Revealing hidden potentials

Assessing cognition in individuals with congenital deafblindness

Nordic Welfare Centre

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– Assessing cognition in individuals with congenital deafblindness

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Foreword

People with congenital deafblindness often have hidden cognitive potential that those around them fail to detect. This can lead to these people missing out on communication, or not even having the opportunity to develop a tactile language. In order for other people to better support such development, tools are needed to discover this hidden potential. This book is intended to help professionals assess cognition – and thus be able to develop adapted strategies so that people with congenital deafblindness can develop their full potential.

The purpose of the book that you are now holding in your hand is to make a difference for people with congenital deafblindness.

The book is aimed at professionals who are involved in making examinations and assessments of cognition in cases of congenital deafblindness in both children and adults. It is also an important contribution to further research in this area. Knowledge about the brain's structure and function has increased in recent decades and deepened our understanding of the neurological mechanisms behind mental and cognitive development. One important task is to develop the deafblind-specific aspects of this knowledge and this book is a step in this work.

The Nordic region has a history dating back to the 1970s of jointly developing knowledge in the field of deafblindness and disseminating it. The population of persons with congenital deafblindness is small in each country and the professional groups are small. For this reason, there are great benefits in the Nordic region from jointly developing knowledge and creating larger centres of excellence through networks of specialists and professionals working across the Nordic countries' borders.

The Nordic Welfare Centre creates meeting places and is responsible for knowledge-development networks, expert groups and education in the entire area of welfare in general and in deafblindness specifically. As part of this, the Nordic Welfare Centre has previously published books on topics such as communication and language development and tactile working memory. This book has been produced by members of one of the Nordic Welfare Centre's networks,

Foreword (cont.)

consisting of experts in the field, including psychologists and special educators with assignments in research and clinical and educational work.

The Nordic Welfare Centre has also coordinated the work of developing a Nordic definition of the disability deafblindness to create a common Nordic basis for further work on knowledge development. The definition, which you can read more about in the introduction, is based on the UN Convention on the Rights of Persons with Disabilities. To be able to comply with the Convention, knowledge of deafblindness and its consequences must be developed.

The collaboration within the Nordic countries will work to strengthen welfare and make the Nordic region socially sustainable – for all. In this book, we focus on creating the conditions for achieving these goals for people with the disability deafblindness through increased knowledge. This is of course true everywhere, so our intention is that knowledge will be disseminated and used not only in the Nordic countries but also internationally..

The Nordic Welfare Centre would like to thank all the authors and the editorial team who have reviewed the quality of all texts. Without you, the development of knowledge would not have taken this important step.

Eva Franzén
Director
Nordic Welfare Centre

Chapter 1

Introduction: Perspectives on assessment of individuals with congenital deafblindness

Saskia Damen
Joe Gibson
Jude Nicholas

Deafblindness is a term used to describe serious combined vision and hearing impairment. According to the Nordic Definition of the Deafblindness, the combination of these sensory impairments in people with deafblindness is "of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability." (Nordic Welfare Centre, 2018). Deafblindness is a heterogeneous condition that varies in aetiology and severity of disability, is characterised by great diversity among those with the condition and can be found in all educational and social contexts. People with deafblindness often have other conditions, such as neurological disorders, epileptic seizures or neurodevelopmental disorders. Based on the age of onset, three subgroups are usually distinguished: 1) people who are born with this condition or who acquire it before language acquisition begins (congenital deafblindness, hereafter CDB), 2) people who acquire deafblindness during their lives, and 3) people who acquired this condition in old age. Besides the differences between these subgroups, commonalities are described. All people with deafblindness experience serious problems in the following three areas: a) communication, b) information access and c) orientation and mobility (Dammeyer, 2012). The focus of this book is the group of people with CDB.

The World Federation of the Deafblind states that the prevalence of deafblindness is estimated to be 0.2%-2% of the global population. The exact number of people with deafblindness in the world, however, remains unknown (WFDB, 2018). Although there are indications that the number of people with deafblindness is underestimated (WFDB, 2018; Fellinger, Holzinger, Dirmhirn, Van Gijk, & Goldberg, 2009), deafblindness appears to be a low incidence condition.

The low incidence, heterogeneity and complexity of CDB make it hard for professionals to develop adequate knowledge within the field. In order to develop knowledge of deafblindness, professionals need to collaborate with each other. An important topic for knowledge development is the assessment of the cognitive potentials of people with CDB. Cognitive delays are common for individuals with CDB (Bruce, 2005a). However, formal cognitive assessment tools used for individuals with normal vision and hearing, may not be suitable for individuals

with CDB (see Mar & Sall, 1994). When using standardised cognitive tests or other assessment tools, it is important that the assessor is familiar with the assessment tool that is applied, the constructs the tool aims to assess in case assessment adaptations need to be made, and with CDB itself. Without such expertise, there is a risk that the assessment will lead to inaccurate judgements of the person's cognitive potentials or inappropriate labelling that lead to the provision of insufficient education and support.

This book focuses on the assessment of cognition in individuals with CDB. The authors aim to share knowledge that has been developed through a network of professionals in the field of CDB (the Nordic Cognition Network in Relation to Congenital Deafblindness, hereafter referred to as the Cognition Network).

"When using standardised cognitive tests or other assessment tools, it is important that the assessor is familiar with the assessment tool that is applied, the constructs the tool aims to assess in case assessment adaptations need to be made, and with CDB itself."

The Cognition Network has produced this book as a sequel to Guidelines for cognitive assessment in people with CDB (Ask Larsen & Damen, 2014). The first book explains how the Cognition Network views cognition and cognitive assessment, what is specific to assessment of cognition in individuals with CDB and general guidelines for reliable and valid assessment. Specific procedures and guiding principles for the assessment of cognition in people with CDB that are described in the first book are the use of video-analysis, the focus on the bodily-tactile modality as the main (but not the only) modality on which to perform assessment of cognition, optimization of the interaction/dialogue before assessment takes place, and the application of dynamic assessment (Ask Larsen & Damen, 2014).

With this new book, the authors aim to present the practical applications of these procedures by describing how professionals perform assessment in practice. In chapters 2 through 8, assessment practices are described that highlight various aspects of cognition such as tactile working memory or problem solving. In chapter 9 a group of psychologists from the Nordic countries describes different cognitive domains on which psychological assessment of individuals with CDB can focus and illustrates these with case-examples.

1.1 Perspectives on cognition and cognitive assessment

There are several theoretical foundations or approaches for understanding cognition. Vygotsky emphasises that the development of complex mental activities is most effective through social learning (Vygotsky, 1987), while Piaget describes how children move through stages of development that allow them to think in new, more complex ways (Piaget, 1952, 1954). The transactional model of Sameroff emphasises that learning is a result of people's interactions with other people (Sameroff, 1975). Bronfenbrenner's ecological systems theory focuses on the quality and context of the child's environment, the complex interaction within these environments and the complexity that arises as the child's physical and cognitive structures grow and mature (Bronfenbrenner, 1979). The neurobiological approach describes cognitive development as closely dependent on brain areas and circuits (Nichols & Newsome, 1999). Finally, the information processing theory emphasises the role of information processing mechanisms in cognitive development, such as attention control and working memory (Miller, 1956). These different theories all attempt to understand cognitive development, but from different perspectives.

Some of the perspectives mentioned above were clearly present in the first book as shown in the following definition of cognition: "Cognition is a mental process of making sense of/in the world that is observable in motivated action, that is situated and interactive. Cognition is an imbedded dynamic system; culture and social relationships are part of that dynamic system" (Ask Larsen & Damen, 2014, p. 11). As our Cognition Network has expanded, new perspectives such as the neurobiological perspective has been included which provide a more diverse picture of cognition and cognitive development.

Different perspectives on assessment are also present in this book. In the first book, we defined cognitive assessment as "(...) based on our access to cognition. Assessment of cognition is recognising cognitive ability and evaluating the meaningfulness and the success of the actions of the other. Assessment of cognition always has a purpose in a given context" (Ask Larsen & Damen, 2014, p. 12). In this definition, cognitive assessment is not the work of a specific profession or professional background. As laid out in this book, the recognition of cognitive abilities and evaluation of the meaningfulness of the actions

of a person with CDB can be performed individually by clinical psychologists, educationalists, deafblind consultants, teachers or caregivers, or through a multidisciplinary evaluation. However, the assessment of cognition will be influenced largely by the theoretical approach, the specific abilities targeted by the assessment and the purpose of the assessment.

We will return to the different purposes for assessing cognition in people with CDB later in this chapter. We will then also present a general framework for categorizing the purposes and procedures applied in the assessment of cognition of individuals with CDB. First, we want to explain the challenges of cognitive development for people with CDB. These challenges are faced by every professional when performing cognitive assessment in individuals with CDB.

1.2 Challenges in cognitive development for people with CDB

Several researchers have described cognitive delays in people with congenital deafblindness (see Bruce, 2005b; Dammeyer, 2014). However, there is no evidence that can explain how functional impairments in both vision and hearing, personal characteristics and environmental factors together lead to specific learning outcomes. So far, systematic longitudinal studies on cognitive development and factors influencing this development in people with CDB is lacking (Ravenscroft & Damen, 2019).

It is generally believed that cognitive delays are associated with a lack of experience and practice. It is also believed that the experiences of people with CDB are different from the experiences of people who have functional sight and hearing. According to Bruce, deafblindness leads to limited and fragmentary information (Bruce, 2005a; b). Nicholas states that people with CDB have less access to the world because they are dependent mainly on tactile physical modalities (Nicholas 2013). Access to the environment may be limited in individuals with CDB because the tactile sense is a proximal sense (i.e., we feel things close to us or in contact with us), tactile information is not continuously present, and perception of the sense of touch is different from visual or auditory perception. For instance, individuals with normal vision and hearing initially perceive wholes and then focus on details, a so-called "whole-to-parts approach", while individuals with CDB need to generate an overview of details through the tactile modality. The latter is called a "parts-to-whole approach" and is a much more complex task (Bruce, 2005a; b). All these aspects that limit access to information from the surrounding world will affect the development of cognition in people with CDB in a negative manner.

Van Dijk, Klomberg and Nelson (1997) describe how fragmentary perception makes it difficult for the child with CDB to develop cognitive schemes. Piaget defines cognitive schemes as knowledge structures that enable the child to

understand the world (Piaget, 1952). According to Van Dijk and colleagues, the child with CDB has little chance of developing such structures because his or her own actions often provide the child with too little coherent information to be able to compare and link to existing knowledge and store this in memory (Van Dijk, et al., 1997).

Cognitive limitations for people with CDB can also be understood as originating in problems with learning through communication and social interaction transfer. In studies on interactions between people with CDB and their communication partners, serious problems were found, such as communicative breakdowns, lack of affective attunement, lack of joint attention, and lack of mutual understandings. In several studies, social partners struggled with adapting

"Cognitive limitations for people with CDB can also be understood as originating in problems with learning through communication and social interaction transfer."

their interaction strategies to the needs of the person with CDB (Damen, Janssen, Ruijssenaars, & Schuengel, 2015; Janssen, Riksen-Walraven, & Van Dijk, 2003). A Danish study showed that people with CDB often do not have access to a tactile language system (Dammeyer & Ask Larsen, 2016). Other authors have noted that people with CDB hardly receive any information about the actions of others, which means that learning from imitation and exemplary behaviour is almost impossible (McInnes, 1999, Van Dijk & Janssen, 1993). As a result of deprivation, the person with CDB can experience the environment more or less as an extension of himself or herself, becomes trapped in his or her own world and has little or no opportunities for exploration or information gathering (Van Dijk, 1982; Van Dijk & Janssen, 1993).

It is likely that cognitive problems in people with CDB are not only characterised by a limited understanding of the world for the reasons described above, but also by problems in developing effective strategies for monitoring their own thinking processes and gathering knowledge. For instance, Piaget describes how constructive processes such as generating hypotheses, experimenting and

drawing conclusions, play a role in the acquisition of knowledge (Piaget, 1952; 1954). In typical development, qualitative improvements in these processes occur with increasing age, as over time, people develop better strategies for directing and organising their thinking processes and their experiences in acquiring knowledge. Piaget calls this improvement of learning strategies "self-regulation". According to Piaget, self-regulation is an important factor in explaining how children learn (Piaget, 1964). In children with CDB, various problems have been described that may hinder their self-regulation, such as being insufficiently challenged by their educators to solve problems and to reflect over their problem solving, and rarely having the opportunity to experience the effects of their own actions (see McInnes, 1999; Van Dijk & Janssen, 1993).

The challenges of cognitive development of people with CDB described in the literature can be used as a basis for assessment and intervention. Problems in self-regulation, for example, make learning strategies an important issue to consider when assessing cognition in people with CDB. Chapter 8 describes the importance of providing appropriate learning strategies in the bodily-tactile modality to promote the development of working memory in people with CDB. By providing specific perceptual, cognitive and social cognitive learning strategies in the bodily-tactile modality to people with deafblindness, we may be able to help them create unique experiences, and to promote multisensory integrative capabilities (Nicholas, Johannessen & van Nunen, 2019). Problems in access to experiences and exercise suggest that it can be worthwhile to assess the child during participation in novel activities (chapter 3). Problems with learning through social interaction require the assessor to observe interaction during the assessment (chapter 4).

1.3 Adopting the International Classification of Functioning, Disability and Health (ICF) model for understanding cognitive development

Given the heterogeneity of deafblindness and the multiple factors that influence cognitive development, a dynamic framework is needed for understanding how cognition develops in a person with deafblindness. The International Classification of Functioning, Disability and Health (WHO, 2001), hereafter ICF, can be used as a common platform for understanding cognitive development. The ICF model conceptualizes a person's level of functioning as a dynamic interaction between her or his health conditions, environmental factors, and personal factors. The ICF model can also be used as a basis for designing a cognitive assessment plan. It is a biopsychosocial model of disability, based on an integration of the social and medical models of disability. The model suggests that both disabilities and functional resources should be described by collecting and organising functional measurement data in a multidisciplinary, biopsychosocial data matrix. The model includes two main domains: 1) functioning and disabili-

ty, and 2) contextual factors. Within the functioning and disability domain, one needs to consider physical function and structure, participation, and activity. Contextual factors include personal and environmental factors. All factors interact and may affect the overall health, well-being and cognitive development of the person with CDB.

