Beyond the eyes

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CHAPTER

3

Assessment of communication in people with deafblindness: A systematic review of the literature on measurement instruments

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ABSTRACT

People with congenital deafblindness face complex problems in communicating and this poses an enormous risk factor to their development. This study conducted a systematic review of the instruments available to measure the communication abilities of people who are deafblind and their communication partners, with the aim of discerning the instruments that can be used for the assessment of this population, which in turn can guide intervention. 27 instruments were identified. Each instrument was then evaluated concerning the aspects of communication that were measured, the representation of tactile sense in the items and the psychometric properties of the instruments. Seven aspects of communication were considered important to assess: the communication form, symbolisation, social interaction, communicative function, receptive communication, intentional communication and supportive partner abilities. The review revealed that there is a limited focus on the assessment of partner abilities and the use of the tactile sense by both. Six of the instruments demonstrated adequate reliability and/or validity. The results indicate the need for further research on the abilities that are important for communicating with people with deafblindness, and the development of a new, objective instrument that focuses on both the person with deafblindness and the communication partner, including abilities related to the use of the tactile sense.

3.1 INTRODUCTION

Congenital deafblindness refers to a combined visual and hearing impairment present at birth or before language develops, affecting all situations in life (Rødbroe & Janssen, 2006). An enormous risk to the development of people who are congenitally deafblind is the complexity of problems they experience in communicating on a daily basis (Bruce, 2005; Hart, 2006; Janssen & Rødbroe, 2007; Rødbroe & Janssen, 2006). 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). As a consequence, communication does not occur without intervention (Rødbroe & Souriau, 1999).

Appropriate intervention must be built on careful assessment (Huebner, Prickett, Welch, & Joffee, 1995; Vervloed et al., 2006). Assessments are often used to obtain information about the knowledge and skills a person has acquired thus far. However, the translation of the results into Individualized Education Programs (IEP) and educational goals is a common problem and a concern raised by many professionals working with people with deafblindness (Rowland, 2009). The use of assessments that have a dynamic perspective has the ability to overcome this major issue, as they link assessment with intervention and are therefore strongly recommended for use with people with deafblindness (Boers, 2012; Boers, Janssen, Minnaert, & Ruijssenaars, 2013; Mar, 1995).

Dynamic assessment is generally defined in terms of an interactive test – intervene – retest model (Haywood & Lidz, 2007, p. ix). Rather than only focusing on what the person has learned thus far, it also focuses on the process of learning. The great value of dynamic assessment lies in the fact that it has some capacity to reveal the 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). Many dynamic assessment procedures have already been developed on the basis of the theories of Vygotsky (1896–1934) and Feuerstein (1921–2014). However, a dynamic assessment procedure specifically designed for people with deafblindness, is still lacking (Boers et al., 2013).

When implementing a dynamic assessment procedure for people who communicate at a prelinguistic level – as many people with congenital deafblindness do – it has been found extremely important to include the communication partner, who may be a parent, teacher, peer, or caregiver (Boers et al., 2013; Kublin, Wetherby, Crais, & Prizant, 1998; Snell, 2002; Van der Schuit, Van Balkom, Segers, & Verhoeven, 2008). Firstly, this allows the examination of the impact of the partner on the communicative development of the person, and the identification of variables that support the person's communicative competence; and secondly, it provides the opportunity to teach the partner new abilities during the assessment, promoting the development of the communicative potential of the person with deafblindness (Boers et al., 2013). The inclusion of familiar communication partners and the assessment of their abilities is well

founded (Downing, 2005; Siegel-Causey & Bashinski, 1997; Wasson, Arvidson, & Lloyd, 1997), as it is known that communication with people with congenital deafblindness is often challenging and partners are thus often in need of support to interact in such a way that promotes development (e.g., 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).

To improve communication in people with congenital deafblindness and to determine their communicative potential, our long-term goal is to develop an adequate dynamic assessment procedure for this specific target group. To make judgements about a person's communicative skills during pre- and retesting, their communication potential, and the impact of the partner on the development of the person, a valid and reliable measurement instrument must be included in the dynamic assessment. This instrument should allow the observation of all of the important behaviours required for high-quality communication between the person with congenital deafblindness and their communication partner. One important skill needed in communication with people with congenital deafblindness is the use of the tactile sense. While their communication partner's are used to relying on the simultaneous input of auditory and visual information, the person with congenital deafblindness is strongly dependent on the tactile sense to establish interpersonal relationships and experience the world (Miles, 2003; Nafstad & Rødbroe, 1999; Nicholas, 2010, 2012; Rødbroe & Janssen, 2006). Because the tactile sense is of great significance and an indispensable component in interaction with people who are congenitally deafblind, it requires the attention of the measurement instrument.

Literature on instruments developed to measure communication specifically in people with deafblindness is sparse and a recent overview of measurement instruments addressing communication in people with deafblindness is lacking. We therefore undertook such a review addressing the following questions: (1) Which aspects of communication are measured in people with deafblindness and their communication partners? (2) To what extent do the current instruments specifically assess the use of the tactile sense? and (3) What are the psychometric properties (validity and reliability) of the instruments?

3.2 METHOD

3.2.1 Search strategy and inclusion criteria

An electronic search of the following databases was carried out up to and including 3 February 2012: Academic Search Premier, Communication and Mass Media Complete, Cumulative Index of Nursing and Allied Health Literatures (CINAHL), Education Resources Information Center (ERIC), Linguistics and Language Behavior Abstracts (LLBA), MEDLINE and PsycINFO. The following terms were used: 'deaf-blind*', 'deafblind*', 'multi-sensory impair*', 'multisensory impair*', 'dual sensory loss', 'dual sensory impair*', and 'multiple disabilities', matched with 'assessment', 'test', 'instrument', 'measure*', and 'communicat*', 'interact*' and 'language' (the asterisk is a truncation symbol which means that all words starting with those letters are included in the search). These search terms were applied to whole texts, except in the LLBA which only searches the abstract, title and subject headings. We found 45 studies that mentioned measurement instruments which satisfied the following criteria: (1) people with deafblindness are named as the population or one of the populations for which the instrument was developed; (2) the instrument includes at least five items on communication abilities; and (3) the instrument is still available and access information is offered by the study or on the internet. Measurement instruments were excluded if people with deafblindness – having visual as well as auditory impairments – were not specifically mentioned as target population of the instrument, if the instrument solely targeted aspects other than communication abilities, and if the instrument was no longer available (i.e., the study or the internet provided no information on how to access the instrument). Only studies published in English were included.

