessarily refer to individuals who are completely deaf and completely blind from birth. In fact, it is possible that a person who is diagnosed with deafblindness has dealt with deteriorated vision and hearing since late adulthood and had some useful vision and hearing left at the time deafblindness was diagnosed. The term 'congenital deafblindness' refers to the group of people who suffer from severely impaired vision and/or hearing from birth or a very early stage in life, before they have acquired a first language. Deafblindness cannot be simply defined as being blind and also deaf, nor as being deaf and also blind. Therefore, deafblindness should be defined as a unique condition that has its own concepts and terminology, its own methods of assessment and education and its own modes of communication (Aitken, 2000, Balder et al., 2000; Larsen & Damen, 2014; Mesch, 2001).

Deafblindness is often related to additional impairments that make social development, cognitive development and language development even more complicated. Additional neurological impairments can develop later in life and can make the receptive and expressive language that is used by a person with deafblindness unusual and difficult to understand. Many people with deafblindness are also confronted with motor impairments that may affect the production of speech and/or signs from the beginning or at a later moment in life, even though their comprehension of language may be normal. Some people with deafblindness function below age-appropriate cognitive levels because of sensory deprivation or brain damage (Aitken, 2000; Balder et al., 2000; Mesch, 2001).

The total number of people with deafblindness is relatively small. In the Netherlands, no proper prevalence numbers are known, but Vaal and Deeg (2005) found that there may be 35,000 elderly people with deafblindness. A recent study in Denmark found the number of adults with CDB to be 1 in 29,000 (Dammeyer, 2010). In the past, the main cause of congenital deafblindness was infection with the Rubella virus in utero. Since the introduction of vaccinations that prevent this infection, the number of individuals who suffer from related deafblindness has been substantially reduced. Today, premature birth, pre- and post-natal trauma and genetic conditions (i.e., CHARGE) are more commonly reported causes of congenital deafblindness (Balder et al., 2000).

Due to the differences in time of onset of the dual-sensory impairments and the heterogeneity in the degrees of sensory loss, there is a large variety of different communication methods and associated languages that can be used by deafblind individuals. The method used with a particular

deafblind individual, of course, depends upon the causes of the dual-sensory impairments, the onset of the dual-sensory impairments and how much useful residual sight and/or hearing is available. In some cases, a combination of communicative methods may be used.

1.2 Aim of the Intervention

The intervention presented in this thesis aims to teach the communication partners of people with CDB how to better use the tactile-bodily modality in interaction and communication in order to create better opportunities for the people with CDB to achieve their interactive and communicative potentials. The focus of this thesis is fourfold: 1) a description of the ways in which the difficulties that underlie problematic interactive and communicative development can be minimized by applying a newly developed intervention model; 2) a single-case experimental study that enables testing and fine-tuning of the application of the intervention model; 3) a first effect study that gives insight into the effectiveness of the intervention model; and 4) a second effect study that gives insight into the effectiveness of the intervention model and its results during replication.

The main research question of this study has been formulated as follows: in which ways does application of the new intervention model on tactile communication improve communication partners' use of tactile-bodily interactive and communicative behaviors in interaction and communication with persons with CDB? To answer this main question, four sub-questions were formulated: one for each study presented in this thesis.

1) What is the importance (necessity) of developing an intervention model with its focus on tactile communication?

2) Which intervention effects can be reported for applying the Intervention Model on Tactile Communication according to the pilot study that is carried out?
3) Which intervention effects can be reported for the first effect study in which the Intervention Model on Tactile Communication is applied?
4) Which intervention effects can be reported for application of the Intervention Model on Tactile Communication in a new sample of children and communication partners?

1.3 Outline

This thesis consists of four parts, that have been submitted for publication as articles in scientific journals. First, a theoretical article on the development of the IMTC is presented. In addition to a description of the theory on which the IMTC is based, this article also describes the general importance of the use of intervention programs for the improvement of interaction and communication with people with CDB. Moreover, this article shows the contents and the different intervention phases of which the final intervention model consists.

The second part describes the single-case study that was carried out to implement and test the application of the IMTC. It involved a boy with congenital deafblindness and two of his communication partners and gives a first impression of the ways in which the different intervention phases were carried out in practice.

The third and fourth parts describe the implementation of two effect studies. The first effect study describes the application of the IMTC for five

persons (adults and children) with CDB and their communication partners. To be able to more specifically determine the effectiveness of the IMTC, that effect study was replicated by carrying out a second effect study in which the effects were measured for three children with CDB and their communication partners.

Each part presents the theoretical framework that underlies the particular study.

The concluding chapter of this thesis links the results of all the studies back to the research questions and describes the limitations, implications for clinical practice and suggestions for future research. The outline of this thesis is presented schematically below.

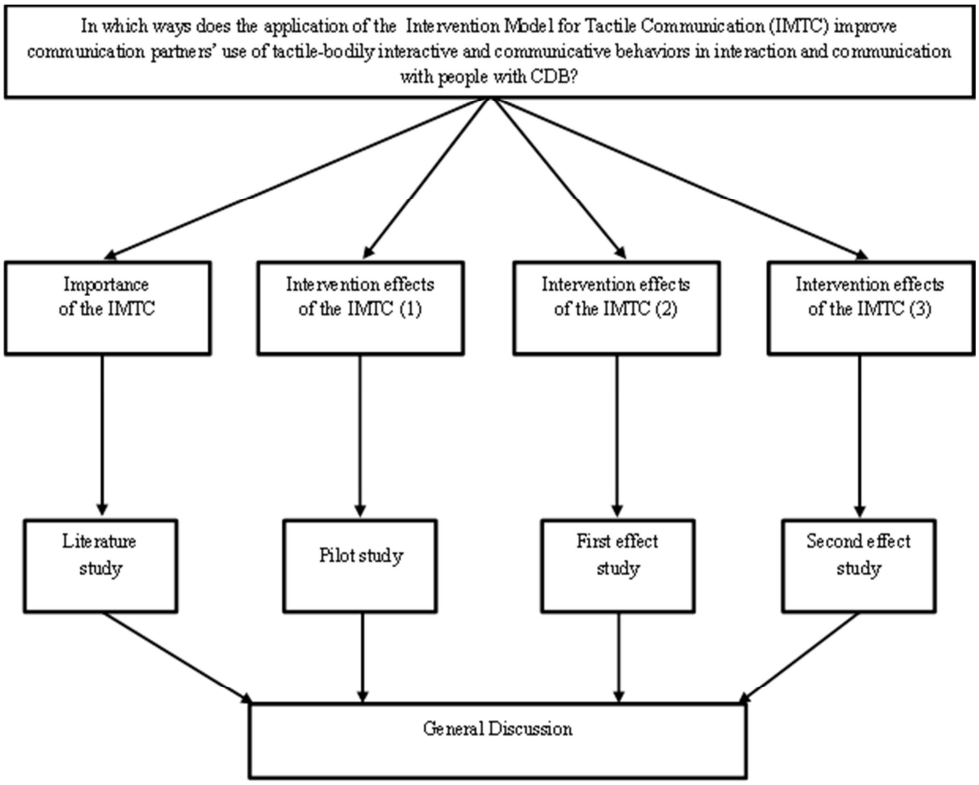

Figure 1. Schematic outline of the thesis.

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