1.4 Assessment framework

The previously described cognitive challenges for people with CDB make clear why evaluation of their cognition is important. The presumed nature of these challenges, such as the lack and different types of physical and social experience, make it especially relevant to observe interactions between the person and his or her physical and social environment. Information on these interactions is not only informative but can also form a basis for intervention. In practice, various approaches are currently used in the cognitive assessment of people with CDB. Figure 1 presents a framework for the categorisation of assessment approaches developed by the Cognition Network. In the following, we will further explain the three layers of this assessment framework.

Purpose

The first layer of the framework concerns the purpose of the assessment. The definition of cognition formulated by the Cognition Network in 2014 states that assessment of cognition must always have a purpose in a given context. From the case examples presented in the different chapters, we see that the purpose of cognitive assessments may differ. Professionals can carry out an assessment with the aim of obtaining a general impression of a person's learning potential and the extent to which cognitive abilities are stimulated by educators in a way that is adapted to the needs and abilities of the individual. In other case examples, ideas or hypotheses about cognitive problems or about what causes or maintains such problems inspire assessment. The purpose of the assessment in these cases is to test these ideas or hypotheses. Finally, we describe case examples in which assessment is used to measure specific behaviours of the individual, the communication partner or both.

Assessment procedure

The second layer of our framework considers the assessment procedure. The definition of cognition above makes clear what assessors do when assessing cognition: they evaluate the meaningfulness and the success of the actions of the person. In our first book we described that observation is an important instrument for such an evaluation. We referred to Ask Larsen, who states that when using observation for cognitive assessment, "it is important to have a method of observation that will embrace behaviour as an expression of cognition in a manner that includes the full complexity of the theoretical understanding of cognition as well as the full range of contextual influences on the situated instance of ongoing cognition that we observe" (Ask Larsen & Damen,

2014. p. 9 & 10). Other assessment tools that we can use are interviews, questionnaires and tests. Observation is always one of these tools. When we interview a parent or ask them to fill in a questionnaire about the functioning of their child, they will base their responses on their previous observations. When we test a child, we observe the responses of the child in the test situation.

If we want to apply a procedure that is in line with our understanding of cognition, it should enable us to evaluate the person's actions and ongoing interaction with her or his physical and social environment. In order to be able to draw conclusions about the meaningfulness and successfulness of the person's actions, we also need to gather adequate and relevant data about these actions as well as the context in which they occur.

Clearly, not all procedures provide adequate and relevant information. An example is a situation in which a child with CDB is observed while lying on a mat to rest after school. In this situation, few actions and interactions can be observed. In order to be able to gather relevant information about the cognitive abilities of a person, specific situations can be selected or created. An observation is still a "naturalistic observation", when the assessor observes the individual in her or his natural environment and does not manipulate the situation. Unfortunately, situations in daily life do not always provide enough information about cognitive abilities. The assessor can then consider manipulating natural situations, for example by asking parents to perform an activity with their child with CDB. Such a manipulation also provides the opportunity to see the results of specific interventions. When natural situations, such as classroom situations or daily events at home, are adapted with the aim of observing specific behaviours, the assessment becomes semi-structured[1]. When the situation is largely adapted by the assessor, for example by determining where the observation takes place, at what time, under which circumstances or by using a standardised (test) procedure, we speak of a structured assessment.

Analysis

Regardless of the level of structure of the procedures, the gathering of data such as the act of observing the person with CDB in a specific situation is not sufficient to draw conclusions about his or her cognitive abilities. Some form of analysis is always needed. The third layer of our assessment framework, therefore, considers the analytic procedure chosen by the assessor. As the case examples show, these analytic procedures may differ. The assessor may decide not to look for specific aspects beforehand, but to determine what is relevant while analysing the gathered material. This is an "open", inductive method of

1 We prefer the terms "semi-structured" and "structured" to indicate the extent to which the assessor influences the assessment situation, instead of the terms "semi-controlled" or "controlled". These latter terms could give the misguided impression that the assessment approaches are meant to approximate experimental situations.

analysis. This type of analysis is often used in qualitative research and known as Grounded Theory (see Glaser & Strauss, 1967). On the other hand, the assessor may decide to focus on the analysis of specific themes. The selection of themes can be based on practical knowledge as well as on theory. We refer to this type of qualitative analysis as Thematic Analysis (Flick, 2014). Finally, analytic procedures may have the form of rating specific behaviours, for example when using an observation scale (Robson, & McCartan, 2016). This is an example of a quantitative way of analysing assessment data.

Figure 1.
Assessment framework

Purpose	Getting an impression	Testing an idea/ hypothesis	Measuring behavior
Procedure	Naturalistic observation	Semi-structured assessment	Structured assessment
Analysis	Open analys	Thematic analysis	Rating

The three layers of our framework categorise purposes, procedures and analytic approaches (see Figure 1). It is important to note that the position in the figure of a specific category does not say anything about its importance.

The layers and the categories within these layers connect with one another. When an assessor tries to get a general impression of something, it is likely that she or he uses naturalistic observation and an open form of analysis. When an assessor wants to measure something, she or he will likely set up a structured assessment procedure and use rating as the analytical procedure. More combinations are possible, however. Measuring behaviour can also be done by using observational material gathered in a naturalistic observation. An example is the video-recorded observation of a play situation with construction materials in a pre-school setting, that the observer continuously codes each time the child explores the materials and each time they build something. It is also possible for the assessment process to consist of multiple elements that are combined or applied subsequently. For example, the assessor may start the assessment process with the aim of obtaining a general impression of a person's functioning and therefore use naturalistic observation. The subsequent open analysis of the observational material can lead to specific

ideas about problems of the functioning of the person with CDB. The assessor may then decide to use the same video-observational material to focus on the specific themes identified. Alternatively, the assessor can decide to set up a semi or fully structured assessment to analyse the behaviour of the individual in specific circumstances. It can also be the case that the assessor applies a specific intervention and observes its effects. Other combinations are possible: a structured assessment can lead to results that make the assessor wonder how the individual functions in natural situations and to decide to perform a naturalistic observation.

When naturalistic and (semi-) structured observations are combined, several data sources are used. The use of multiple data sources for assessment in people with CDB is in accordance with recommendations for good quality assessment (see Mar, 2010). In order to be able to better understand the actions of the individual with CDB in a specific situation, it can also be helpful to combine observation with other types of data sources that provide information about the person and the context. This information can, for example, be obtained by file study or by interviewing parents or teachers. In addition, the use of standardised tests may sometimes provide specific information about the person with CDB. However, when engaging a person with deafblindness in a standardised test situation, special concessions and considerations may be required, and we must be extremely cautious in interpreting the test results. This is because scores may not be valid once there is departure from standard procedures (Mar, 2010), and because standardised instruments seldom include children with deafblindness as a norming group (Bruce, et. al., 2018).

When observation is conducted repeatedly before, during or after an intervention to assess the results of the intervention, a dynamic assessment approach is applied. Such an assessment approach enables the assessment of learning potential and is especially relevant when educational situations are not well-adapted to the needs of people with complex communication needs (Broers, Janssen, Minnaert, & Ruijssenaars, 2013).

The examples of assessment processes above may give the impression that the assessor is the one who decides the steps to be taken and is the only person to draw conclusions about cognitive abilities in individual cases. In practice, this is usually not the case. In our first book, we recommended assessors of people with CDB to closely collaborate with other professionals, preferably in a multidisciplinary team, and with parents or other people who know the person well (Ask Larsen & Damen, 2014). The collaboration of professionals, parents and other proxies will likely enhance the exchange of complete, reliable and valid results and conclusions, and can help in the formulation of useful advice for practice and selection of feasible and effective interventions.
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1.5 Reading guide

As explained earlier, the chapters in this book describe varying assessment purposes, procedures and analytic approaches that make up our assessment framework (Figure 1). Figure 2 provides an overview of how the chapters fit into the assessment framework.

Figure 2.
Overview of how the chapters fit within the assessment framework.

	Naturalistic observation	Semi-structured observation or assessment	Structured observations or assessment
Getting an impression	Humour (chapter 2) Climbing the wall (chapter 3) Analysing learning processes (chapter 4) Grounded theory (chapter 5) Arousal (chapter 6)	Climbing the wall (chapter 3) Analysing learning processes (chapter 4) Grounded theory (chapter 5) Arousal (chapter 6) Water play (chapter 7)	TWMS (chapter 8) Water play (chapter 7)
Measuring something			Arousal (chapter 6) TWMS (chapter 8) Psychological Assessment (chapter 9)
Testing an idea or hypothesis		Climbing the wall (chapter 3) Grounded theory (chapter 5) Arousal (chapter 6)	TWMS (chapter 8) Water play (chapter 7)

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Chapter 2

Humour and playfulness within social cognition

Jonathan Reid
Jacky Smith

Humour, laughter and play are integral and enjoyable aspects of life for all of us. Neely, Walter, Black and Reiss (2012) suggest that the study of humour often reveals complex levels of cognitive processing, highlighting that humour plays a central role in the social development of children. Humour processing has been described as "a complex information processing task that is dependent on cognitive and emotional aspects" (Willinger, Hergovich & Schmoeger, et al. 2017, p. 162). Pagliano, Zambone and Kelley (2007) characterise this process as not reliant on language, and as an important step towards human relationship building and meaning making. Therefore, to share laughter with another not only reveals a moment of shared connection within a communicative partnership but may also reveal something about the cognitive processing abilities of the partners. Reddy (2008) tells us that "Understanding what's going on in humour is potentially a rich source of mind knowledge" (p.183).

Thinking about humour in this light suggests an interesting area for observation when considering assessment of cognition for a person with congenital deafblindness (hereafter CDB). In this chapter we explore the role humour can play in assessing cognition. We will illustrate this by examining a series of interactive sessions between a woman with CDB and two of her communication partners. By examining instances of humour within the sessions, we aim to highlight the complex cognition that is involved, and how this can be revealed through the tactile modality. We examine the definitions of play, the links between play, engagement, humour and social cognition, and describe some examples from our work. Play is most often considered in relation to children. We have widened our thinking in this area and considered play, clowning and teasing as part of a much broader life-long framework.

2.1 Ethical considerations

In this project, our aim was to increase our understanding of Kate so that the support offered to her could be the best possible. Our input had been requested, and the sessions were part of Kate's weekly planned activities. Feedback

was given to the staff member supporting Kate after every session, and written feedback was shared with her staff team and family. Kate's parents have given permission for this study to be included in this publication. Some details, such as her name, have been changed to protect Kate's identity.

2.2 Project participants

Kate

Kate is a woman in her 30s with CDB. She has no useful sight or hearing. Kate has a fun and outgoing personality. She is supported by a social care organisation.

Jacky

Jacky has known Kate for over 20 years and was part of the team that supported her at home during 15 of those years. Although she does not support her directly at present, they still maintain contact.

Jonathan (Jon)

Jonathan has known Kate for 17 years but had rarely worked directly with her until the beginning of this process. Jon has previous experience of using dance, movement and dramatic techniques within a deafblind support context.

2.3 Theoretical Perspectives: Why do we think play and humour can help support cognitive assessment?

The Aesthetic Space Encounter

Mark Johnson considers the field of aesthetics within embodied cognition. He writes:

> "...we need a philosophy that sees aesthetics as not just about art, beauty, and taste, but rather as about how human beings experience and make meaning. Aesthetics concerns all of the things that go into meaning - form, expression, communication, qualities, emotion, feeling, value, purpose, and more" (Johnson, 2007, p.212).

Reid (2019) builds on this within the context of CDB and describes several components of an aesthetic space encounter involving a space of improvisation, emotion and sensory adaptation to the other. Within this framework, playfulness and safety are paramount, and the focus is on sharing the world together declaratively, rather than viewing the other in terms of a functional, imperative agent of practical needs. He brings together some of the various criteria by which an aesthetic space might be recognised as follows:

- A space in which one can observe oneself in action – and be observed by others
- An intersubjective space, between two or more brains
- A space of potential and improvisation
- A declarative space, to do with emotion
- An evolving process of adaptation to the other
- A space explored through the senses
- A space of imagination and creativity

Within this framework, which can be linked closely to the playful frame, we will go on to discuss how tasks, objects and gestures are not organised in terms of fixed definitions and notions. Rather, they both contain and afford improvisatory qualities and opportunities and enable participants to imbue these with novel and playful characteristics.

Play

Maslow (1943) includes play in the third level of his well-known five-level hierarchy of human needs. Included in his Love and Belonging level are: "relationships with others, family, friendships, play and work groups, affection, sexual intimacy, and companion animals" (p. 377). Clearly, he felt that play was an essential component of a fulfilling life. Arthur Koestler (1964) shared much of this philosophy, firmly placing humour between the pillars of science and art as a central thematic of human creativity and learning. He defines humour as the "ha-ha" reaction, science as the "aha" reaction and art as the "ah" reaction (p.96). Corke (2011) simply sees playfulness as "an experimental frame of mind" (p.10). Bateson (2015) brings together some of the various criteria by which play behaviours might be recognised, as follows:

- The behaviour is spontaneous and rewarding to the individual; it is intrinsically motivated, and its performance serves as a goal in itself.
- The behaviour consists of actions (or thoughts) expressed in novel combinations.
- Playful play is accompanied by a positive mental state in which the individual is more inclined to behave (and think) in a spontaneous and flexible way.

Bateson (2015) reports that Mihaly Csikszentmihalyi (1996) suggests finding spaces and places that enhance reflective thought and creativity. He then suggests that these points also apply to the conditions in which playfulness can be encouraged. Goffman (1974) defines a frame as the basic elements of a situation that are built up in accordance with principles of organisation which govern social events, and our subjective involvement in them. Reddy and Mireault (2015) describe the "playful frame", which is socially constituted and involves rich social engagement. Within this playful frame all the people involved understand that the situation is a playful one.

Clearly there are some aspects that are common to both the aesthetic space and the playful frame. For clarity, we shall refer here to the playful frame with a broadened definition to encompass aspects of the aesthetic space encounter. What is striking within these descriptions is the mention of thought, thinking, imagination and indeed, one's brain. Play has to do with thought, and as such the playful frame may be an ideal situation for the assessment of cognition.

Links between playfulness and humour

Bateson (2015) suggests that play shares common features with humour, in that both involve social signals, are associated with a positive mood and are sensitive to prevailing conditions. As with play, certain forms of humour rely on the generation of novel combinations of thoughts. For Bateson, play is about breaking away from established patterns and combining actions and thoughts in a new way. Again, thoughts are as central to these descriptions of humour as they are in the proceeding descriptions of play.