To determine reliability of the inclusion and exclusion of the instruments named in all studies, the search was carried out twice by the first author three months after the initial search. One new instrument was found to include.

The titles of the measurement instruments were then used individually as keywords for a second round of electronic searching using the same databases and scholar.google.com. In this search, the terms 'validity' and 'reliability' were used in combination with the instrument titles.

3.2.2 Data extraction

The initial search identified 629 citations. Duplicates were deleted, reducing the number of papers to 544. Titles and abstracts were then scanned for relevance, further reducing the number of papers to 338, while 51 additional studies were discarded because the full text of the study was not available – mainly studies from before 1985, theses and conference proceedings – and another 7 because the paper was not written in English. The remaining 280 studies were read in full by the first author of this study. Articles that did not mention any instrument at all, or only mentioned an instrument that was developed for research purposes – for example to observe the effect of an intervention – and which were not generally available, were culled. This reduced the total number to 115.

The titles of the instruments in the remaining articles and the first developer of the instrument were then used individually as keywords to search the same databases, scholar.google.com and google.com, to find further information on the population for which the instrument was developed for. If people with deafblindness, multi-sensory impairments (visual as well as auditory) or dual sensory loss/impairments were mentioned as the target population, and communication abilities were measured by the instrument, information on its availability was sought. This was done by examining the initial study, and if no information about ordering the instrument was found, the title of the instrument and the first developer of the instrument were matched with 'order' on google.com. Instruments mentioned in 70 articles did not meet the inclusion criteria. Upon completion of the data extraction, 45 studies were found, reporting on 27 instruments available developed for people with deafblindness, addressing communication abilities. All of the instruments were obtained and their content analyzed.

Once the data extraction was complete and the measurement instruments were identified, the second round of the electronic search found three additional papers that provided evidence of reliability or validity. In one case the manual of the instrument reported that information on validity and reliability was available from the editor, which we duly received.

3.3 RESULTS

A total of 27 measurement instruments were identified for inclusion in the review. Table 1 provides a summary of the instruments reviewed, listing the target group of the instrument, the purpose of the instrument as stated by the author, the type of instrument, the aspects of communication targeted, and the number of items that address communication. Of the instruments that assess communication as well as other domains, the names of the subscales that include items on communication are provided. Information on where the instrument can be ordered is also available.

The instruments can be subdivided into three groups (see also Table 1). The first group are the developmental scales. All of these instruments score the child's developmental age, except for the Ability Screening Test, which translates the development of the child into three levels (lower, middle and higher). The second group of instruments translate the communicative behaviour of the person to levels of communication. The third group of instruments solely provide a description of communicative abilities. This is the largest group.

3.3.1 Key aspects of communication measured

By analyzing the items of the instruments and coding the content, we discovered several aspects of communication that the communicative assessment of people with deafblindness focuses on, independent of the type of instrument (developmental scales, levels of communication, or descriptions). In this section our goal is to classify those aspects of communication that are considered important, starting with the aspect that is measured most often and ending with the one that is measured least.

Communication form. The way a person communicates is addressed by most instruments (n = 21). Some listed several forms of communication to choose from, others used open questions. The *pre-symbolic forms* mentioned were crying, smiling, aggression, emotional reactions, alertness, sounds, babbling, vocalisations, tantrums/fuss, gaze shift, physical manipulation, changes in posture, moving, gestures, giving, showing, reaching (tactual), touch cues, simple acts with people or objects, extending object, contact pointing, distal pointing, withdrawal/self-stimulation, head shake, head nod, and facial expression. The *symbolic forms* mentioned were signs, coactive signs, tactual sign language, two-hand manual, finger spelling, objects of reference (tangible symbols), texture that has been designated as a symbol for something, tactile symbols, photographs, drawings, graphic symbol sets, pantomiming actions or objects, mimics sound, print on palm, communication board, communication book, electronic or mechanically adapted equipment, augmentations, VOCA (voice output communication aid), real-time captioning or note-taking, written or printed text, Braille, computer, mobile computing, text messaging, TTY/Bell Relay Service, and verbalisation/speech.

Gothelf, Crimmins, Woolf, & Prickett (1995), King Miller, Swanson, Steele, Thelin, & Thelin (2011), Luiselli, DeCaluwe and Jacobs (1995b), Nelson, Van Dijk, Oster and McDonnell (2009), Rowland (2012), Rowland, Schweigert and Stremel (1992), Siegel-Causey (1995), Stremel and Wilson (1992b, 1992c), and Tedder and Sikka (1992) not only addressed communication forms used in general, but differentiated between the forms used to communicate a specific kind of message (for example, when asking for information, when communicating likes or choices or preferences, or when communicating desire for more food, milk or juice). Wolf-Schein and Schein (2009) differentiated between the forms used to express particular words (for example, the forms used when symbolizing 'bathtub', 'eyeglasses', 'dirty').

A small number of instruments (n = 5) focused on the communication form used by the communication partner of the person with deafblindness (Dalby et al., 2009; Gothelf et al., 1995; Rowland et al., 1992; Siegel-Causey, 1995; Tedder & Sikka, 1992).

Social interaction. This is understood as the process in which two individuals mutually influence each other's behaviour (Bjerkan, 1996; Janssen, 2003), and it is measured by many of the instruments we identified (n = 18), examining the ability of people to interact and play with peers and adults, or describe such interaction in the following terms.

