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### Beyond the eyes

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CHAPTER

**1**

*Introduction*



## 1.1 INTRODUCTION

Assessment is crucial to the development of a person who is congenitally deafblind. Congenital deafblindness is a combined visual and hearing impairment present at birth or before language develops that affects all situations in life (Rødbroe & Janssen, 2006). The social interaction process is tremendously affected by the dysfunction of these two important distal senses. If they are to make developmental progress, people with congenital deafblindness need support and education (Buete, Vohr, & Herer, 2013; Perez-Pereira & Conti-Ramsden, 1999). Appropriate assessment is a fundamental aspect of such intervention (Huebner, Prickett, Welch, & Joffe, 1995; Losarda & Syverson, 2011; Rowland, 2009; Vervloed, Van Dijk, Knoors, & Van Dijk, 2006).

While professionals and researchers in the field of congenital deafblindness agree upon the importance of appropriate assessment, they face three major problems. First, the severe visual and auditory disabilities of people with congenital deafblindness and the huge difficulties they experience communicating with others make the administration of an assessment a challenge. Measurement instruments often involve language, hand-eye coordination and reading, and rely on the subject being able to see stimuli, understand written or spoken language, or respond verbally or motorically (Fewel, 1991; Mar, 2010; Rowland, Chen, Stillman, Mar, & Syler, 2009; Rowland, 2009; Wolf-Schein, 1998). The validity of such assessments can be called into question when administered to people with congenital deafblindness and the test scores often mask a person's true skills and competencies (Crooks, 1999; Mar, 2010; Rowland, 2009; Wolf-Schein, 1998).

Second, communication partners tend not to be included in assessments. Communication with people with congenital deafblindness is challenging (Downing, 2005; Wasson, Arvidson, & Lloyd, 1997) so communication partners such as parents, teachers, peers and caregivers need intervention, to help them interact in a way that promotes development in the person with congenital deafblindness (Rødbroe & Souriau, 1999). Therefore, it is crucial to assess not only the abilities of people with congenital deafblindness, but also the ways in which others interact with them (Miles and Riggio, 1999; Siegel-Causey & Bashinski, 1997). However, existing measurement instruments developed for people with deafblindness have a limited focus in terms of the assessment of partner competencies (Boers, Janssen, Minnaert, & Ruijsenaars, submitted).

The third major problem faced by professionals and researchers in the field of congenital deafblindness is the translation of assessment results into Individualized Education Programmes (IEP) and educational goals (Rowland, 2009). There is a call for assessments that evaluate the learning of people with congenital deafblindness, and that determine promising interventions (Losardo & Syverson, 2011).

Careful assessment is important because assessment results can influence educational decisions about a person for years to come, for better or worse (Rowland, 2009). Accurate, comprehensive and applicable results are therefore essential to the child's educational and personal success.

## 1.2 DYNAMIC ASSESSMENT

The current thesis focuses on dynamic assessment as an appropriate approach to assessing people with congenital deafblindness and their communication partners. Dynamic assessment links assessment with intervention and is generally defined in terms of an interactive test – intervene – retest model (Haywood & Lidz, 2007, p. ix). Dynamic assessment not only provides information on performance or mastery of skills but also on the person as a learner (Haywood & Lidz, 2007; Losardo & Syverson, 2011). It is future oriented, having the capacity to reveal barriers to better learning and performance, the kind of assistance required to improve performance, the response to intervention and the investment required to promote long-term gains in performance (Haywood & Lidz, 2007, p. 12-14). Different models of dynamic assessment have been posited over recent decades. They include determining the amount of change demonstrated by a person on a given task in response to intervention (Babad & Budoff, 1974; Budoff & Corman, 1976; Peña, Quinn, & Iglesias, 1992); determining the amount of mediation needed to bring the person to a specific level of competence (Campione & Brown, 1987; Campione, Brown, Ferrara, & Bryant, 1984; Ferrara, Brown, & Campione, 1986; Resing, 1993, 2000); determining the extent to which children benefit from assistance (Hessels, 2000; Hessels & Hamers, 1993); and identifying inhibiting factors in learning and processes or means that enable the individual to learn a new task to determine promising interventions (Bosma & Resing, 2006; Feuerstein, Miller, Rand, & Jensen, 1981; Feuerstein et al., 1979). Although the assessment approaches are different, they all highlight the general principle that guided learning can make a valuable contribution to the assessment process (Jitendra & Kameenui, 1993).

## 1.3 AIM OF THE RESEARCH

As the complexity of problems experienced in communicating presents an enormous risk to the overall development of people with congenital deafblindness (Bruce, 2005; Hart, 2006; Janssen & Rødbroe, 2007; Rødbroe & Janssen, 2006; Rødbroe & Souriau, 1999), the main aim of this thesis was to develop a dynamic assessment procedure that would address communication in people with congenital deafblindness. To achieve this, two questions first needed to be answered. The first was whether dynamic assessment procedures aimed at people who rely on prelinguistic communication should take a different approach from those aimed at people who use speech to communicate. People with congenital deafblindness most often rely on prelinguistic communication (Bruce, 2005; Rødbroe & Janssen, 2006). The use of prelinguistic communication poses a real challenge to examiners wishing to develop a shared understanding with participants during the assessment. It was therefore supposed that a different approach would be needed from the dynamic assessment procedures developed for children who use speech. The second question that needed to be answered was if available measurement instruments can be implemented for pretesting and retesting in a dy-

dynamic assessment addressing high-quality communication. As the existing instruments did not appear to be meet our requirements, we would need to develop a new measurement instrument that could measure the communicative abilities of people with congenital deafblindness as well as the partner abilities needed for high quality communication. We would also need to investigate the reliability of this new instrument. Our final aim was to pilot test the new dynamic assessment procedure on people with congenital deafblindness and one of their most familiar communication partners.