"Bateson (2015) suggests that play shares common features with humour, in that both involve social signals, are associated with a positive mood and are sensitive to prevailing conditions."

Incongruity Humour

Reddy and Mireault (2015) discuss incongruity humour and suggest that the understanding of this type of humour requires "the awareness of a norm or a typical pattern which has been violated" (p.22). Humour is established when there is surprise that something has happened in a different or unusual way. As an example, we may explore that most universal and commonly held schemata of humour, that of a person slipping on a banana skin. In this common scenario, we can see the ingredients of incongruity coming together. It is considered "out of the norm" to slip on a banana skin, and, for the protagonist, is rarely funny. For the observer, however, the subversion from the normal script, the mismatch between intent and reality within the playful frame, constitute a commonly held response. In fact, this very image has become so common that when questioned about how to film the "perfect banana skin moment", comedian Charlie

Chaplin replied "First you show the banana peel, then you show the lady eyeing it, walking towards it and carefully stepping over it. Then the last thing you see is her falling down the open manhole cover she didn't notice" (Schochet, 2010, p.13). It is the mismatch, the deviation from the expected that appears to give rise to humour. From the clown's car door falling off to the disguise of gender within Shakespeare's Twelfth Night, incongruity and novelty are key components within the architecture of humour.

As Morreall (1989) describes, incongruity humour relies on the enjoyment of surprise. However, we know that not all surprising things are funny in themselves. Surprise can also be scary, unsettling, confusing and unpleasant. The success of this type of humour then relies on an understanding of the playful frame. For the surprise to be pleasant and enjoyable, indeed funny, everyone involved needs to know that the context is a playful one. Therefore, observing laughter in response to incongruity can be a way of assessing cognition, in that it demonstrably reveals an understanding of the playful frame.

Clowning and Teasing

Reddy, Williams, and Vaughan (2001) note that typically developing infants from around 8 months begin to engage in clowning (repeating acts to re-elicit laughter from others) and teasing (engaging in acts which violate newly developed shared understandings, or which provoke prohibition from others or cause disruption to on-going actions of others). These actions are clearly social in origin and share aspects of incongruity humour. For infants, teasing and clowning are important markers of the awareness of other minds and show their awareness of this triadic link. Reddy and Mireault (2015) note that teasing is based on the awareness of another's intentions and "involves playing in the realm of minds" (p. 23). Furthermore, they remark that

> "Looking at mind as embodied (rather than as a hidden and internal entity) allows us to see how infants are drawn into understanding others' intentions and expectations by engaging in playful interactions. Infant teasing not only reveals what infants know about others' embodied intentions and expectations but reveals a powerful process of exploration by the infant of the nature and boundaries of mind – others' as well as their own" (p.23).

What Reddy and others are pointing to here is a psychosocial journey towards intersubjective engagement and joint attention within a framework of playfulness and social understanding. Therefore, observation of teasing and clowning could support the assessment of cognition, as it can make visible what the partners understand about each other's intentions.

Social Cognition

De Jaegher, Di Paolo and Gallagher (2010) describe social cognition in these terms:

> "We use social cognition as a general term to describe cognition involving others, for example understanding others' emotions, intentions and actions and acting towards and with them in social settings. It involves understanding others but also understanding with others. 'Understanding' in this context does not require a capacity for verbalising reasons for actions, but rather a pragmatic ability to act appropriately in a situation. Following embodied approaches, we take social cognition to involve the know-how that allows us to sustain interactions, form relationships, understand each other, and act together" (p. 441).

In order to be manifested, the above social cognitive abilities require a partner, and by providing playful partners it may be possible to assess these cognitive abilities. In providing a structure that creates optimal conditions for interaction, these abilities may be highlighted and explored.

Engagement

Reddy (2008) sees the mind as "transparent within active, emotionally engaged perception" (p. 26). This is an intriguing proposal, as it suggests that those of us who want to assess cognition are more likely to succeed if we create conditions where there is the opportunity for emotional engagement between partners. Reddy (2013) describes different forms and intensities of engagement, and she identifies direct engagement as the most vivid, most intense, and most rich. Reddy argues that this direct engagement allows a "felt response in infants to specific aspects of mind" (11:03). For Reddy, the minds of all the partners in an interaction are made transparent through direct emotional engagement. Thus, for adults as well as infants the lack of such engagement would affect the perception of minds. She says, "give us two years in a prison ... and our conception of people and minds are going to be somewhat different" (11:38). It may be that this rich engagement not only supports the assessment of cognition, but also affects cognition itself.

2.4 Methods

2.4.1 Structuring a space to observe cognition

It was against this backdrop that we set out to create a space in which we could interact with Kate and film our interactions. The semi-structured assessment that we employed emphasised structuring a playful frame, where all parties understood that anything done within the context of this frame was playful. Berger and Luckmann, cited in Søbstad (1999) set the tone in suggesting that the act of travelling from everyday reality and entering a world of play must be acknowledged against this framework. Reid (2019), strikes a similar note, in his description of entering a space of imagination and creativity. One way that cognition can be observed and assessed is by looking for behaviour that suggests that Kate understands this playful frame. Therefore, the con-

struction of a playful framework is reliant not only on environmental factors, but also on the perceived agency of the other.

Creative

Building upon this, Csikszentmihalyi (1996) suggests that playfulness can be encouraged by finding spaces and places that enhance creative aspects of play. We chose to hold these sessions in a place removed from our usual environment, within an art room rather than in Kate's home or an office base. We wanted from the start to promote the understanding that there were no pre-agreed tasks involved and that the space was playful and offered opportunity for improvisation. To borrow from Redl and Wineman (1952) we wanted to create "a meeting place that smiles, props which invite, and space which allows" (p. 42). As for props, Aitken (2000) suggests encouraging children with deafblindness to explore objects during play, especially objects that are just out of reach. We felt that this was equally applicable in this context with adults, so we selected several (what we thought were) tactilely interesting objects that were included within the sessions. This also chimes with Reid's (2019) suggestion of the potential for improvisation within an aesthetic space encounter.

"We use social cognition as a general term to describe cognition involving others, for example understanding others' emotions, intentions and actions and acting towards and with them in social settings."

Movement

We also drew from the work of Aitken (2000), who suggests how to facilitate a play session with children with deafblindness. He suggests that "play sessions should emphasise using gross body movements" (p. 31). In line with our thinking on play being a life-long pursuit, we adopted his suggestion and structured our playful sessions to include such movements. Reddy (2008), when describing ways to elicit laughter, suggests that incongruities can lie in the vigorousness or the extremeness of an action. Building on these thoughts on movement and action in play and humour, we set out to include exaggerated, large, bold movements during our interactions. Encouraging strong physical sensations such as

stretching, along with anticipatory tension and emotion would also support narrative in the bodily tactile modality.

Engagement

We knew that we wanted to be able to create conditions where there could be rich social engagement as suggested by Reddy (2013) and involved emotions as suggested by Reid (2019). We wanted to promote sustained interactions, and opportunities to understand one another and to act together, as De Jaegher, Di Paolo and Gallagher (2010) have suggested that these are involved in social cognition. Although engagement between people clearly is not something that can be guaranteed or forced, we felt that having an attitude of genuine interest and enjoyment ourselves would support this. Central to this was our abandonment of agreed outcomes for each session. This promoted the opportunity for each participant to influence the overall direction of each session. The overarching principle that we kept in mind was simply to give each other our full attention for the duration of the session. As Reddy (2008) postulates "if you cannot tune in to what someone else is laughing about, it is difficult to really engage with that person in their reaction" (p. 195).

Bodily Tactile

We wanted to be able to see what we could learn about Kate's understanding and assess cognition as demonstrated through the tactile modality. The processing and integration of information through active touch is a robust and fully functional cognitive system equivalent to the visual and auditory cognitive systems (Nicholas, 2013). Gregersen (2018) describes social cognition as being difficult for a person with congenital deafblindness. However, he outlines the idea that some mental states can manifest themselves in the whole body and be accessed more directly by a tactile perception of the large parts of the body. He describes how a boy with deafblindness attuned himself to his partners' laughter through body-with-body interactions: interaction in which two bodies are aligned with one another, especially with the back of the person with deafblindness aligned and in contact with the stomach and chest of their partner. Gregersen argues that this position provides the optimum conditions for perception and cognition. It seems clear that this would be a good position for sharing emotions and playfulness. We endeavoured to be in contact in this way whenever it was appropriate, following Kate's lead. This position would be especially useful for sharing laughter in a bodily tactile way, as during laughter the entire body including head, torso, and shoulders is involved (Mancini, Varni, Glowinski, & Volpe, 2012).

2.4.2 The Playful Interactions

We filmed 10 sessions, and in this chapter, we will focus on sessions 4 (The Apple) and 5 (The Apple Revisited), as they displayed a range of interactions that could demonstrate the cognitive potentials of Kate.

We will briefly describe the actions we observed in the video, and then go on to further explore these actions in relation to aspects of humour and social cognition theory. We will focus on our observation and interpretation of:

- Understanding the playful frame
- Understanding the intentions of others
- Clowning
- Teasing
- Engagement
- Elaboration

The structure of the playful interaction was as follows:

- Located in an art room in order to use space which already enhances creativity (Csikszentmihalyi, 1996).
- Actions were expressed in novel combinations (Bateson, 2015).
- Interactions were through the tactile modality.
- Clowning and teasing were introduced by participants throughout the session.
- We used gross body movements and rhythms to support anticipation in a tactile way.
- We had no other aim than to have fun, and a deep consideration of the other within the encounter.

Our aim was to create conditions in which playfulness could flourish, as we felt that this structure would provide an optimal opportunity to make observations of Kate's social cognition. However, as Bateson attests, "the motivation to be playful comes from within" (p.12), so although we could do our best to provide what we felt were ideal conditions, there was no guarantee that we would succeed.

2.4.3 What do we bring to this encounter?

We knew we wanted to:

- follow Kate's lead
- be fully engaged with Kate
- be bodily tactile, and aware of our own and each other's bodies, not just hands
- look for novelty
- be playful

The sessions were planned to take place once a week on a Friday afternoon, and to last approximately an hour.

The structure of the sessions was as follows:

- Each session took place in an arts space, located within a service in Scotland that supports people who have complex communication support needs.

- The room was set up with a wooden bench towards the back, with a table running along one side. The bench was made of thick wood planks. There were always items on the table, usually covered with a piece of fabric.
- Whenever possible both Jacky and Jon participated. However, if only one was available the session still went ahead.
- The video camera was positioned at the far end of the room and switched on before Kate entered the room.

Session One was an introductory session. In sessions Two and Three there was increased engagement, attention to each other and lots of laughter.

Picture 1. The room setup for the session.

2.5 Description and Analysis of the Sessions

After each session, Jon and Jacky watched the recording of the session together. We were interested primarily in the times when we were all laughing together. Laughter gave us the best indication of connectedness and cognition. Watching videos of those occasions gave us an opportunity to analyse exactly which actions had led to laughter. We asked ourselves if we could see any actions which we thought could illustrate Kate's social cognitive abilities. We then discussed ways that these could be built on in future sessions.

2.5.1 Session Four – The Apple

At one point, Jacky sits behind Kate and she sits in front of Jacky with her legs out straight. Jacky's legs are out straight outside of Kate's, and Kate's back is leaning again Jacky's chest. Kate holds an apple and an orange, one in each hand, and they make big stretching movements backwards. The apple in Kate's hand happens to be near Jacky's face, and Jacky takes a bite from it. Kate

spends some time exploring the surface of the apple with her fingers. Jacky then pretends to lightly "bite" Kate's head, in a gentle and playful manner, intending to re-confirm what had just happened and suggest that Kate could now bite the apple. Kate laughs and then Jacky makes a motion to softly pretend-bite the back of her hand, the same hand that is holding the apple. They are both laughing, and Kate pulls her hand away. Kate then moves her hand back up towards Jacky's mouth, with Jacky blowing on the back of Kate's hand to let her know how far away her mouth is, and Kate pulling her hand away and laughing when it gets close to Jacky's mouth. They continue doing this a few times; Kate seems relaxed throughout and laughs and giggles. It must be noted that Jacky is at no point using any force or strong grip to move Kate's hand toward her mouth, but rather suggests initiating this movement through gentle pressure. Kate then turns her hand around, presenting Jacky with the apple to bite instead of her hand. They share laughter over this, and then Jacky makes pretend-biting motions with her hand on Kate's arms and torso, and, again, softly pretend-bites her head. After being on the floor for 15 minutes they move back to the bench and Jon replaces Jacky. Kate still has the apple and orange in her hand, Jon pretends to bite it and they continue to play and interact with the apple.

Understanding the Playful Frame

When Jacky is teasing Kate, and pretending to bite her hand, they are laughing together. At one point, Kate uses her other arm to support her elbow to keep her hand up close to Jacky's mouth, as if to prolong the game. It is clear here that Kate understands that she is in a playful setting, the playful frame, and that her hand is not actually going to be bitten. The overall feeling and movement within the dynamic is one of gentle attentiveness with Kate remaining an engaged protagonist within the action rather than a passive observer. It is of utmost importance to underline that although the term "pretend-biting" is used here, this refers to extremely gentle and subtle non-threatening movements. The abstract nature of the gesture, and perhaps the novelty of the action give rise to equal attention and engagement from both. Kate allows her hand to be moved up towards Jacky's mouth several times as they laugh together. This demonstrates her ability to understand this social situation and how to behave with another within it. Reddy and Mireault (2015) describe how, in typically developing infants, when an adult is teasing the infant, he or she immediately looks up at the adult's face, knowing the face will reveal the intention. However, for Kate, intentions can only be revealed through the tactile modality. Her laughter and continued participation seem to suggest that she has detected and understood these intentions successfully. Kate's reaction of laughing further underlines her comfort in the security of the playful frame. It is clear that if Jacky were suddenly to meet Kate in a different contextual scenario such as a shop or the street and start biting her, she could well react in a different way, which suggests that she has the understanding that this is a safe environment where "anything goes".

Picture 2. Jacky "bites" the back of Kate's hand.

Understanding the Intentions of the Other

When Kate turns her hand around to offer the apple to 'bite' instead of her hand, this could demonstrate that she understood that Jacky's playful intention was to continue pretend-biting her hand. This demonstrates her understanding that another person can have an intention in their head of what action they plan to carry out. She then violates that action: she turns her hand to stop it from being bitten.