Table 1 Overview of the measurement instruments

Name	Author	Target group		Purpose	Type	Target aspects of communication	Items
		Diagnosis	Age				
Developmental Scales							
Ability Screening Test: 'Communication' and 'Socialization' *Education Resources Information Center (ERIC) www.eric.ed.gov/*	Lyall, Henry, Graham, & Lassiter, 1972	Deafblind and multiply handicapped people.	Not mentioned	To determine the functional ability level and individual program needs.	Observation	Form Social interaction Symbolisation	11
Assessment of Developmental Levels by Observation (ADLO): 'Relationship skills', 'Communication development-receptive' and 'Communication development-expressive' Contact the author via *www.smileassociationmethod.com/*	Wolf-Schein, 2000	People who have impairments of both hearing and vision.	< 6 years (da)*	To determine current performance levels.	Observation	Receptive communication Social interaction Symbolisation	111
Callier-Azusa Scale 'G': 'Cognition, communication & language' and 'Social development' *www.utdallas.edu/calliercenter/academic/azusa-scale*	Stillman, 1978	Deafblind and severely and profoundly handicapped children.	0–108 months (da)	To provide information necessary to synthesise developmentally appropriate activities for a child and to evaluate a child's developmental progress.	Observation	Form Function Receptive communication Social interaction Symbolisation	156
Callier-Azusa Scale 'H' *www.utdallas.edu/calliercenter/academic/azusa-scale*	Stillman & Battle, 1985	Deafblind and severely and profoundly handicapped people.	0–24 months (da)	To provide assessment information relevant to planning individualised, communication-based intervention programs and to provide a means for documenting developmental change in both communicative competence and the cognitive and social abilities related to communicative development.	Observation	Form Function Intent Receptive communication Social interaction Symbolisation	189
Communication Placement Assessment: Area I, III, IV, V, VI *Education Resources Information Center (ERIC) www.eric.ed.gov/*	Stremel & Wilson, 1992a	Students with dual sensory impairments/severe handicaps.	0–28 months (da)	To give a description of the communication skills and needs for IEP planning.	Observation	Form Function Intent Receptive communication Social interaction Supportive partner abilities Symbolisation	146
INSITE Developmental Checklist: 'Communication' and 'Social emotional' *www.hopepubl.com*	Morgan & Watkins, 1989	Children who are deafblind, deaf with other handicaps, or blind with other handicaps.	0–6 years (da)	To assess the development of the child, on the basis of which appropriate goals and activities for the child and family can be planned.	Observation	Form Receptive communication Social interaction Symbolisation	391

Name	Author	Target group		Purpose	Type	Target aspects of communication	Items
		Diagnosis	Age				
Levels of communication							
Communication Matrix *http://www.communicationmatrix.org/ www.designtolearn.com*	Rowland, 2012	People who have severe communication impairments, including severe sensory, motor and cognitive impairments, and young children without severe disabilities who are in the early stages of communicative development.	0–24 months (da)	To pinpoint exactly how an individual is communicating and to provide a framework for determining logical communication goals in terms of specific behaviours and communicative functions or intents to be targeted.	Observation Interview	Form Function Intent Symbolisation	506
Dimensions of Communication Education Resources Information Center (ERIC) *www.eric.ed.gov/*	Mar & Sall, 1999	People who have multiple disabilities including severe or profound mental retardation and deafblindness.	Not mentioned	Generate a broad profile of an individual's communication skills and behaviours.	Observation Interview	Intent Receptive communication Social interaction Symbolisation	30
Educational Schema for Children with the Dual Disability of Deafness and Blindness *Education Resources Information Center (ERIC) www.eric.ed.gov/*	Hewitt, 1978	Severely intellectually retarded and multi-handicapped children, including deafblind children.	Not mentioned	A schema for use by teachers to assess the prelanguage levels of deafblind children on a hierarchical language schedule.	Observation	Symbolisation	5
Description of communicative abilities							
Unnamed *www.amazon.com*	Downing, 2005	Students with severe disabilities, including both vision and hearing impairments.	Not mentioned	To determine a student's communicative skills by questioning significant communication partners.	Interview	Form Function Social interaction Symbolisation	9
Assessment Intervention Matrix *www.smileassociationmethod.com/*	Wolf-Schein & Schein, 2009	Severely disabled individuals, particularly those with significant communication or sensory impairments, including people with deafblindness.	Not mentioned	To enable the individual to achieve optimal independence in activities of daily living at home, school and work, assessing and developing communication and daily-living skills.	Observation	Form Symbolisation	373
Classroom Environmental Assessment *Education Resources Information Center (ERIC) www.eric.ed.gov/*	Luiselli, DeCaluwe, & Jacobs, 1995a	Young children with deafblindness.	Not mentioned	To analyze environmental, child-specific, and peer-mediated factors in the classroom.	Observation	Supportive partner abilities	14
Coding Scheme for Communicative Forms and Functions *Pluralpublishing.com*	King Miller, Swanson, Steele, Thelin, & Thelin, 2011	Individuals with CHARGE syndrome.	Not mentioned	Providing a description of capabilities and limitations of the individual to understand the individual's current communication abilities.	Observation	Form Function Symbolisation	38
Communication Observation Schedule (COS) *www.blind.msstate.edu/publications/ purchase/deafblindness*	Tedder & Sikka, 1992	Students who are deafblind and multi-handicapped communicating at the pre-language level, and their teacher or significant others.	Not mentioned	Analysis of communication, and analysis of the context (partner).	Observation	Form Function Social interaction	26

Name	Author	Target group		Purpose	Type	Target aspects of communication	Items
		Diagnosis	Age				
Description of communicative abilities							
Communication Profile *Education Resources Information Center (ERIC) www.eric.ed.gov/*	Luiselli, DeCaluwe, & Jacobs, 1995b	Young children with deafblindness.	Not mentioned	To evaluate the impact of vision and hearing loss on the child's communication development.	Observation	Form Function	25
Communication Skills Scale *Education Resources Information Center (ERIC) www.eric.ed.gov/*	Starkovich, 1972a	Preschool deafblind children.	Not mentioned	To give a description of the subject's communication skills.	Oral examination Observation	Form Receptive communication Social interaction Symbolisation	56
Communication Style Assessment *www2.afb.org/store*	Gothelf, Crimmins, Woolf, & Prickett, 1995	Students who are deafblind.	Not mentioned	To give a description about the subject's communication style.	Question-naire	Form Function Social interaction	9
Deafblind Supplement of the InterRAI Community Health Assessment: 'Communication' and 'Social interactions' *http://catalog.interrai.org*	Dalby et al., 2009	Adults who are deafblind.	18 years and older	To understand the needs of adults with deafblindness.	Interview	Form Social interaction	17
Functional Communication Assessment Form *Education Resources Information Center (ERIC) www.eric.ed.gov/*	Downing, 1993	Individuals who are deafblind and have a severe intellectual impairment.	Not mentioned	To identify communication needs within the context of meaningful activities and to observe discrepancies in performance, targeted for intervention.	Observation	Supportive partner abilities	5
Home Talk: 'Communication skills' and 'People skills' *http://www.ohsu.edu/oidd/d2l/doc/HomeTalk.pdf* *www.designtolearn.com*	Harris et al., n.d.	Children who are deafblind and have other disabilities.	Not mentioned	To help parents and care providers to participate in the planning of their child's educational program by providing a picture of their child's skills, special interests, and personality.	Observation	Form Function Receptive communication Social interaction Symbolisation	26
List of Forms and Functions *www2.afb.org/store*	Siegel-Causey, 1995	Students who are deafblind, and their significant others.	Not mentioned	To give a description of the subject's communicative forms and functions and of the adults communicating with the subject.	Observation	Form Function	46
Observing and Enhancing Communication Skills *www.amazon.com* *(in book of Downing, 2005)*	Rowland, Schweigert, & Stremel, 1992	Students with severe disabilities, including deafblindness.	Not mentioned	To assess the form of behaviour and the function of communicative messages from the person and his or her communication partner.	Observation	Form Function Social interaction	25