#### 1.4 OUTLINE OF THE THESIS

Four research papers form the basis of the thesis. Figure 1 summarizes the content of the chapters and the structure of the thesis.

**Chapter 2** provides a descriptive review of dynamic assessment procedures that address communication abilities of people who communicate at a prelinguistic level and of young children who use speech to communicate. The differences between the dynamic assessment procedures for the two groups are discussed in this chapter, along with the key elements identified for dynamic assessment that addresses communication in people who do not use a linguistic system to communicate.

**Chapter 3** presents a systematic review of the measurement instruments available that address communication in people with deafblindness. It provides an overview of these instruments and their psychometric properties, and pinpoints their general shortcomings in relation to our assessment goal.

**Chapter 4** describes the development and reliability of the Interaction and Communication Analysis List (ICAL), an observational measurement instrument developed to assess the acquired communication abilities in people with congenital deafblindness and their communication partners and to pinpoint the abilities that need to be worked on so as to ensure high-quality communication between them.

The new dynamic assessment procedure is the central focus of **Chapter 5**, which presents the results of a pilot test. For this study, the dynamic assessment procedure was performed on three children with congenital deafblindness and one of their most familiar communication partners.

This thesis concludes with **Chapter 6**, which comprises an overall discussion of the main findings from the different chapters. This chapter also explains the strengths and limitations of the present study, and presents recommendations for researchers and those working in the practical field that emerged from the findings.

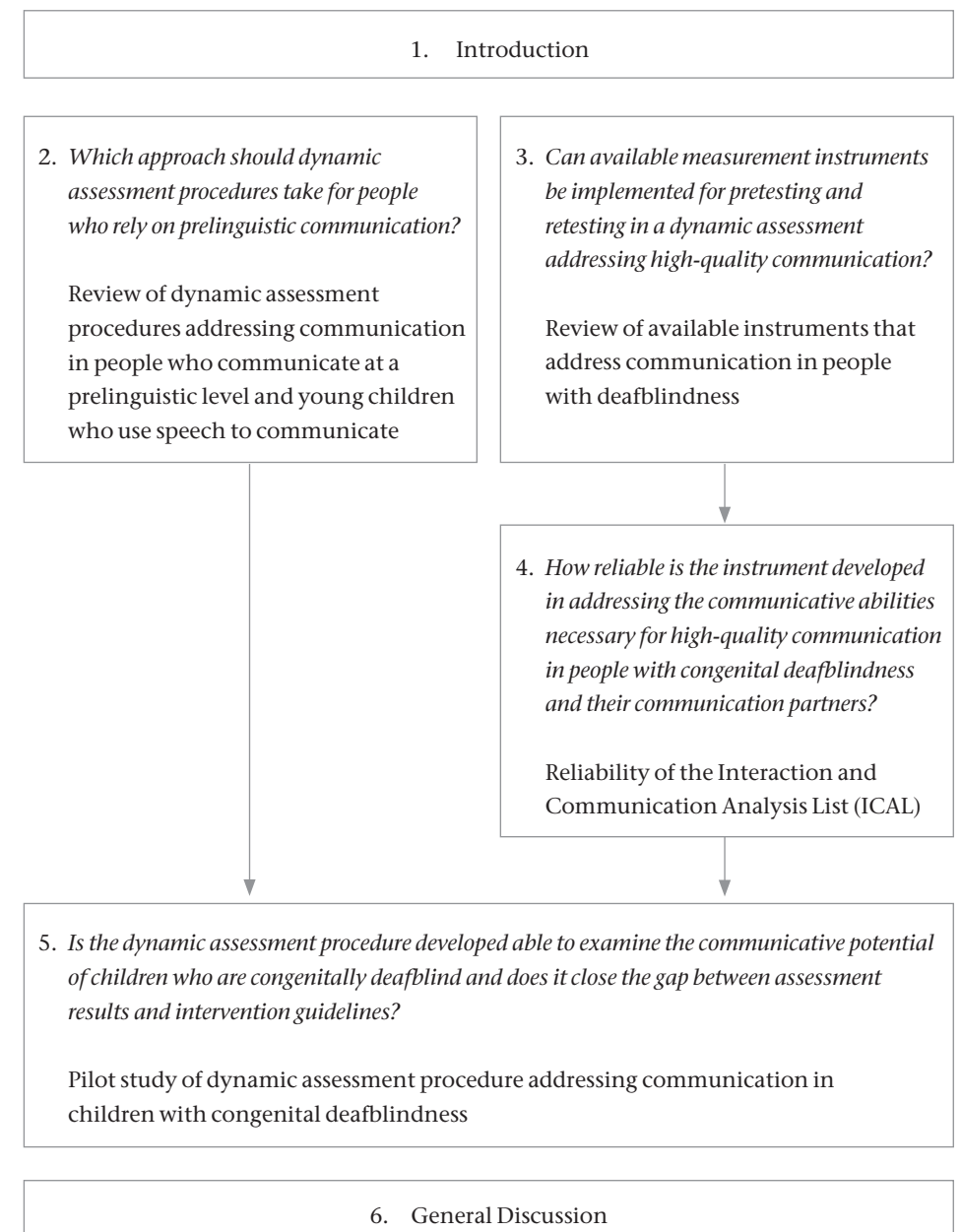


Figure 1 Outline of the chapters