Clowning and Teasing

Reddy and Mireault (2015) define clowning as absurd, often non-verbal behaviour which involves violations of normal patterns of social life, specifically to elicit or re-elicit amusement. In this example, Jacky can be seen as engaging in clowning in the sense that in the normal pattern of their interactions, she doesn't usually bite Kate; here she is doing it within this playful frame in order to amuse Kate. Kate appears to counter the clowning with teasing, something that Reddy and Mireault suggest is more explicitly provocative than clowning. It has been seen that Kate violated a planned action, and Reddy and Mireault define teasing as being initially about foiling intentions and violating expectations. Secondly, for it to be teasing, the violation must have the intention to provoke emotional reactions. It can be seen here that Kate both violated a planned action and had the intention of doing this to provoke laughter. This suggests some quite complex social understanding on Kate's part. Firstly, as described, she must understand that the situation is a playful one. Secondly, she must understand that Jacky has a plan to "bite" her hand. Thirdly, she must herself plan how she will thwart Jacky's plan, with the intention of being funny.

Picture 3. Kate gives Jacky the apple to bite.

All this wrapped up in the confidence that her actions will be taken as amusing and will continue the interaction with no negative reaction from Jacky.

Engagement

Reddy describes engagement as allowing a felt response to specific aspects of mind that allows development of a mutuality of expanding action, response and exploration. For her, engagement cannot be forced and is not a feature of the amount of interaction in an encounter, but rather concerns the quality of emotional interaction. Jacky reports that in this encounter she felt totally engaged with Kate and felt that they had shared an emotional experience.

2.5.2 Session Five – The Apple Revisited

At the start of this session, Jacky introduces the notion of biting again. After about 15 minutes of being playful around this notion, Jacky motions that she is going to pretend to bite Kate's hand. Immediately Kate moves her other hand up towards Jacky's mouth, cupped as if she is holding an apple in it. Kate holds her right wrist against her own left hand, which Jacky is holding. The positioning of Kate's wrist against her hand is close to the place and manner Jacky held her wrist the previous week. Making this gesture can be interpreted as referring to the previous shared experience of the apple, the biting and her teasing. At the time, Jacky was looking at Kate's other hand, and reports that she did not recognise the gesture within the moment and thus did not respond to it.

Picture 4. Kate gestures 'as if' holding the apple, possibly telling the story of offering the apple.

Elaboration and Teasing

It is possible that Kate is referring to the previous week, and gesturing "as if" she is teasing with the apple again. Jacky makes the same motion of pretending to bite her hand that led to the teasing episode the previous week. There is the possibility that Kate is referring to this initial teasing, but this time she doesn't have an apple in her hand, so she teases in a different way. This action seems both to refer to the action of the previous week and builds upon it as Kate elaborates the gesture and therefore develops the incongruity of the theme.

Later in the session Jon enters, and he and Kate explore under the cloth. One of the items is a sponge, which Kate feels immediately and starts to explore (there is also an orange, an apple and a pompom under the cloth). As Kate explores the sponge and Jon explores the pompom side by side, Kate lifts her right hand, which is holding the sponge, up to her mouth and pretend-bites the back of her hand.

Picture 5. Kate "bites" her hand, as Jacky did.

Kate's body is turned away from Jon. It could be here that Kate is referring to the previous week in which the themes of the apple and pretend-biting of the hand were established.

The sponge in this case is being used to represent the apple. Kate is still in contact with Jon; they are both holding the same round woollen pompom which could be representing the orange that Kate was holding the previous week. Turning away from Jon could be an elaboration of the story by Kate moving her body closer to how it was aligned during the original experience. It could also be an attempt to get into the body-with-body position to better understand Jon's reaction to this "joke" she is telling. This sequence of gestures seems to suggest complex understanding and thought processing by Kate.

2.6 Discussion and Conclusion

Within the context of this chapter we have outlined several concepts pertaining to humour and the theory of humour within a social context. At the root of this has been an enquiry into the embodied approaches needed to sustain interactions, form relationships, understand one another and act together. Central to this has been the establishment of a framework based on a semi-structured model of assessment, called "the playful space", which has engendered a playful milieu of humour and enabled a focus aimed at the detection of cognition.

We can see that sharing this playful space produced actions that we can interpret as

- Understanding the social context of the interaction
- Understanding the intentions of others
- Violating the intentions of others
- Initiating teasing
- Referring to past events with the person the event was shared with
- Referring to a past event with a person the event wasn't shared with
- Using one object to represent another object

If we go back to De Jaegher, Di Paolo and Gallagher's (2010) description of social cognition as

- Cognition involving others
- Understanding others' emotions
- Understanding others' intentions
- Understanding others' actions
- Acting towards others in social settings
- Acting with others in social settings

Then we can see that we have robust evidence for assessing Kate's cognitive abilities, as demonstrated through these extracts from the play sessions. Her cognitive potentials have been made visible by the careful construction of conditions that promote meaningful bodily tactile expressions.

"Perhaps most central to our learning has been the realisation that the framework within which humour may arise in these interactions requires a level of belief and investment by the communication partner."

However, the literature on sharing rich social engagement implies that, as well as creating conditions for observing cognition, the participants will have been somehow altered, or changed. Reddy (2008) contends that active emotional engagement between people is a process of "constituting - or creating - the minds that each comes to have" (p.27). In establishing a playful framework within which improvisation may occur, routines are introduced and broken, and mismatch is present, the interactions between Jon, Jacky and Kate have had

space to breathe and develop. The overall nuance of each session has not been concerned with the completion of a designated task; rather, the overarching theme has been simply to share aspects of each other's minds and impulses through tactile social contact. As Brownell and Carriger (1990) suggest, social relationships are the contexts in which knowledge is formed.

In this light, then, we can see the importance of humour within the field of work with our partners with deafblindness. The ability to play and to engage in humorous activity and laughter with another takes us far beyond the initial development of meaning making and communication, it enables us to cognize who we are in relation to the other. As Meadows (1999) reminds us, our "cognitive abilities are not 'internal and individualistic' but built up in interactions with the world and people around you" (p.21). Within this chapter we have explored the resonance of the above within the tactile modality in our use of humorous play. The ability to play, to tease and elicit laughter is reliant on a cognitive collusion with the other, and can be perceived through touch, amongst other modalities. Perhaps most central to our learning has been the realisation that the framework within which humour may arise in these interactions requires a level of belief and investment by the communication partner. As Reddy and Mireault (2015) note, "the range of things infants can do to tease their parents seems as large as the expectations parents have of the infants" (p.23). Within the playful frame, the constituent social and emotional ingredients for humour and agency are held in bright definition, and the participants encouraged to search beyond language, towards a collusion of minds.

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Chapter 3

Climbing the wall: Assessment of cognition through video analysis

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This chapter outlines the initial phase of an ongoing project, the aim of which is to find suitable conditions for detecting and understanding cognition and cognitive function of a teenager with congenital deafblindness (hereafter CDB) who is severely affected by self-stimulating behaviour. His limited functional verbal communication, including lack of speech combined with sensory loss affecting both vision and hearing, makes cognitive assessment with standardised psychometric methods challenging. The psychological test procedures needed to obtain psychometric data in a more standardised fashion that would be extremely time-consuming and challenging for both the child and professionals involved and is therefore not considered ethically or socioeconomically justifiable. To develop some understanding of his functional profile, assessment was performed using naturalistic and semi-structured observation. Subsequent phases of the project generated observations that were more structured. The project is an example of collaborative work between teachers, activity pedagogues, a developmental psychologist and a neuropsychologist.

In this context, assessment refers to a clinically based evaluation of cognitive function by using the presented behaviour as observational cues. The first goal is to identify an environment that motivates the child to engage in activities where his cognitive function will be expressed in observable action. The next goal is to identify behavioural components that indicate cognitive engagement and try to identify the cognitive processes that are involved. The final goal in this phase of the project is evaluating each cognitive component in order to develop a profile of the child's cognitive and psycho-motor abilities.

We first searched through videos previously collected during natural unplanned sessions with no research agenda, to identify situations in which the child's self-stimulating behaviour was reduced, as these would provide more optimal conditions for assessing cognition. We selected one of these scenarios and made more formal semi-structured observations, described further in the methods section, to see if we could recognise expressions of cognitive function with the aim of fine-tuning the activity and data collection methods.

3.1 Theoretical perspectives employed in the project

Our analysis of cognition in action was predominantly based on three theoretical perspectives: outdoor education, developmental psychology and neuropsychology. Outdoor Education refers to the method of using outdoor or adventurous activities in a planned and structured way towards predetermined goals. It leans heavily on the work of Kurt Hahn and the Outward Bound movement (Miner, 1990, Richards, 1990) and educationalists such as John Dewey (Dewey, 1938, 1966) and Patrick Geddes (Boardman, 1978). More recently, the use of outdoor education with people with congenital deafblindness has been examined (Gibson, 2000; 2005; 2018, Gibson & Ask Larsen, 2009, Gibson & Nicholas, 2018). The developmental psychology perspective taken here was that of a bioecological model of development according to which we see cognitive potential as realised in action; for example, in proximal interaction processes between child and environment (Bronfenbrenner and Ceci, 1994).

Our third perspective was a neuropsychological perspective based on the idea that cognitive functions can be seen in observable actions and analysed in terms of the complexity of orientation, planning and execution that is required to complete them. We focused on three cognitive functions that emerged from our observations: executive functions, spatial cognition and social relationships. Executive functions refer to a set of neurocognitive processes involved in goal-directed behaviour (Blair & Raver, 2015; Carlson, Zelazo, & Faja, 2013; Zelazo, 2015). It is an umbrella term that includes working memory, inhibitory control, and cognitive flexibility (Miyake et al., 2000; Brydges, Fox, Reid, & Anderson, 2014). The emergence of executive function abilities during early childhood plays a foundational role in development and can have a predictive power with reference to developmental outcome. If the individual has developed strong executive abilities, he or she will be better able to meet the demands placed on him or her in the home (for example, following rules) and in the classroom (for example, sitting still). On the other hand, having poor executive skills during childhood can cascade into negative long-term outcomes in terms of academic achievement, income and health status (Moffitt et al., 2011).

In this context, spatial cognition refers to mental skills that enable the person to interact with her or his environment using accumulated knowledge of spatial relations between objects in the world. According to Linn and Petersen (1985) spatial ability refers to "skill in representing, transforming, generating, and recalling symbolic, non-linguistic information" (p.1482). Reasoning about space involves processing information about distance, angles, and direction, and starts developing from infancy (Piaget & Inhelder, 1967). From early childhood to adolescence, the use of individual frames of reference and the ability to flexibly combine different types of spatial information gradually improves. In adulthood, the individual's competence in spatial cognition is fully developed making her or him able to integrate distance and categorical information hierarchically. The different levels of competence are associated with the maturation of spe-

cific brain regions and the accumulation of experience (Frazier, & Bryant, 2019). Spatial cognition is tied to the concept of embodied cognition (Shapiro, 2019).

The outdoor activity perspective led us to focus on observations of explorative activity over increasing stretches of time and over increasing space (Gibson, 2005, Gibson & Ask Larsen, 2009). Indoor climbing is merely a controlled, easily accessible version of outdoor climbing, and many of the aspects are the same, excluding reliance on dry weather and the need for travel. Following our developmental theoretical perspective, we specifically observed how the participants engaged in refined co-regulation of distance and proximity to each other during explorative micro-sequences (Nafstad & Rødbroe, 2015). These observations provided us with a grounded analysis of the fundamental relational prerequisites for engagement by the child with CDB in the event. Lastly, within our neuropsychological perspective, we observed concentrated engagement in the activity as indicative of a state of "flow" in micro-sequences with intense and sustained explorative activity as observational cues (Csikszentmihalyi, 1990).

"From early childhood to adolescence, the use of individual frames of reference and the ability to flexibly combine different types of spatial information gradually improves."

The relevance of the theories that ground these observations is discussed in relation to how they are used in the project and in relation to the results. However, the conceptual core of Flow Theory is described briefly below because the concept of "flow" seems to connect the three guiding theoretical perspectives in our project to one another, and thus may contribute to the validity of observations of cognitive function in action. Flow theory and research originated from the observations of Getzels and Csikszentmihalyi (1967) of the phenomenon intrinsic motivation, that some activities seem to be rewarding in themselves independent of their results. "Flow" is described as a mental state induced by activities that are intrinsically enjoyable and perceived as worth doing for their own sake, even if no further goal is reached (Csikszentmihalyi, 1990; Nakamura & Csikszentmihalyi, 2002). When in flow, the balance between challenges and the skills needed to meet those challenges are optimally adjusted to the individual, who then can function at his or her fullest capacity. As such, flow theory and the Zone of Proximal Development (hereafter ZPD)

(Vygotsky, 1978) are greatly associated. Mental states are vulnerable to disruptions, and the effects of these can be an experience of apathy (low challenges, low skills), anxiety (high challenges, low skills), or relaxation (low challenges, high skills) (Csikszentmihalyi, 1997a). The flow state is one that induces development. Individuals seek to replicate flow experiences because they are intrinsically rewarding. Through practice, greater levels of skills are achieved, and more complex capacities are developed. In Flow theory, concentration, interest and enjoyment in an activity must be experienced simultaneously for flow to occur (Csikszentmihalyi, 1997b). Firstly, to get into a "flow" state, the attention must be focused on a limited stimulus field, one in which the individual is in a state of intense concentration and complete involvement in the activity of choice. Ensuring continuing motivation and engagement in the activity is central, as interest in an activity is another fundamental aspect of the flow experience. Lastly, flow activities provide feelings of enjoyment which often occur in retrospect as all concentration is on the task during actual engagement (Csikszentmihalyi, 1990). Under such circumstances, worry about failure is absent from action and awareness. One's self-consciousness disappears and sense of time becomes distorted. The actions create experiences that becomes autotelic, (generating their own reward), and are therefore replicated and refined.

"Ensuring continuing motivation and engagement in the activity is central, as interest in an activity is another fundamental aspect of the flow experience."