Name	Author	Target group		Purpose	Type	Target aspects of communication	Items
		Diagnosis	Age				
Description of communicative abilities							
Orientation and Mobility Assessment Fact Sheet: 'Communication systems, modes, and devices' and 'Social skills' *www2.afb.org/store*	Joffee, 1995	Students who are deafblind.	Not mentioned	To assess the student's possibilities and needs in orientation and mobility.	Observation	Form Social interaction	21
Parent Needs Assessment: 'Expressive forms/functions' and 'Receptive communication' *Education Resources Information Center (ERIC) www.eric.ed.gov/*	Stremel & Wilson, 1992b	Students with dual sensory impairments and severe handicaps.	Not mentioned	To assess the needs of the parent by describing how their child communicates at home.	Question-naire	Form Receptive communication	20
Prelanguage/Language Communication *Education Resources Information Center (ERIC) www.eric.ed.gov/*	Stremel & Wilson, 1992c	Students with dual sensory impairments and severe handicaps.	Not mentioned	To provide a description of learner performance, specific to communication skills and needs.	Observation	Form Function Social interaction Supportive partner abilities Symbolisation	28
Social Skills Scale: 'Adult interaction', 'Classroom behaviors' and 'Social communication' *Education Resources Information Center (ERIC) www.eric.ed.gov/*	Starkovich, 1972b	Preschool deafblind children.	Not mentioned	A scale for viewing the social skills of the person.	Observation	Intent Social interaction	14
The van Dijk Approach to Assessment: 'Interactions' and 'Communication' *www.drjanvandijk.org*	Nelson, van Dijk, Oster, & McDonnell, 2009	Children and youth with sensory impairments and multiple disabilities.	Not mentioned	To gather information about the underlying processes involved in learning.	Observation	Form Function Intent Receptive communication Social interaction Symbolisation	14

***** *da = developmental age*

Attention is one of the skills considered to play a role in social interaction, examined in terms of the orientation to people and remaining engaged in a social activity (Gothelf et al., 1995; Harris et al., n.d.; Joffee, 1995; Mar & Sall, 1999; Morgan & Watkins, 1989; Nelson et al., 2009; Starkovich, 1972a, 1972b; Stillman, 1978; Stillman & Battle, 1985; Stremel & Wilson, 1992a; Wolf-Schein, 2000). The ability to be aware of others and pay attention to another person, as well as the ability to gain attention and the manner in which this was done were all measured.

Initiation is a second aspect of social interaction that was measured, looking at whether the person seeks contact and initiates an interaction and how the person initiates interaction (Downing, 2005; Mar & Sall, 1999; Morgan & Watkins, 1989; Rowland et al., 1992; Stillman, 1978; Stillman & Battle, 1985; Stremel & Wilson, 1992a; Tedder & Sikka, 1992; Wolf-Schein, 2000). Tedder and Sikka (1992) and Stremel and Wilson (1992c) also assess the initiation of interaction by the partner and Downing (2005) assesses whether there are opportunities to initiate interaction.

A third aspect of social interaction concerns *responding*, which was measured both in terms of whether the person responded to other people appropriately (Downing, 2005; Harris et al., n.d.; Joffee, 1995; Lyall, Henry, Graham, & Lassiter, 1972; Mar & Sall, 1999; Morgan & Watkins, 1989; Rowland et al., 1992; Starkovich, 1972b; Stillman, 1978; Stillman & Battle, 1985; Stremel & Wilson, 1992a; Tedder & Sikka, 1992; Wolf-Schein, 2000), as well as whether the partner responded to the person (Downing, 2005; Rowland et al., 1992; Stremel & Wilson, 1992c; Tedder and Sikka, 1992).

The fourth aspect of social interaction that was measured was *reciprocity*. The instruments developed by Downing (1995), Harris et al. (n.d.), Mar and Sall (1999), Morgan and Watkins (1989), Nelson et al. (2009), Starkovich (1972b), Stillman (1978), Stillman and Battle (1985), Tedder and Sikka (1992) and Wolf-Schein (2000) assessed the ability of people to participate in communicative exchanges and to understand the patterns and conventions of social interaction. The items vary from the ability to engage in turn-taking and the number of turns that are taken before disengagement, to the ability to sustain, expand and end the interaction, and the duration of the interaction between the person with deafblindness and the communication partner.

Other aspects of interaction measured were showing a sense of humour and affection (Morgan & Watkins, 1989; Wolf-Schein, 2000), the complexity and amount of interaction games (Wolf-Schein, 2000), the circumstances in which the individual interacts with others (Gothelf et al, 1995), the ability to interact without intervenor (Dalby et al., 2009), and whether the student has a way to correct a communication breakdown (Downing, 2005).

Symbolisation. The third aspect considered important to assess is the presence or absence of symbolic ability of the person (n = 16). The lowest level is non-symbolisation, with the basic responses being crying and smiling, responses or reflexes that must be interpreted and communicative behaviour such as gestures, sounds, body movements or vocalisations which most people can interpret and understand. Other non-symbolisation aspects that were assessed include recognition of objects presented and whether the person was able to use them in the way they had been taught, anticipating routine events, participating in and initiating familiar motions and activities, the ability to copy and imitate movements, gestures or vocalisations, and the ability to recall images even when the object is not presented.

Symbolisation is defined as the ability to use symbols to represent objects, people, needs, simple events, basic actions and thoughts. According to Hewitt (1978) and Mar and Sall (1995) the highest levels of symbolisation involves the use of an extended symbol system that is equivalent to a primary form of communication (e.g., sign, speech), capable of representing abstract ideas and concepts symbolically, making references to the past and future, and encompassing the ability to conceptualize and refer to objects or situations that may not have been experienced personally (imagination). The instruments distinguish the complexity of symbolization in terms of the production of single words, simple sentences, complete sentences, compound sentences or the length of the sentence, the use of plurals, verbs, pronouns, tense, prepositions, and possessives, the insertion of negatives, the meaning of the words used (standing for objects, feelings, body parts, numbers etc.), the consistency with which the words are used, the ability to use one word for one single reference, the ability to carry on a conversation, the appropriateness of vocabulary, and the number of words or subjects used. Some instruments specifically ask whether certain gestures or symbols are used, such as 'bottle', 'toilet', waving goodbye, making gestures to body parts, saying 'thank you', 'yes' or 'no', calling family members by name, counting to 30, and whether words such as 'what', 'where', 'in', 'on, 'mine', 'I' are used (Harris et al., n.d.; Starkovich, 1972a; Stillman, 1978; Stremel & Wilson, 1992a; Wolf-Schein, 2000; Wolf-Schein & Schein, 2009). Three instruments examine whether signals are understood by other people (Downing, 2005; Stremel & Wilson, 1992a; Stremel & Wilson, 1992b).

Communicative function. It was also considered important to assess the communicative function of the behaviour of the person (n = 14). Except for Downing (2005), Nelson et al. (2009) and Gothelf et al. (1995) who used open questions (i.e., what is the probable meaning of the communications, list the different functions of communication, what kinds of communication does the person communicate), the instruments listed several functions. The functions assessed were requests (for object, contact, action, social routine, comfort, help, permission, information, clarification, more, and attention), protest, rejection, continue an activity, termination of interaction, greeting, instruction/information, praise, discipline, calling, showing, showing off, comments, providing information, imitation, statements, confirmation, performative acts (humour, teasing, joking), making choices, comfort or discomfort, responses to requests (for action, clarification, attention, assertiveness and performative acts), repetition, assistance, feelings (anticipation/excitement, boredom, fear, frustration, affection), attending behaviour, transfer, offering, sharing, directing another's attention, polite social forms, interest in other people, asking and answering questions. While most in-

struments measured the function of the message the person communicated, Tedder and Sikka (1992) did not specifically explore this but instead assesses the purpose of the interaction between the person and the partner. The specific function of the message of the partner was measured by two instruments (Rowland et al., 1992; Siegel-Causey, 1995).

Receptive communication. Another aspect of communication measured by the instruments was the comprehension of a communicative message and the understanding of words (n = 10). The instruments developed by Morgan and Watkins (1989), Stillman (1978), Stillman and Battle (1985), Stremel and Wilson (1992a) and Wolf-Schein (2000) included many items on this topic, starting from unresponsiveness to the environment, whether the child becomes calm when picked up, and changes behaviour when stimulated or responds to interesting events produced by an adult, to the child understanding a few words referring to familiar objects, anticipating a familiar event from whole body cues, finding an object which is out of sight when adult uses verbal and gestural cues, understanding words concerned with feelings, responding appropriately to a 'why' question with a reason, understanding each request in two-part requests in any sequence, understanding words and gestures in a context different to that in which they were originally understood, and understanding up to 5,000 words. The instrument developed by Mar and Sall (1999) was less detailed, assessing the level of comprehension, varying from awareness or responsiveness when another person begins or ends an interaction, to having a broad understanding of social situations, directions, and conversations. Harris et al. (n.d.) and Nelson et al. (2009) included a few general items on receptive communication such as following a simple command and demonstrating an understanding of communication symbols. Starkovich (1972a) and Stremel and Wilson (1992b) included a few items on the ability to respond to certain sounds and commands (e.g., run, throw the ball) and the understanding of certain words. This type of approach was also used by several other instruments, questioning the understanding of certain categories of words (e.g., activities, actions, people and word combinations such as verb-noun) and/or examining the comprehension of specific words and sentences such as 'what', 'where', 'why', 'big/little', 'no', 'one', 'mine', 'give me that', 'come', 'beside', 'under', 'what do we cook?', 'what is your name?', 'what is a forest made of?' or 'what do you do when you are thirsty?' (Morgan & Watkins, 1989; Stillman, 1978; Stillman & Battle, 1985; Stremel & Wilson, 1992a; Wolf-Schein, 2000).

Intentional communication. Intentional communication emphasizes the development of the ability to show intentions to others, assessed by some instruments (n = 6). This ability can be discerned from information about the function of the communicative message signaled (which communicative intentions are expressed by the person), measuring whether the person is able to communicate intentions, and at what level of intentionality they act. Stillman and Battle (1985) assessed this in the greatest detail,

including items such as 'has behaviours which serve to elicit contact from others', to 'spontaneously uses gestures and words (oral or manual) in novel situations to point out or to comment on actions or objects'. The child's level of perseverance in making the intention clear was also measured. Rowland (2012) also assessed the level of intentionality, varying from pre-intentional behaviour that must be interpreted by the caregiver to intentional communication where gestures and symbols are used with the intent of influencing the caregiver's behaviour. Mar and Sall (1999) measured levels of intentionality from the basic level of responsive and reflexive behaviours to more complicated, planned communication. Stremel and Wilson (1992a) distinghuised between two levels: the ability to point to an object to request the adult to get it and the ability to point to another person or an object to get adult to look at it. Two instruments included some items on intentional communication more generally: the ability to indicate wants (Starkovich, 1972b) and whether the person demonstrates communicative intent through the use of signals, vocalisations, gestures, etc. (Nelson et al., 2009).