3.2 Ethical considerations

There are always ethical considerations in research involving people. In this project, our aim was to describe the procedures we used to evaluate cognition in a child with CDB by documenting the steps we took from spontaneous naturalistic observations to identification of the conditions under which specific cognitive functions could be observed through semi-structured observations. Several steps were taken to ensure the highest ethical standards. Firstly, the child's mother participated in the entire process. She gave her consent for the project and received continuously updated information on progress, asked

questions and read drafts of the chapter. Secondly, the project was formally approved by Regional Committee for Medical and Health Sciences Research Ethics, Southeast Norway. Thirdly, the child with CDB has been anonymised in the project report and all the video collected during the project has been stored on a non-networked computer and a password-protected pen drive. Finally, all aspects of the project were part of the child's weekly activities. Filming and using semi-structured observations for in-depth analysis of the child's every action and reaction can be potentially invasive. This is especially true for this child, as his behaviour is the basis for diverse interpretations by his partners that he cannot evaluate, understand or contradict. Nevertheless, the project has had a direct, positive impact on the child's participation in the specific activity as well as on work with the child more generally.

3.3 The Case

The child is a thirteen-year-old boy who has been identified as having CDB. He has some functional vision with a cerebral visual impairment, which makes his vision fragmented and functionally variable in an unpredictable manner. He is profoundly deaf and most often uses bodily motion, bodily positioning, bodily posture and touch patterns to orient and express his attention, focus, and interest in the here and now space. He is well developed motorically and is an athletic child who enjoys being physically active. He has problems with self-regulation and often engages in self-stimulating behaviour that escalates and can result in self-injury. Experts outside the deafblind field have the opinion that the child has severe mental retardation and have concluded that it is not possible to assess his cognitive function. The project team had not observed evidence to support such traditional diagnostic labelling.

3.4 Methods

The aim of the project was to identify and understand the cognitive function of someone who is difficult to assess with standardised tests. The procedure involved the following steps:

1. Select videos of situations with optimal conditions (reduced self-stimulation and increased engagement and interaction)
2. Analyse videos of the child in situations with reduced self-stimulation to find other commonalities
3. Choose one activity
4. Repeat and fine-tune the activity
5. Collect the data
6. Analyse the data

Step 1: Select videos of optimal conditions
Several previously collected videos were selected that seemed to present better conditions for assessing cognitive function. These conditions were that there was reduced self-stimulating behaviour and the activities were all well-known scenarios to the child. We had the assumption that there was an inverse relationship between the child's engagement in self-stimulation and his engagement in task-oriented activities. Our initial observations were unstructured, apart from that of the key parameter of reduced self-stimulation. Below is a brief overview of the video situations and corresponding observations.

Climbing	No self-stimulation, strong relational aspects (repeatedly reaching to be in contact with his partner and regulating his location in relation to his partner) at the climbing wall – in the gym with two teachers.
Laying the table	Engaged and participative in preparing the table for lunch, minimal self-stimulation that reduces over time, directing partners actions – in the kitchen with a teacher.
Playing with watch	No self-stimulation, directing partners actions – on the sofa in his room with a teacher.
Day planner	Engaged despite low arousal, maintaining contact with partner, self-stimulation begins near the end – sitting on his stool in his room with a teacher.
Asking for more to drink	Engaged and directing partners action – sitting at the table in the kitchen with a teacher.

Step 2: Analyse videos with reduced self-stimulating behaviour to find other commonalities
In the selected clips, self-stimulation was generally reduced. However, there was a variation in the occurrence and intensity of self-stimulation. We wondered why self-stimulation decreased when it did, and what the common elements were in each scenario. The basic common element in the chosen clips was fine-tuned, co-regulated, reciprocal accessibility and availability between the child and his interaction partners. The partners filled multiple roles in the interaction: one was a trusted, more competent climbing guide, one was an equal participator in the game of climbing, one was a companion and one was a secure base.

We assumed that the complexity of roles and the partners' prominent child-oriented focus in making dynamic shifts between roles supported the child's explorative agency and thereby his sense of self. This assumption follows and is supported by the dialogical theoretical thinking underlying the intervention model Communicative Relations (Nafstad and Rødbroe, 2015). This model describes how the four basic dynamic environmental relations of attachment, exploration, social interactive play and conversational interactivity connect in the

child's communicative development, and how the specific contributions by both child and partner can be analysed, to be discovered and empowered. Although these environmental relations are all fundamental and robust (Tetzchner, 2019), they are vulnerable to distortions and are demanding to maintain in the atypical case of CDB. Maintaining balance between attachment and exploration requires extremely fine-tuned co-regulation of proximity and distance from both partners, often within arms' length of the child (Nafstad and Rødbroe, 2015). In sum it was clear that both the child and his partners had an interest in the same activity and in each other's engagement in the activity. Alongside the relational aspect, we identified three further elements that also seemed to be prerequisites for the child to be cognitively engaged:

- Physical
- Intellectual
- Psycho-motoric

Also, if one or more of these elements became challenging or difficult, there seemed to be a reduction in self-stimulation. The child seemed to be very sensitive to changes in the elements outlined above. For example, while laying the table, he was engaged and participative while still mildly self-stimulating (hitting his head with his hand). Then at a certain point he stopped self-stimulating. On examining the video, we could see his self-stimulating stopped when his partner changed from signing, "now collect plate" or "now collect knife" to "now collect what?", which we interpreted as meaning that there was an increase in the intellectual challenge for the child.

Step 3: Choose one activity

Laying the table highlighted the benefit of being able to adjust the level of intellectual challenge for the child within the activity, his self-stimulating behaviour reduced when he was challenged intellectually. However, laying the table is difficult to meaningfully expand because of its already ritualistic and fixed nature. Also, there was not much in the way of physical challenge in this activity, and this is an important aspect for this child. The limited scope for expansion and lack of physicality was also the case for the activities in the "Playing with watch", "Day planner" and "Asking for more to drink" videos. One of the activities however, climbing, seemed to have a more complex dynamic structure, where the child could regulate his access to the secure base (partner) and switch between contacting the secure base and engaging in explorative activity encompassing the important physical aspect (Gibson, 2005; Gibson & Ask Larsen, 2009). It was decided therefore to focus on the climbing wall for these and the following reasons:

- All the important relational aspects were a fundamental component of the activity, (joint attention/spatial regulation/secure base). The other activities did not contain all of these.
- The climbing wall as an activity containing all three of the key elements (physical, intellectual, psycho-motoric).
- The levels of these key elements could be meaningfully adjusted.

- The activity offered the opportunity to progress.
- The activity followed the child's obvious talent: athletic activity.
- We had daily access to a climbing wall at the gym.
- The partners liked the activity and were experienced climbers. This is important so that partners can authentically express enthusiasm and have the necessary level of expertise.

Step 4: Repeat and fine tune activity

The climbing wall is a permanent feature at one end of the gym. This means it is very familiar to the child who usually indicates that he expects it to be present. It runs up the middle of a wooden gym ladder attached to the wall. It is comprised of flat wooden boards with holds bolted on and is vertical from the bottom to the top. The wooden gym ladder is exposed on either side of the lower section of the wall. There is a crashmat underneath the climbing wall area.

During the climbing wall sessions, the child enters the gym, puts on his climbing harness and begins to climb. One of his partners belays standing on the child's left. The other partner climbs next to or beneath the child as required and is available to support and encourage him and to provide a secure base from which to explore, as well as a model for the activity. When the child is finished climbing and has been lowered to the ground, he will often take a break. During this pause, he will stay in the gym before climbing again. The pause in the activity is often necessary for the child to self-regulate.

The climbing wall sessions were conducted on a weekly basis with the possibility for three sessions each week, and whenever possible video footage was collected. A combination of three partners in total participated in the climbing wall sessions, with one belaying and one climbing alongside the child in each session. Between the first and last sessions in the project, we made several changes to fine-tune the climbing activity based on our analysis:

- Some of the holds were moved around. This was to make the route a little easier to start so the child could begin more independently.
- The child was given climbing shoes to wear. Climbing shoes have a better grip to increases the psycho-motoric challenge by giving a new feeling on the feet to remain closer to the sense of the sport.
- A bell was hung at the top of the wall for the child to indicate when he was finished climbing and ready to come down.
- Climbing the ladder on the left side of the wall was "too easy", so to sustain the right level of challenge it was covered up.

2 Belaying is the process of holding the ropes that are attached to a climber and securing them if they fall. At the climbing wall, the rope runs from the climber up to the top of the wall, then down to the belayer standing on the ground.

Step 5: Data collection
The footage of the climbing sessions was collected in a semi-structured manner. Where possible a third person operated the camera to be able to keep the whole of the child in the shot while climbing and to follow him during the pauses between climbs. Alternatively, the camera was set on a tripod to capture the whole of the climbing wall. We focused on collecting footage from the climbing, before the climbing began, during any pauses and after the climbing was finished. Filming during the pauses might show if and/or when the child's self-stimulating behaviours returned. Five separate sessions were filmed between August and November with the child climbing 14 times. All the footage was viewed, and the first session (26/08/17) and the last session (21/11/17) were analysed in detail.

Step 6: Data analysis
To analyse the footage from the first and last sessions a recording table was developed to show the relationship between what we observed (behaviour) and what we thought the behaviour indicated or expressed (interpretation) in relation to cognitive function (see Figure 1). The group conducting the analysis consisted of the three teachers who participated in the climbing wall sessions with the child, his contact teacher, the head teacher, a developmental psychologist and a neuropsychologist. Analysis was conducted in a group setting with all participants able to watch the footage and add to the recording sheet. We focused on three cognitive functions that emerged from our observations: executive function, social relationship and spatial cognition.

Figure 1. Sample from recording sheet.

Video code & time code	Observational cues	Interpretation	Cognitive function
August 26, clip 1 01:08	Harness on shoulder	I know where this goes	Executive function
August 26, clip 1 08:59	Right hand looking for Olai	Where are you?	Social Relationship
August 26, clip 1 11:50	Pushing rope to come down	I know how this works	Spatial cognition

3.5 Further analysis and discussion

The climbing wall activity contained aspects that made it an optimal situation for the identification of targeted cognitive domains using three perspectives: outdoor education, developmental psychology and neuropsychology. In this section, we will highlight how neuropsychology builds on the other two perspectives to widen the understanding of cognition in action, thus underpinning the

importance of an interdisciplinary approach. The outdoor education perspective provided an assessment condition, which made fine-tuning of the activity and modification of the demands made on the child possible on a sustained basis. The developmental psychology perspective was used to identify the relational prerequisites for active use of cognition. This in turn created the basis on which the neuropsychological perspective could be used to identify cognition in action.

As described earlier, the interdisciplinary team initially searched for an optimal context for further investigation using video analysis of random situations. Different theoretical assumptions guided choice of context. From the assumption that complex and reproducible behaviour is indicative of mental processing (i.e. observable signs of thinking), a prerequisite for detecting and evaluating cognition is observable action and reaction. We chose to use video-based observation of a highly motivating activity that promoted the child's engagement, instead of automatic behaviour in which actions and reactions (such as reflexes) can operate without the involvement of higher-level mental processing. Further, with the assumption that the observable behaviour is indicative of cognitive processes (Lezak et al., 2004), it was beneficial to use a context in which the child could present easily detectable behavioural expressions of a certain complexity. It is important here to point out this inference is not bidirectional, i.e. it cannot be concluded that the lack of obvious or vague expressions indicates lack of complex thought processes. Lastly, if established functions and abilities indicate stages of development (Piaget, 1972), the presented behaviour must be a part of the child's repertoire.

In this specific case study, the team chose "climbing" as the most complex behavioural unit for further analysis. From a neuropsychological point of view, climbing stood out from other activities by providing optimal conditions for the child to exhibit his cognitive potential. First, video analysis showed that climbing was an activity in which the child's self-stimulating behaviour significantly diminished, and even absent for a longer period. Further, video analysis showed changes in the child's facial expression when he engaged in climbing indicating a change in his emotional state (Ekman, 1979). In the transitional phase from one context and activity to starting the climbing, the child's facial expression went from "worried" to "at ease" and "content". His body language underpinned this, especially the degree of restless wandering and other motoric fidgeting. The discovery gave rise to the hypothesis that climbing was an activity that promoted a state of flow (Csikszentmihalyi, 1990). According to Nakamura and Csikszentmihalyi (2014), experience of flow refers to a state where "perceived challenges, or opportunities for action … stretch (neither overmatching nor underutilizing) existing skills; a sense that one is engaging challenges at a level appropriate to one's capacities" and where there are "clear proximal goals and immediate feedback about the progress that is being made" (Nakamura and Csikszentmihalyi, 2014, p. 90). Thus, the flow state is associated with happiness. Further, this would indicate an activity that allows the child to be at his best.

The analysis of behaviour focused on identifying the specific cognitive functions of executive function, spatial cognition and social cognition. Executive function is considered an umbrella term and refers to top-down mental processes that underlie goal-directed behaviour (Stuss & Alexander, 2000). These functions include abilities such as response inhibition, interference control, working memory updating, and set shifting (mental flexibility) (Friedman & Miyaki, 2017), and are crucial for the temporal organisation of purposeful behaviours such as language and reasoning. Spatial cognition refers to the mental processes involved in gaining and using knowledge and beliefs about spatial environments. It includes elements of perception, memory, language, learning, and problem solving. Some of the same elements are involved in different cognitive processes. In this way, spatial cognition has a definite executive component.

In this case study, we found that the climbing activity shown in video footage required several of these cognitive elements (executive function, social relationship and spatial cognition), as well as sensory integration. When the child had recognised the climbing context, he showed progressively greater agency in the setting by demonstrating:

1) Directed attention and concentration towards the teachers' input
2) Taking the initiative to find and put on the harness
3) Moving toward the climbing wall before being asked to do so
4) Finding an easier route to the top without any help from the teacher

"In this case study, we found that the climbing activity shown in video footage required several of these cognitive elements (executive function, social relationship and spatial cognition), as well as sensory integration."

These behavioural elements can indicate several executive functions. The first suggests both goal-directed attention and inhibition. The child remained in a listening position, although both his body and facial expression indicated excitement. As soon as the partner was finished, the child took the initiative to follow the partner's suggestion (climbing) by moving in the direction of the harness and positioning himself correctly in reference to the climbing equipment. The child further demonstrated a definite understanding of spatial concepts, both

in terms of bodily awareness and in reference to spatial movement (up, down, sideways). In addition, the ability to find an easier climbing route indicated bodily sense of self, as well as problem solving skills. The child found this out himself through a kind of bodily deduction, after being introduced to the original path several times (i.e. the partner showed him the alternative route).

The skills presented in the climbing activity indicated that the context contained motivating, dynamic components in terms of fine-tuned athletic challenges and fine-tuned relational trust behaviours in which the child's potential could be seen and evaluated. Looking through the unused footage, it is easy to see that none of the other situations gave rise to this complexity and level of cognitive function. Maintaining the "climbing" script and its relational dynamics over time made the context transparent for the child (and us) and made it possible to both detect and describe different cognitive processes involved.

3.6 Conclusions

As stated in the beginning of the chapter, this is the initial phase of a project in which we are not testing the cognition of the child but trying to find an alternative to the cognitive assessment procedures used when evaluating typically developed individuals. Nevertheless, it has resulted in a more positive perspective of the partners towards the child's cognition and we now look for activities that include the four elements identified (relational, physical, intellectual, and psycho-motoric aspects) and challenge or adjust the levels of them to a greater extent. The concrete results of the project are three hypotheses that require further testing and analysis:

- There seem to be four elements (relational, physical, intellectual and psycho-motoric) that are vital in activities for this child to reduce his need to self-stimulate.
- Adjusting the levels of these elements seems to be key to maintaining the child's decreased need to self-stimulate.

There is something about climbing as an activity that seems to provide favourable conditions for assessing cognition in a child who would otherwise not be tested.

Further testing and analysis of the hypotheses, and refinement and evaluation of the assessment procedure will require moving to more structured observations and trying out the procedure with other children. The initial observations and analysis of the video have also raised several issues that are beyond the scope of this article but can be the focus of future studies:

- The significance of the access to and availability of the climbing partner.
- Does this assessment method work with other children?
- Does the child sit in the harness to self-regulate, stimulating his proprioception?
- Finishing the climb or hanging around. What is the climbing activity for this child?

Development and refinement of the assessment procedure will be pursued by the authors in further work with the issues raised above. We hope this chapter is of interest and informative for other practitioners wishing to assess cognition in children with CDB.

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Chapter 4

Analysing learning processes with the Child-guided Strategies of Van Dijk

Saskia Damen

Assessing individuals with congenital deafblindness (hereafter CDB) is a complex matter. Norm-based psychometric tests are often not appropriate for the assessment of the abilities of this target group. For this reason, alternative procedures for assessing individuals with CDB have been developed (see Ask Larsen & Damen, 2014; Chen, Rowland, Stillman, & Mar, 2009; Damen & Worm, 2013; Vervloed & Damen, 2016).

An example of an alternative assessment procedure is the Child-guided Strategies of Van Dijk. In this procedure, semi-structured observation is used for individuals with sensory and multiple disabilities: the assessor interacts with the individual and observes his or her reactions. The interaction is captured on video for further analysis and used as a basis for a conclusion about the individuals' strengths and for guiding educational goals and intervention strategies. In this chapter I will describe the assessment method and how it was used in the assessment of a five-year-old girl with CDB in addition to naturalistic observations.

4.1 Assessment method

As a result of his clinical experiences with assessment of people with sensory and multiple disabilities, Van Dijk developed the Child-guided Strategies (CGS) also known as The Van Dijk Approach to Assessment (Nelson, Van Dijk, McDonnell, & Thompson, 2002). According to MacFarland, Van Dijk developed his assessment method for four reasons: a) individuals with sensory and multiple disabilities do not experience the world in a typical manner, b) test situations are often not the best situation for the person to show his or her abilities, c) test situations often do not provide an accurate picture of the strengths of the individual and his or her learning potentials, and d) test situations often do not show ways to facilitate learning and quality of life (MacFarland, 1995). These assessment issues were also addressed in the Guidelines for the Assessment of Cognition in People with Congenital Deafblindness (Ask Larsen & Damen, 2014).

The Child-guided Strategies focuses on the learning processes of people with sensory and multiple disabilities, including the learning strategies the person uses and appropriate interventions. Previous research (Nelson, Janssen, Oster, & Avaramn, 2010) has shown high integrity in the manner of application of the method by assessors who learned it after three hours of training. However, there was high variance of performance among the nine participating assessors. The method is based on three theories: information processing theory, theory of arousal, and attachment theory. These theories are briefly explained below.

Information processing theory

The information processing theory deals with the study of the information flow and the analysis of the sequence of events that occur in a person's mind while receiving a new piece of sensory information. For information to be stored in the brain, it must be sufficiently processed. Information processing begins with external information, the stimulus, received through the senses. For this information to be processed, the individual must be able to orient to the stimulus. This orientation allows the individual to notice and focus on the stimuli. The next step in information processing consists of a comparison of the stimulus with information that is already stored in memory, so that the individual can determine whether the stimulus is relevant or not. When the stimulus is no longer relevant, the person will stop orienting to it, and this is called habituation. Relevant information will be connected to existing information and then stored in the memory. Information processing theory has also been used in the development of the Tactile Working Memory Scale (Nicholas, Johannessen, & Van Nunen, 2019; see also chapter 8 of this book).

Behavioural states and level of arousal

Following the work of Simeonsson and colleagues, Van Dijk distinguishes nine behavioural states/arousal levels (see table 1). These states refer to the level of alertness of the individual. The quiet and active states are optimal states for learning and Van Dijk emphasizes that formal parts of assessment should be performed when the child is in such a state. According to Van Dijk, both internal as well as external stimuli can influence the behavioural state/arousal level. Internal stimuli are for example hunger, tiredness, comfort or discomfort. Examples of external stimuli are light, temperature and movement. Individuals with deafblindness often have difficulty moderating their arousal levels and therefore with dealing with environmental stimuli. Over-arousal may precipitate sleeping in these individuals as a way for them to cope with external events that are beyond their control. According to Van Dijk, the general rule for state manipulation is that variety awakens, and repetition soothes (see Nelson, van Dijk, Oster, & McDonnell, 2009).

Behavioural states/ Arousal level	Description
Deep sleep	Lack of body movement and responsiveness
Quiet sleep	Smooth regular respirations and a general lack of movement
Active sleep	Irregular respirations, movements of eye and face, increased responsiveness
Drowsy	Delayed responsiveness and glazed eyes
Quiet awake	Minimal body activity and attentiveness to stimuli
Active awake	Much body activity and attentiveness to stimuli
Fussy awake	Heightened sensitivity to stimuli, general fussiness
Mild agitation	Irregular respirations
Uncontrollable agiation	Crying, changes in color, very iregular respirations

Table 1. Behavioural states and arousal levels observed in the Child-guided strategies.

Attachment theory

Van Dijk refers to Bowlby in the definition of attachment as "lasting psychological connectedness between human beings". He distinguishes four characteristics of attachment:

Proximity Maintenance The desire to be near the people we are attached to.

Safe Haven Returning to the attachment figure for comfort and safety in the face of a fear or threat.

Secure Base The attachment figure acts as a base of security from which the child can explore the surrounding environment.

Separation Distress Anxiety that occurs in the absence of the attachment figure.

4.2 Assessment procedure

The Child-guided strategies are not a strict protocol; rather, they are a guide with eight observation areas for the assessor to investigate: 1) behavioural state, 2) orienting response, 3) learning channels, 4) approach-withdrawal, 5) memory, 6) social interaction, 7) communication, and 8) problem solving. The method combines assessment and intervention and can therefore be considered a dynamic assessment procedure. Characteristic of the procedure is that the assessor interacts with the individual with disabilities, using a multimodal approach, repetition, structure and predictability as well as attunement to the child's interests while creating motivating learning opportunities. During his or her interaction with the individual, the assessor carefully observes the individual's reactions. In the manual of the Child-guided Strategies, questions are formulated for each of the areas of observation as well as techniques for the assessor to apply during her or his interaction with the individual (see Nelson, van Dijk, Oster, McDonnell, 2009).

4.3 Ethical consideration

Consent was given by parents of the child with CDB described in the case example below to present her case as an example for other professionals. The parents are the legal representatives of the child. A fictive name for the child was used in order to ensure her anonymity.

4.4 Case example

Louise is a five-year-old girl born with blindness and deafness as a result of prematurity. She also has a severe motor disability and uses a wheelchair. Louise lives at home with her parents and brother. She visits a day-care centre for children with multiple disabilities near her home. Her parents asked for an assessment because they wanted to know about Louise's learning potentials. This request was supported by the day-care centre. Before the assessment, the parents had an interview with a psychologist who is specialized in children with visual and intellectual disabilities, but not in deafblindness. In the interview, the parents said that Louise had been assessed previously, but that they did not agree with the results. Because of the distance between her home and the assessment centre, Louise had been very tired and that had had a negative influence on the results. The psychologist who interviewed the parents consulted the assessor (the author), an educational psychologist, consultant and researcher in deafblindness. They decided that the assessor should offer a hands-on-assessment of Louise at the day-care centre and formulate suggestions for her support. Both the parents and the professional caregivers agreed with this plan.

Before the semi-structured observation using the Child-guided Strategies took place, the assessor performed two naturalistic observations to form a first impression of the child's functioning and interests. The observations were analysed together with a second deafblind consultant. The first observation was performed at the day-care centre. Louise was sitting in her wheelchair in a room with five other children. There were two caregivers present. During the observation, the caregivers explained that they had questions about suitable activities for Louise. There was no interaction observed between Louise and her caregivers during the observation. The caregivers talked to Louise but did not make physical contact with her during the observation. Louise performed self-stimulating behaviours in the form of scratching her face. The second observation was a short video made by her parents at home. Louise was lying on a bed surrounded by toys. Her mother and brother interacted with her in a tactile way. Louise was touched repeatedly on her face and chest and cuddled. Soft toys were laid against her face. Louise smiled and vocalized, but the tempo was high and there was limited opportunity for her to take her turn.

"The assessor took the hand of Louise, put this hand against her mouth, started talking (causing vibration) and then let Louise's hand go and waited for Louise to put her hand back on the assessor's mouth."

The hands-on-assessment of Louise was performed in a quiet room at the day-care centre. During the assessment Louise was lying on a mat and a familiar caregiver was present in the room. The situation was filmed by a second deafblind consultant. The caregiver was the first person to have contact with Louise in the room. The caregiver laid her on the mat and then touched her chest. This made Louise smile. The assessor then started to make contact by touching Louise's hand. During the assessment several interactive routines developed. First, a "talking in the hand" game developed. The assessor took the hand of Louise, put this hand against her mouth, started talking (causing vibration) and then let Louise's hand go and waited for Louise to put her hand back on the assessor's mouth. Another routine developed in which the assessor drew circles on the mouth of Louise when she smiled. A third routine developed with a vibrating turtle toy. The turtle produces vibration, sounds and flickering lights whenever a button on top is pushed and then stops again. The button then needs to be pushed again to activate the turtle.

The following is a description of each observational category, the techniques used by the assessor, and the observations made by the assessor and her colleague.

Behavioural state

For the duration of the assessment, the assessor was focused on the full range of behavioural states but had a particular interest in the duration of an alert state. The extent to which Louise had the ability to control or modulate her state and the types of stimuli that affected her behavioural state were also observed. Louise was actively awake in the beginning and responded rapidly when the assessor put her mouth against the palm of Louise's hand and started talking. After this talking in the hand game, Louise's state changed to one of mild agitation. She was restless and started to rub her face. Soft touching of her cheek made her immediately take a deep breath and become drowsy. Rhythmic touching of her chest then made her actively awake. She had a long period in which she was in an active awake state while she enjoyed the vibration of the turtle toy held in the hand of the assessor, with moments of heightened sensitivity and movement when the toy stopped vibrating. After a longer period of interacting with the turtle toy with her mouth and tongue, she stopped moving and went into a sleep state for a few minutes. The assessor then waited and kept herself and the turtle available. Louise began to return to the game with the turtle after this break, by turning her face and mouth to the turtle and appearing actively awake again.

Orienting response

At the beginning of the assessment the assessor helped Louise to orient to her. She laid down next to Louise on her left side. The space between them was the length of Louise's arm. The assessor took Louise's hand, then spoke briefly with her mouth against the palm of Louise's hand and then paused to observe her reaction. Louise immediately turned her body towards the assessor and brought her hand towards the mouth of the assessor. She also put her left foot on the assessor's leg. The tactile information provided by the assessor clearly triggered an orientating response in Louise. This response was also visible towards the vibrating toy turtle. The assessor first placed the vibrating turtle against Louise's hand. When the toy stopped vibrating, Louise started to reach for the toy with her hands.

Learning channels

During the assessment the assessor examined the channels Louise used to take in information and learn. There was no eye contact during the assessment and no visible reactions to sounds. She reacted solely to bodily-tactile information and used her whole body to obtain this information. When she was laid in the middle of the mat, she started to move by herself. This seemed to be a way to explore the space. She stopped doing this when the caregiver made physical contact with her. She used her hand and foot to interact with the assessor. She

remained with her foot on the assessor throughout the whole assessment as a way of maintaining contact. She started smiling when the assessor gently stroked her cheek and smiled more broadly when the assessor drew a circle around her smiling mouth. When the turtle toy stopped vibrating, Louise moved her hands and face towards it. Because of her motor disabilities, she clearly could not control her hands to let them work together to manipulate the toy. The assessor helped her to focus on using her tongue by bringing the toy close to her mouth and holding her left arm. Eventually, she learned to push the button of the toy with her tongue and then continued to use her tongue to manipulate it.

Approach-Withdrawal

During the assessment the assessor observed what Louise tended to approach and what she withdrew from. This information was used to select interesting play materials for her. The vibration produced by the assessor when she talked with her mouth against Louise's hand palm was something that she approached, because she directed her body towards the assessor and put her hand back on the mouth of the assessor when the talking stopped. She also approached a hard, plastic vibrating toy that produced loud sounds and lights, though she never looked at the toy. She withdrew from a massage instrument when this was placed against her feet and hands. The previous observation with her mother and brother had already provided information about her positive reactions towards gentle and affective ways of touching her cheeks and chest. Also, during the assessment situation, she responded with positive emotion to the gentle caressing of her cheeks and chest by the assessor.