Supportive partner abilities. Downing (1993), Luiselli, DeCaluwe and Jacobs (1995a), and Stremel and Wilson (1992a, 1992c), included items that focus on preconditions for optimizing communication in persons with deafblindness (n = 4). Luiselli et al. (1995a) have the most extensive interest in this topic, measuring partner abilities such as introducing activities by distinct cues, whether a communication program is appropriate for the individual in question, whether the partner allows adequate response time, and the use of prompts and reinforcement to demonstrate social skills or concepts (e.g., turn-taking, initiating). It is also considered important to assess whether peers have been instructed about how to interact and communicate with a child with deafblindness, such as teaching them specific strategies for communicating/interacting, and prompting peers to share materials and praising them for interacting with the child. Stremel and Wilson (1992c) addressed physical assistance, imitation, gesture/signing, giving responses and the initiation of communication as types of support. Stremel and Wilson (1992a) included four items on this topic regarding the provision of opportunities for communication, positive feedback, expansion of language to higher levels, and demanding the use of language rather than pre-language. Downing (1993) specifically focused on which visual and auditory cues prompt certain communicative behaviours in the person with respect to different activities.

3.3.2 Tactility

The implementation of the tactile sense was the criteria used to examine all instruments, with nine instruments embedding the tactile sense in their items. These were the Communication Placement Assessment (Stremel & Wilson, 1992a), Deafblind Supplement of the InterRAI (Dalby et al., 2009), INSITE (Morgan & Watkins, 1989), the Callier Azusa Scale 'G' and 'H' (Stillman, 1978; Stillman & Battle, 1985), the Classroom Environmental Assessment (Luiselli et al., 1995a), the Assessment of Developmental Levels by Observation (Wolf-Schein, 2000), the Assessment Intervention Matrix

(Wolf-Schein & Schein, 2009) and The van Dijk approach (Nelson et al., 2009). Apart from Stillman and Battle (1985), all specifically mentioned tactile communication modes in some items, namely two-hand manual/coactive signing, adapted interactive tactual sign language, tactual cues, tactile symbols, and signals presented tactually. Other tactile components embedded in the items concern whether the person understands signals presented tactually (Stillman, 1978), readily accepts being touched, held, rocked and cuddled (Stillman & Battle, 1985), respond to tactually stimuli (person, object), attends, explores or recognises objects, animals or people tactually (Morgan & Watkins, 1989; Stillman, 1978; Stillman & Battle, 1985; Stremel & Wilson, 1992a; Wolf-Schein, 2000), participates in a familiar motion after the teacher has initiated it when being in physical contact, anticipates a routine event from tactile-kinesthetic cues (Stillman, 1978), awakens or calms down in response to a caregiver's touch, imitates vocalisation by feeling the vibrations produced and the mouth movements of others, looks at simple pictures or objects or people when feeling them, touches several body parts when named, and touches pictures of familiar things in a story book (Morgan & Watkins, 1989). Nelson et al. (2009) examined whether the person demonstrates an understanding of communication symbols which can be tactual. Wolf-Schein (2000) focused on the use of the tactile sense by the assessor when implementing the instrument.

3.3.3 Psychometric properties

The psychometric properties of seven instruments were available. Five instruments reported on reliability as well as validity (the ADLO, the Callier-Azusa Scale (former edition of the 'G'), the COS, the Ability Screening Test and the Deafblind Supplement of the InterRAI Community Health Assessment). One instrument only reported on reliability (the van Dijk approach) and one instrument only provided information on validity (INSITE).

Evidence of reliability was found for six out of 27 instruments (see Table 2). The Callier-Azusa Scale (a former edition of the 'G'), the COS, the ADLO and the van Dijk approach were found to have excellent interobserver reliability, with values exceeding 80 percent or 0.80 (Kazdin, 1975). In general, the Deafblind Supplement of the InterRAI Community Health Assessment also had an acceptable interrater reliability, with a mean Kappa value of 0.76 for the items on modes of communication (range 0.21 – 0.99) and 0.70 for the item on social interaction. The actual reliability score for the Ability Screening Test was not given. It is only mentioned that preliminary reliability measures by independent examiners consistently yielded non-significant differences in test results. No information on internal consistency and intrarater reliability (test-retest) was provided on the communication sections of these instruments.

Information regarding validity was found for six instruments, summarised in Table 3. The concurrent validity of two instruments, the ADLO and the INSITE Developmental Checklist, was reported. Both correlated well with another instrument, ADLO with the VABS (Sparrow, Balla, & Cicchetti, 1984) and INSITE with the Callier-Azusa Scale (edition not named), with agreement of 70 percent (ADLO) and correlation coefficients of 0.64 to 0.70 (INSITE). Content validity was demonstrated in three instruments. The Deafblind Supplement of the InterRAI Community Health Assessment and the COS were both reviewed by a panel of experts, who also commented on whether the items covered a representative sample of the behaviour domain. The content validity of the ADLO was demonstrated by pretesting the tasks and scripts, after which the instrument was refined. In addition, the validity of the ordinality of the items in the Expressive Language and Receptive Language was demonstrated for a former edition of the Callier-Azusa Scale 'G' (edition 'E'). The percentage of subjects who 'passed' each item was computed and a Guttman Scaleogram Analysis was done to compute the coefficients of scaleability for each subscale, which ranged from .76 to .99, well above the level of .60 suggested for acceptability (Menzel, 1953). Based on the results of the analysis and the percentage passing each item, some revisions were made to ensure even stronger ordinality of the items making up each subscale. The Ability Screening Test only mentioned that preliminary validity measures by independent examiners consistently yielded non-significant differences in test results.