Memory

During the assessment of Louise, the assessor looked for signs of anticipation, routine learning and habituation. A routine was established in the hand-talking game. The assessor took Louise's left hand, talked with her mouth against her palm and then let the hand go. Louise then returned her hand to the mouth of the assessor. The assessor often waited a few seconds to respond to see if Louise would make a bigger effort to locate her mouth, which indeed happened. After a while, Louise stopped participating in this game. She turned her body away and put her left hand on her own mouth. This seemed a way for her to process the previous information and was interpreted as a form of imitation. Routine learning was also seen in her play with a plastic vibrating turtle. In the beginning, the assessor put the turtle beside her cheek and pushed a button on the turtle with her hand after it had stopped vibrating. Subsequently, the assessor stopped pushing the turtle and this made Louise move her hands towards the toy, which suggests that she had an idea that the turtle needed to be activated. Because the assessor noticed that Louise was physically unable to manipulate the toy with her two hands, she put the button against Louise's mouth. Louise explored the toy with her mouth and was able to push the button with her tongue. She repeatedly pushed the button after the vibration stopped and the assessor complemented her physically by grabbing her thumb and moving it in excitement, every time she succeeded. After a break, Louise showed that she

remembered the toy and the way it could be manipulated by turning back to the toy and immediately pushing the button with her tongue. This demonstrates object permanence. After a while, she turned away from the toy and started vocalizing. This seemed to be a sign that habituation had been achieved: the toy was not novel and interesting anymore for her at that moment.

Social Interaction

The assessor started to interact with Louise when she was still in the proximity of a familiar caregiver. After the interaction between Louise and the assessor was established, the caregiver moved away but stayed in the same room to observe her reactions. The deafblind consultant who was filming the assessment procedure asked the caregiver several times if she thought Louise was feeling comfortable and behaving as she usually did. The caregiver confirmed that Louise was comfortable and stated several times that she was functioning above expectations. Right from the beginning, Louise oriented towards the assessor and a turn-taking game developed. The assessor followed Louise's initiatives of putting her hand on the mouth of the assessor by repeating talking against her hand palm. There were several turns taken by Louise before she stopped this interaction game. She also added to the interaction by putting her left foot on the legs of the assessor and held it there during the whole assessment. Louise smiled when she was touched gently on her cheeks and chest, in a similar way as shown in the video with her mother and brother. She started laughing when the assessor drew a circle around her mouth when she began to smile. This developed into an interaction game, which made Louise smile and laugh even more. The laughing was imitated by the assessor by making a shaking movement with her body while Louise had her foot on her leg.

Communication

During the assessment the assessor introduced a pleasurable routine in the form of talking against Louise's hand palm and then paused the routine, to see if Louise would communicate that she wanted the assessor to continue. Louise's communicative initiatives were confirmed when the assessor touched her hand and spoke with her mouth against Louise's hand palm each time Louise put her hand on the assessor's mouth. During the assessment, the assessor used several communicative gestures, such as body pointing, tapping on an object with her hand and making the conventional sign for "laughing" on her body. Furthermore, "good job" and "goodbye" was performed by the assessor with Louise's hand. She did not withdraw her hand when these signs were made and even remained sitting for a while with her hand in the goodbye position when the assessor had gone.

Problem solving

To observe problem solving, the assessor looked for Louise's attempts to acquire a desired object or to make interesting events recur. Louise demonstrated these attempts when she tried to reach the mouth of the assessor during the hand-talking game. She also reacted when the turtle toy stopped

vibrating. Especially in the last situation, the observation was made that Louise made several efforts to make the toy vibrate again using her hands and face, and finally developed an understanding of cause and effect when she achieved the desired result by using her tongue to push the button of the turtle toy.

"The assessment led to the conclusion that Louise clearly showed learning potentials."

Recommendations for educators

The assessment led to the conclusion that Louise clearly showed learning potentials. When she was able to interact in a bodily-tactile way and was in an alert state, she showed engagement in social activities, communicative efforts, tactile memory skills, an understanding of object permanence and cause and effect, as well as problem-solving skills. The assessment also revealed strategies that supported her learning and the types of activities and play-materials that were motivating for her. The results were shared with her parents and caregivers and illustrated with video clips from the assessment. A video-feedback intervention was offered to the caregivers and her family to support them in the implementation of suggestions for further support for Louise.

4.5 Conclusion and discussion

The assessment revealed Louise's strengths and resulted in concrete ideas and examples of how to stimulate her development. Crucial for the results of the assessment was that the assessor herself interacted with Louise and used techniques to support her learning processes. These strategies included following the child's interests and movements, the use of the bodily-tactile modality, responding to the child's initiatives, expressing emotions and gestures in a communicative manner, developing enjoyable routines and the pausing of routines to elicit communicative and problem-solving behaviours in the child.

The assessor, who is also the author of this chapter, received training in the Child-guided Strategies by Dr. Van Dijk. Van Dijk passed away in 2018, but his method is still being used worldwide.

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Chapter 5

Semi-structured assessment using grounded theory processes: interpretive, qualitative analysis and video transcripts as texts

Kirsten Costain

In this chapter I present a description of qualitative, interpretive video analysis which can be located at the least structured end of the spectrum of semi-structured assessment procedures. This form of analysis is structured in terms of coding processes from grounded theory described below. This micro-analysis is very intensive and time-consuming, so is less manageable in terms of continuous assessment through video analysis. It is most appropriate for exploring phenomena in depth when the main goal is to generate possible interpretations of complex or particularly interesting events.

5.1 Theoretical perspective: interpretive, qualitative research and Grounded Theory

In one sense, all social scientific research is interpretive to a certain extent; even statistical evidence obtained using highly structured methods must be interpreted in order to construct a holistic picture of the results of the study or experiment. In addition, the data material described in most of the chapters of this book is entirely or partially qualitative – that is to say, based on observation and/or video film. These are naturalistic forms of data, and often collected during ordinary practice. Qualitative data is collected with the aim of generating as much information about a phenomenon as possible in order to describe it in-depth, explore its properties, and devise interventions to address specific problems or areas of interest.

5.2 Ethical considerations

The case presented here is illustrated with still photographs taken from a film of the child. Care has been taken to use photos that exclude the face of the child to protect anonymity, and only general details of the case will be described below. Written information was given to the parents, who were also contacted by telephone to discuss in-depth the use of this material for the purposes of this book. A letter describing use of the material and confirma-

tion of permission was signed by both parents following this communication. Previous permissions have been obtained in connection with my Master's thesis and publication of an article based on the thesis (Seeing and Supporting Embodied Cognition in a Child with Congenital Deafblindness and Multiple Disability, University of Groningen, Master's thesis; Costain, Souriau and Daelman, 2019) as well as for other use of the same material for the purposes of training of professionals working in the field and in relation to earlier work in the cognition network.

5.3 Case description

The child (M) has been identified as having congenital deafblindness (heareafter CDB). He was 12 years old at the time of the video analysis, is completely blind and has residual hearing. His physical hearing function is intact, but it is unclear how he interprets sound and speech. He has muscular hypotonia which makes it impossible for him to stand or walk, and leaves him with limited control over his limbs, hands and feet. However, he displays keen attention to sound as well as interest in touching objects and textures with his fingertips. He is used to being spoken to vocally with support using signs from Norwegian Sign Language in a tactile modality, and is familiar with 'listening' hands (the listener's hands resting on the speaker's hands) and 'speaking' hands (the speaker's hand under the listener's hand) when signing.

5.4 Method of analysis and results: grounded theory coding processes

Grounded theory results emerge through use of the coding processes described and illustrated below. Results are always a product of the analyst(s), and their worth/usefulness is meant to be tested out in practice and/or in the context of further research (the notion of scientific inquiry here is one of participation in continuing research conversations with other practitioners and the work of other researchers). The process of coding proceeds at increasingly abstract levels until a basic social process is identified with its component parts (categories and subcategories). This framework is the theory, or explanation of what is happening in the data. Aspects of the central social process of recycling (described in greater detail below) by the child of elements from an interaction and the results of coding in the identification of this process are described throughout the chapter.

The analysis is structured through application of Grounded Theory coding processes as described by Corbin and Strauss (2015). Grounded theory employs three central coding practices that gradually move from descriptively opening-up empirical material or data, to more abstract, theoretical coding based on conceptual codes (codes from the analysis of the data) or relevant concepts

from existing theory. These three stages of coding progress from open coding (generation of conceptual labels), to axial coding (construction of categories based on groupings of concepts), and selective coding (the writing -up of the final account or report; Corbin & Strauss, 2015). In this example, the analysis is based on a written transcript of the film, which transforms the film into a text. The film is the "raw" or first-order data, and the transcript is the transformation of the film into second-order data in the form of a text.

The analysis of the transcript is cross-checked through further viewings of the film. The film is never abandoned in favour of the transcript, but the focus of the analysis shifts between the two with a different emphasis from film to text at different stages. All description is interpretation however; there is no such thing as a completely objective account, though the aim of producing the transcript is to describe as closely as possible what one has seen and how it appears to be presented before beginning to code it formally. Producing a transcript is a time-consuming and potentially endless process, as one is never finished noticing things in the film and can never be specific enough about the things one has noticed. However, after successive viewings and versions, a transcript is produced that is as satisfying and accurate as possible, including timings, correspondence of descriptions with viewings, inter-rater discussions with colleagues and the like, and is ready for the next step.

"The process of coding proceeds at increasingly abstract levels until a basic social process is identified with its component parts (categories and subcategories)."

Through the core process of constant comparison (Glaser & Strauss, 1967; Corbin & Strauss, 2015), the emerging theoretical or explanatory framework is continuously tested out against the data in a "flip-flop movement" (Glaser & Strauss, 1967) where the researcher's perspective is deliberately shifted from data to conceptual explanation and back again. A kind of "hypothesis-testing" is performed in which the analyst poses questions to the data and the emerging explanatory framework and tests out how well each concept responds to the others to reflexively challenge the developing conceptual picture. Coding proceeds through levels of abstraction, though all three coding processes are present from the mid-point to the conclusion of the analysis. The "flip-flop" movement is increasingly between levels of abstraction, between subcategories of a category and between categories, as well as between the data and conceptual labels.

In this account, the core category of recycling is presented briefly for purposes of illustration. Many other concepts connected to this core category, or central process, were also defined but cannot be presented within the scope of this chapter. For a full account, see Costain, Souriau, and Daelman (2019).

Open, axial and selective coding

The transcript is itself the result of the open coding phase (description is also interpretation as pointed out above), but will also have, following grounded theory method, elements of axial coding as coding progresses. The goal of open coding is to "break open" raw data (in this case the film clip) to identify as many units of meaning as possible and to name these (Corbin & Strauss, 2015). Each time we try to describe what is happening in any (micro)second of the film, we are engaged in open coding. Some of these coding attempts are located at the descriptive end of the scale of conceptual abstraction ("M lifts RT back of hand and places it under his chin"), whereas other codes will contain elements of other theories from the literature or theorized content from methods or practices ("K places M's LEFT hand in 'listener' position"). The idea is to take the data from "raw" to the first level of abstraction, and to indicate where the next level of abstraction, in the axial coding process, is likely to lead. Axial coding is done primarily through memo writing (see the notes on communicative projects below for an example) and is axial because the attempt is made to link open codes that seem to have a conceptual and explanatory relationship with one another to pursue the analysis along more abstract lines according to theoretical concepts. These codes may be in vivo – in the material itself as seen through one's analytical gaze - or from the literature/other theories, for example, the source-path-goal schema (Johnson, 1987), the communicative project (Linell, 1994), or recycling (Anward, 2004; 2014).

Memo-writing in axial coding is the second level of abstraction. The writing of the analysis section of the report is the third level (selective coding). Groups of codes have then become categories within a central phenomenon described in an explanatory framework (the theory). The idea is not that this theory is a new stand-alone theory but rather that a well-grounded explanation of what is going on in the case has been formulated, articulated through the application of concepts the relevance of which is constantly tested against the data itself. This explanation is constructed and defended in such a way that the result can be fed back to discussion in an informed and robust manner, to enter ongoing conversations in the field about meaning and significance.

5.5 The analytical process: practical steps and examples of coding results

Creation of the descriptive transcript is the first stage of analysis/interpretation.

Once the transcript is assessed to be as thorough as possible, the analytical process starts, which involves the following three steps:

1. Open coding begins, consisting of successive readings of the transcript, detailing concepts, noting associations to existing theory, creating labels to describe specific aspects, posing questions to the text, noting ideas and interpretations. Here the focus is on the production of conceptual labels and short descriptions of these rather than lengthy accounts.

The case example here is from a film with a duration of 2 minutes and 30 seconds in which the author (K) is getting her student (M) ready to go swimming. M lies on a changing table and K is taking off his clothes and putting on his bathing suit. When she temporarily leaves him to fetch his wheelchair, he appears to be repeating some of the signs and haptic information that K has used to talk with him about getting changed. This sequence is the focus of the analysis. The aim is to generate an understanding of what the child is doing with his (self-created and new) expressions, and their possible origin in the prior interaction.

Open coding for salience: noting what stands out[3]:

Example from transcript: Expressions, M: high salience (iconicity, sequentiality, maintained/held, etc.):

Time	**Description with codes**
00:06	Kick RT leg against bars (heard, not visible) (K: uses a haptic 'foreshadowing' – a quick movement with her fingers over M's head as if taking off shirts with vocal and tactile information)
00:19	M lifts his head up from table

3 Transcription notes: RT and LFT refer to right and left. The use of manner, place and of inverted commas (' ') is a coding system developed by Ask Larsen and Nafstad (Personal Communication). For example, 'bathing suit' manner on place' describes an expression that seems to refer to "bathing suit", and 'manner' describes the form aspects of this expression (handshape – spread fingers, palms down, and movement - hands out to the sides moved from the top of the suit to the bottom of the zipper). 'Place' is the location of the expression, for example on part of the body, or in relation to the body (over the chest and down to the waist). As Forsgren, Daelman, & Hart have pointed out (2018), handshape, movement and location are required qualities for an expression to be identified as a sign in signed language. The naming of the sign in italics is an interpretation the analyst has made about the signification of the expression.

00:20	K: "Take that one there"
00:21	M lifts both hands up to T-shirt neck in 'helping' manner
00:21	M maintains 'helping' manner hands from 00.21 – 00.26 until they fall
00:26	because K lifts M's torso slightly
00:55	M raises RT leg up from table and holds it up ('pointing' manner)
00:58	until 00:58
02:01	Second RT leg 'point'
02:03	held until 02:03

2. Axial coding: noting emerging theoretical concepts and connections between codes

This is identification of and interpretation of what seems most significant in the transcript and how it fits within the whole transcript. The main process here is memo-writing where the analyst describes how the separate conceptual labels relate to one another and builds categories out of the connected codes. Each category is formed first from codes grouped together through their connections with one another and then organised into sub-categories that together make up the main category of the central social process. Categories are not mere groups of concepts but are constructed through meaningful connections identified by the analyst.