Table 2 Reliability data for those instruments providing such information

Measurement instrument	Study	Participants	Interobserver reliability	Additional information
Ability Screening Test	Lyall, Henry, Graham, & Lassiter, 1972	Unknown	It is mentioned that, based on a small sample size, preliminary reliability measures with independent examiners have yielded consistently non-significant differences in test results.	-
Assessment of Developmental Levels by Observation (ADLO)	Wolf-Schein, 1993	Two sets of raters viewing 30 videotapes	0.86–0.92 (measure not mentioned)	-
Callier - Azusa Scale (former edition of the 'G')	Day & Stillman, 1975	80 children with deafblindness and 95 teachers, aides, parents and specialists at 13 centres, and four observers	*Correlation coefficients subscales* Receptive language: .86 & .92 Expressive language: .88 & .90 Speech: .82 & .89 Socialisation: .68 & .66 *Percentage of agreement subscales* Receptive language: 92.2 Expressive language: 92.9 Speech: 92.5 Socialisation: 90.0	The first number refers to the correlation coefficient of the individual raters. The second one is the paired score: the four observers formed two pairs and filled out another scoresheet on a consensus basis following discussion of their observations.
Communication Observation Schedule (COS)	Tedder & Sikka, 1992	Unknown	*Percentage agreement whole instrument* 0.9	The authors mention practising with a videotape until two or more people arrive at a single rating for each behaviour and an acceptable level of observer agreement was reached. Alternately, a single rater might rate the same videotaped interaction on several occasions and calculate his/her reliability using a test-retest formula. Examples of how to calculate this are provided.
Deafblind Supplement of the InterRAI Community Health Assessment	Guthrie et al., 2011	44 adults with deafblindness and eleven assessors	*Kappa value* Modes of communication: 0.76 (0.21-0.99) Social interactions (1 item): 0.70	All assessors attended a 1-day training session. This session focused on the project protocols and a discussion of techniques for assessing and coding items to ensure consistency between assessors.
The van Dijk approach to Assessment	Nelson, Janssen, Oster, & Jayaraman, 2010	18 individuals with deafblindness communicating primarily on a nonsymbolic level (aged 2–21 years) and 9 educators (assessors)	*Percentage agreement whole instrument* Second observer 1 (18 assessments): mean of 85.3% with a range between 72 and 96 percent Second observer 2 (4 assessments): mean of 86% with a range of 82 to 90 percent	A 3-hour training session on how to conduct and score the assessment framework is given. The assessments were then examined for fidelity (the extent to which assessors implemented the assessment as intended and identified quality indicators), with a mean fidelity between 88–93.5% (4 observers).

Table 3 Validity data for those instruments providing such information

Measurement instrument	Study	Participants	Information on validity
Ability Screening Test	Lyall, Henry, Graham, & Lassiter, 1972	Unknown	The authors mention that, based on a small sample size, preliminary validity measures with independent examiners have consistently yielded non-significant differences in test results.
Assessment of Developmental Levels by Observation (ADLO)	Wolf-Schein, 1993	50 clients with a wide range of developmental disabilities, aged 2–30 years and two research assistants.	The author mention that preliminary scripts covering various areas in which information seemed to be most necessary and a range of tasks to ascertain the client's level of skill were pretested with 50 clients. The scripts were then refined to obtain an observable set of behaviours of sufficient number to allow for designation of an approximate developmental age. Two research assistants then looked at tapes reflecting the tasks and scripts that had been developed, after which behaviours not readily ascertained or equivocal were eliminated. Because the ability level of the clients varied so greatly a series of scripts and sets of materials were added. ADLO ratings were compared with scores derived from the VABS (Sparrow et al., 1984). A comparison between age equivalents on 20 VABS Domains and ADLO areas indicated agreement within one year on 70 percent. It was concluded that the major differences in the remaining 30 percent were due to a greater coverage of some of the areas by ADLO, leading to the more accurate assignments of developmental levels.
Callier - Azusa Scale 'E' (former edition of the 'G')	Day,n.d.	58 children with deafblindness and teachers familiar with both the students and the administration of the Callier-Azusa.	*Percentage passing each item* Receptive language (item 0–13): 100.0; 96.6; 96.6; 93.2; 83.1; 71.2; 40.7; 37.3; 27.1; 22.0; 22.0; 13.6; 11.9; 05.1 Expressive language (item 0–17): 100.0; 98.3; 94.9; 84.7; 74.6; 55.9; 44.1; 33.9; 30.5; 28.8; 25.4; 22.0; 15.3; 08.5; 03.4; 01.7; 00.0; 00.0 *Guttman Scaleability coefficients* Receptive language (items 0–7): .8433 (present order) .8731 (best order supplied by computed analysis) (items 8–13): .8205 (present order) .8205 (best order) Receptive language (items 0–11): .7644 (present order) .8197 (best order) (items 8–17): .9343 (present order) .9880 (best order, completed on items 9–17) There is no information on the 'Socialization' scale.
Communication Observation Schedule (COS)	Tedder & Sikka, 1992	Three people considered by the field as 'expert' in communication and deaf-blindness, and 30 teachers and other raters.	The experts were asked to examine the instrument for comprehensiveness of communication modes and types. Minor revisions were incorporated into the instrument. Thirty teachers and other raters used the COS on multiple occasions with no other suggestions or additions. Therefore, the COS is considered by the authors to have excellent content validity.
Deafblind Supplement of the InterRAI Community Health Assessment	Dalby et al., 2009	Key stakeholders, including service providers, people with deafblind-ness, interveners, policy makers and researchers.	The authors mention that the Deafblind Supplement was developed with extensive feedback from key stakeholders. Convergent validity was also investi-gated by examining the correlation between several key factors, but no information was provided for the items on communication.
INSITE Developmental Checklist	Morgan & Watkins, 1989	29 multi-handicapped sensory impaired children.	The relationship between the Callier-Azusa scores and the INSITE Development Checklist scores was studied. *Correlation coefficient* Communication-Expressive: 0.64 (p = 0.00) Communication-Receptive: 0.66 (p = 0.00) Social-Emotional, interaction with people: 0.70 (p = 0.00)

3.4 DISCUSSION

Valid and reliable measurement instruments which can assess communication skills and needs are an important tool in the development of communication in people with deafblindness. This study has established that there are several instruments available which specifically address communication in people with deafblindness. Overall they provide a good overview of the important aspects of communication that should be assessed in people with deafblindness. However, it was found that most instruments focused on the abilities of the person with deafblindness and not on the abilities of the communication partner, and that only a minority of the instruments included items concerned with the use of the tactile sense. Another issue is that the psychometric properties of most of the instruments were not reported, with only 26 percent providing information on validity and/or reliability.

The abilities of the person with deafblindness that are considered important to measure are the form of communication, the development of symbolic abilities, the communicative function of various behaviours, the receptive communication abilities, the ability to express intentions, and social interaction skills such as paying attention, initiation, responding to others and reciprocity. With respect to the communication partner, the communication form, the communicative function and social interaction skills such as initiating, responding and reciprocity are all considered important to assess. In addition, the supportive abilities of the partner, such as providing physical assistance, providing opportunities for communication, allowing adequate response time and the use of praise and reinforcement are also considered significant.

Although the abilities of the communication partner are just as important as the individual abilities of the person with deafblindness in developing communication in the latter (Downing, 2005; Wasson, Arvidson & Lloyd, 1997), there are few instruments which focus on the abilities of the partner. Only ten instruments measured abilities of the partner (37 percent). Five of them include fewer items on the partner compared to the number of items for the person with deafblindness (Dalby et al., 2009; Downing, 2005; Gothelf et al, 1995; Stremel & Wilson, 1992a, 1992c). The instruments that included an equal number of items (Downing, 1993; Luiselli et al., 1995a; Rowland et al., 1992; Siegel-Causey, 1995; Tedder and Sikka, 1992) were or totally focused on supportive partner abilities or assessed the form and function.

The items available on the partner abilities are of value, pointing to those partner abilities that need to be assessed because of their importance to the development of the person with deafblindness. However, no instruments measure the partner's symbolic abilities, receptive communication abilities, intentional communication skills and social interaction skills such as paying attention; all aspects which are measured in the person with deafblindness. It is known that these partner abilities are important for the communicative development of people with deafblindness. For example, initiating and continuing an interaction requires the partner to pay and maintain their attention

to the person with deafblindness and ensure that this is apparent to the latter (Janssen & Rødbroe, 2007). Symbolic abilities are also fundamental, as people with congenital deafblindness only have the opportunity to develop a lexicon when their partner uses symbols fluently in their communicative exchanges (Souriau, Rødbroe, & Janssen, 2009). Moreover, we should not overlook abilities related to intentional communication. While partners often find it easier to express imperative intentions ('We are going to do this now…') or think that a signal by a person with deafblindness has an imperative function (for example the sign for drinking is interpreted as 'I want to drink'), only by expressing declarative intentions and recognising signals as declarative (directing a person's attention to some event or object in the world) can a person with deafblindness develop an understanding of 'talking about something' without this being linked to a goal (Souriau, Rødbroe, & Janssen, 2008; Camaioni, 1996).

This review also found that although the instruments were developed specifically for people with deafblindness, the tactile sense – which is an important sense for learning in people with congenital deafblindness (Edwards, 2012; Huebner et al., 1995; Janssen, Nota, Eling, & Ruijssenaars, 2007; Janssen & Rødbroe, 2007; Miles, 2003; Nicholas, 2010, 2012) – is given no or little attention. Only 33 percent of the instruments focused on the use of the tactile sense, which was usually reduced to the use of tactile communication modes, reactions to touch and tactual stimuli, and the ability to use the tactile sense to attend, explore or recognize objects, animals or people by the person with deafblindness (Dalby et al., 2009; Luiselli et al., 1995a; Morgan & Watkins, 1989; Nelson et al., 2009; Stillman, 1978; Stillman & Battle, 1985). However, touch and movement can be used for many, more specific reasons by the person with congenital deafblindness, as well as the communication partner. For example, it can be used to make contact, stay in contact, co-actively explore objects or people, to listen by feeling the signs made by another person, to capture the emotions of the person by feeling tension, to lead attention to an object or person, or to confirm utterances (Janssen & Rødbroe, 2007). Furthermore, it is difficult for hearing and sighted communication partners to tune in to this sense as much as we do to vision and hearing (Nafstad & Rødbroe, 1999). To enhance the communicative possibilities of a person with deafblindness it is therefore of great value to include items on the use of the tactile sense by both people involved in the communicative interaction.

The lack of focus on partner behaviours and tactility is a limitation of the instruments discussed here, which also had an effect on the review input. Thus, on the basis of the review alone it was not possible to provide a comprehensive list of all the communicative behaviours that should be assessed in persons with congenital deafblindness and their communication partners. Furthermore, we did not find a comprehensive instrument that can be used for pretesting and retesting as part of a dynamic assessment procedure comprising the observation of all of the important behaviours required for high-quality communication between the congenitally deafblind and their partners, which can enhance the development of the former. Future research must fill the gaps, and in this respect our first goal is to develop a new instrument. The objectivity of the

new instrument should be assured (Fraenkel & Wallen, 2008; Van Loon, Van der Meulen, & Minnaert, 2011), as the conclusions of professionals and researchers are drawn on the basis of the information they obtain using such instruments (Fraenkel & Wallen, 2008), and these decisions have a huge impact on the development of the person with deafblindness. For this reason it is also recommended that the validity and reliability of the instruments currently available should also be assessed.

A second limitation of this study is that relevant data may have been neglected. Not all of the instruments used to assess people with deafblindness are described in journal articles or reports available on the databases. Two instruments, for example, are the Developmental Profile (Nafstad & Rødbroe, 1999) and the Identification of Congenital Deafblindness (Andersen & Rødbroe, 2006), which are available but not described in an article and therefore are untraceable in the databases. Another instrument we know is the Holistic Communication Profile (Bruce, 2010), which is not in a report available on the databases. This may have led us to overlook some significant data. The decision not to include measurement instruments for which no order information is available on the internet, may also have led to the neglect of relevant data. The Wisconsin Behaviour Rating Scale (Song et al., 1980), the Gestural Approach to Thought and Expression (GATE) (Langley, 1976) and the Priority Needs Assessment Scale (Burton, 1978) are three additional instruments which we know of that have been used to assess people with deafblindness in particular, and were named relatively frequently in the literature. No order information was found for these instruments, but perhaps these instruments are still available through their developers. It is not known whether these instruments would have led to additional insights.

3.5 CONCLUSION

As this review illustrates, many instruments are available to address various important aspects of communication that need to be assessed in people with deafblindness. However, it can be concluded that the existing instruments do not sufficiently measure partner abilities and the use of the tactile sense, both of which are essential for the development of people with deafblindness. To accomplish our goal of developing a dynamic assessment procedure for people with congenital deafblindness, a new instrument is needed. This must be a valid and reliable instrument on which we can rely to make judgements about the communicative skills and communicative potential of a person with congenital deafblindnes, and the impact of partner abilities on the communicative development of the former.