Interpretation here is at a more abstract level, also using connections to theory, both constructed theoretical explanations of the analyst and elements of existing theory that seem relevant.

Example of axial coding memo:

Concept:	Recycling
Reference to transcript:	02:05 – 02:14: 4 recyclings of 'bathing suit' manner on place / 'zipper' manner (02:06; 02:08; 02:09; 02:11 – 02:13)
Description:	down-up movements with hands, first over top of suit, then whole suit front
Significance:	Connections here to conversation analytic notions of recycling of frame, stance and alignment (...)

3. Selective coding: pulling the account of the film together and constructing a presentation of the analysis in the finished report.

Selective coding consists of three parts. First, the transcript is divided into sequences: in each sequence, there is a central 'theme' with a narrative structure (a beginning, middle and 'end' where there is a shift over to a new thematic sequence). The term "sequence" refers to actions that occur in a linear pro-

gression and can be of any duration. Here, the sequences are very short, as the film itself is short. They have been conceptualized according to the narrative structure described above, but there are other ways the analyst may choose to define a sequence. Sequencing is a further transformation of the primary description (the transcript): a way of organising and conceptualizing what is happening in the film according to what the transcriber sees. Dividing the film into sequences is done following completion of open coding and as part of axial coding, as the interpretation of 'what is seen' becomes more abstract and informed by the coding work over successive re-readings (and re-viewings of the film cross-referenced with the transcript).

After this, the secondary description is produced. This is an annotated transcript composed of the identified theoretical concepts of interest and discussed in the memos produced through axial coding.

Example: Sequenced and annotated transcript:

Sequence 1: 00:06 – 00:14
M and K getting M changed to go swimming. K is taking off M's tops.

00:06	(M kicks bar of the changing table with RT leg audibly; not visible on film)
00:07 –00:08	Head movement to RT held until 00:11
00:07	M grasps bar of changing table with RT hand (maintained until 00:09)
00:09	Touches K's leg with RT hand
00:10	M grasps bar again with RT hand partially, then fully until 00:11
00:11	M slides RT hand up along bar until 00:12 (head movement from RT to LFT at 00:11)
00:12 –00:13	**M maintains hold on bar of changing table with RT hand until** 00:13
00:13	M holds tightly onto sleeve with LFT hand as K tries to pull it free

Memo:
M's possible intention: exploring/establishing ('framing') physical frame of the rail of the changing table with one hand. M's resistance to releasing his sleeve with his LFT hand at 00:13 can be viewed as part of this 'framing'/exploring rather than as a challenge to K's changing-clothes agenda when viewed together with other exploring/'framing' action; this resistance may also be an additional action within the topic of challenging K's agenda, something M does repeatedly at specific transitional points throughout by using vocalization and several other expressions.

The above activity might be part of a larger project he has with himself to assert his own framing within the frame controlled by K (agenda of changing clothes to go swimming; talking about and doing the changing) and that presented by the physical table with its bars. His actions can be viewed as a challenge to K's control of the shared project of getting ready to go swimming. M's 'impatient' manner vocalizations in later segments indicate his investment in "getting on with" the process of getting ready. His agency (and thus the intentional nature of his activity as action) is suggested by his sustained (whether involving resistance to getting undressed or not) exploring/checking/re-establishing of the physical frame.

The memo notes are interpretations of the analyst and linked to a general interpretive account of the entire film. In this phase, the transcription is complete (see below) and there is an interpretive story of the film clip in place. Reference points in the film connected to the identification of the central phenomenon of interest in this story are marked in this annotated version of the transcript. These points are further discussed in the third part.

In the third part, the analytic account is produced. This is a discursive account (in report form for example) that lays out the interpretation of the film clip and the connections to and between theoretical concepts. In Grounded theory, the explanatory account focuses on explication of the central phenomenon of interest. What is produced here is not a theory in the formalistic sense but rather an explanation linked to concrete evidence in the film and to theoretical ideas and concepts, both those generated by the coders and those that already exist in the field and that can be argued to have relevance for the film clip. This explanation must be argued for. Careful cross-referencing of detail from the transcripts with the codes and the emerging explanation over several re-workings at all levels (from the concrete to the abstract) makes for a rich and accessible account.

Example: Analytic account, central phenomenon of interest:
Recycling with difference or variation (Anward, 2004; 2014).

Based on the analytical account given in parts 1 and 2 and grounded in the interpreted detail presented there, the phenomenon of interest is identified as recycling as defined in conversation analysis, and further defined with reference to its generative function through connections to the notion of recycling with variation, or difference. Recycling in this understanding involves an analysis of frames, stance markers and rhemes.

The table below summarizes the expressions made by the child during the recycling sequences in which he 'recycles' elements from his interaction with the partner and constructs new expressions out of these recycled elements. In conversation analysis, the analyst looks for how central themes in conversation are developed through use of meaningful expressions connected to shared themes known as rhemes. The child's expressions are here identified as rhematic in that they develop a theme of 'closing/joining'.

The table below is a summary of the identified expressions, followed by several photographs illustrating these.

Table 1. Summary of rhematic expressions (R), rhematic expressions w/ variation (RwV), and new rhematic expressions (NR) located within the recycling sequences (S16 – S22) M, with proposed origins (S1 – S15)

R / R w V / NR	Description	Location	Origins
NR	'zipper sound' manner	**S10:** 01:27.8	**S10:** 01:23 – 01:24; 'Velcro sound' manner
R	'zipper' manner on place	**S16:** 02:05.0 – 02:06.1	**S3:** 00:36 – 00:37; **S4:** 00:39, 00:40 – 00:41; **S9:** 01:15 – 01:16; **S10:** 01:18 – 01:30; **S11:** 01:31 – 01:33
R	'zipper' manner on place	**S17:** 02:06.1 – 02:06.9	----«-------
R	'fastening zipper' manner on place	**S17:** 02:07.0 – 02.07.3	**S10**: 01:23 – 01:30
NR	'partially closed zipper – open neck suit' manner on place	**S17:** 02:07.0 – 02:08.0	**S10:** 01:28 – 01:30
NR	'(closed) zipper teeth' manner on place	**S17:** 02:07.4 – 02:08.5	**S5:** 00:44 – 00:54 **S10:** 01:17 – 01:30
R	'zipper' manner on place	**S18:** 02:09.0 – 02:11.0	
R w V	'zipper (with thumbs touching)' manner on place	**S19:** 02:13.0 – 02:13.2	**S10:** 01:29 – **S11:** 01:32

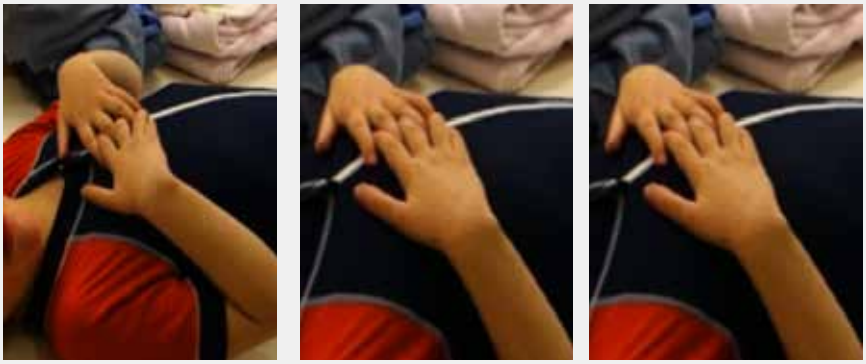
Sequence 16: 02:05 – 02:06

Picture 1. Zipper manner on place.

Recycling of 'zipper' manner on place: DOWN towards source and UP to goal.

Sequence 17: 02:07 – 02:08

Picture 2 A, B and C. 'Open neck suit, partially closed zipper –' and 'closed zipper teeth' manner on place.



Sequence 18: 02:09 – 02:10

02:09: Third recycling sequence all the way to 'source' and back up to 'goal' on either side of zipper
Recycling --> path --> source -->path--> goal
while vocalizing with 'clicking' as hands run up to top of suit and K says "Yes, bathing suit" (...)

Sequence 20: 02:14

Pictures 3 A and B.'Closed teeth' with 'zipper' manners on place = 'fastened zipper' manner on place.

Sequence 21: 02:15 – 02:16

Picture 4. 'Goal' - 'zipper tab' manner on place. + Picture 7. 'Pocket' place and manner.

Through the repetitions, M recycles the original expression of 'zipper' manner on place and adds his own variations within this frame.

5.6 Discussion and conclusion

This chapter is an account of a grounded theory analysis of a filmed case example. This interpretive process is very much from the ground up, as the term grounded theory suggests. In this mode of analysis, interpretive frameworks from already existing theories are not imposed on the data (the film and the transcript). Rather, as the coding proceeds through the three levels of abstraction (open, axial and selective), useful theoretical perspectives from the literature and practice are identified as relevant and applied in the resulting grounded theory explanation, along with the coder's own codes. Some theoretical aspects will also be derived, or constructed, by the analyst. The result is not one complete theory in the sense of a Grand theory such as, for example, theory of mind, but rather a theoretically informed explanation for what is happening in the interaction that the analyst can argue for by referring to concrete evidence for this explanation in the data. The explanation/theory will have to be tested further in practice to see whether it is useful in the analysis of other case examples. Other perspectives may well challenge the theoretical explanation, in which case there will be (one hopes) a research conversation about this that will yield greater knowledge and insight. This is the somewhat lofty goal of interpretive qualitative method.

Although all this may sound very complex and confusing, the test of the grounded theory explanation the analyst develops is pragmatic, based on its usefulness in the field. It will also change as knowledge increases, both that of the practitioner and that in the field generally. Its main usefulness is in challenging the taken-for-granted assumptions or expectations that all practitioners must strive to critically reflect over, and in generating new perspectives. This process of bottom-up (grounded) analysis is time-consuming and complex (it is usually only possible in its entirety when there is time and space for research) but it can challenge our gaze and our assumptions about the child or adult with CDB and lead to greater insight in practice. Also, the essence of the three coding processes can be applied in a more intuitive way in any analytic attempt, however brief.

Acknowledgement

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Chapter 6

Arousal regulating activities in a neuro-affective project

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Lone Rømer Jensen

In this chapter, we will share our experiences with a neuro-affective project about the regulation of arousal. The project was conducted in a residential group home in Denmark in cooperation with adults with congenital deafblindness (hereafter CDB).

The four participants in this neuro-affective project all have developmental delay, non-verbal communication and challenges with self-regulation in relation to calming themselves or to staying awake during the day. This project originated from a previous small project performed by two colleagues working alongside a young woman, Eva, who had extremely low arousal. Eva spent most of her time sleeping throughout the day, even during mealtimes, which made her being underweight, tired, passive, and socially unreachable. When she received help by raising her arousal level through participation in simple daily activities, she became more awake, gained weight and became more open to interaction.

The combination of physical, communicative and cognitive challenges of individuals living in residental group homes often require staff support to provide access to surroundings and opportunities to explore. We found that people were exhibiting self-harm or repetitive behaviour and sucking/biting their fingers. We interpreted these behaviours as attempts to self-regulate arousal. All four adults needed help to create alternative sensory or arousal-regulating activities to stimulate their senses, body, mind and movements.

Before we began this project, we created different activities for the participants to keep them occupied when they were not interacting with anyone and prevent the type of self-stimulating behaviour that often took the form of self-harm. These activities were often sporadic and spontaneous, and inspired by their individual likes and interests. We found it difficult to determine whether these activities had the desired effect. From the project with Eva, a hypothesis emerged that proved to be life-changing: might it be possible to ensure a greater level of attention and readiness for interaction and communication when assessing and supporting arousal regulation? With this question, the neuro-affective project on arousal came to life.

6.1 Arousal: concept and mechanisms

Arousal can be described as the internal energy level in the brain, or the state of alertness. Arousal in the generalized central nervous system is considered to underlie all motivated behavioural responses, emotional expressions, cognitive functions and attention. We all require arousal regulation to function normally. We regulate our own arousal level continuously throughout the day. For instance, when we are concentrating on listening to a lecture, we move and shift position in order to stay awake. This is our brain telling our body to heighten our arousal to an optimal level to stay focused and to be able to learn and develop skills.

Arousal is regulated in the autonomic nervous system located near the brainstem. The autonomic nervous system consists of the sympathetic and the parasympathetic nervous systems. The brain regulates levels of arousal by adjusting flexibly between these two: the sympathetic system increases arousal, and the parasympathetic system has a calming effect which moderates the level of arousal. Both high and low arousal levels are visible in bodily reactions that occur without conscious control and are called autonomic reactions (see Table 1).

Table 1. Autonomic reactions (Gammeltoft, 2016)

Autonomic reactions	
Sympathetic reactions	**Parasympathetic reactions**
Complexion turns pale	Calm and rest
Red blotches on the neck	Calm and lowered pulse rate
Sweating	Decreased sweating
Blood pressure rising	Increased production of urine
Heart beating faster	Deeper respiration and deep sighing
Dilated pupils	Increased intestinal movements
Heightened muscle tension	Relaxed muscles
Attentive facial expression	Uncontrollable crying

The autonomic part of the brain operates instinctively. Without it, our nervous system would be unable to regulate arousal and we would be unable to sense what is happening in our body or in our environment. Structures at this level enable the child's capacity for spontaneous engagement with the world and provide the necessary circuits for attention control, movement impulses, focusing, and the ability to function by remaining present in the moment. A typically developing child learns the ability to self-regulate their arousal level by engaging in synchronized interactions with others. These interactions allow the child to experience and learn engagement and trust (Bentzen, 2018). For more about the assessment of a child's regulation of interaction, see Andersen (2014).

Neuroscientists agree that we need to be able to feel and think in order to be functional, rational people with balanced relationships, and that our neuro-affective development is dependent on contact and interaction with other humans from the day that we are born. When we are born, only 25 percent of our brain is active, primarily at the autonomic level, before it matures and develops through crucial interactions with other humans. The brain is fully developed some twenty years later, but retains plasticity throughout life (Bentzen, 2018).

"When we are born, only 25 percent of our brain is active, primarily at the autonomic level, before it matures and develops through crucial interactions with other humans. The brain is fully developed some twenty years later, but retains plasticity throughout life."

Disorders of generalized arousal can be associated with many medical and public health problems (Calderon et al., 2016). Abnormal arousal level can have developmental consequences in a variety of domains, including: abnormal perception of new information, reduced attention to social information, restricted and repetitive behaviours, self-stimulation, sleep disturbance, hyper-attention, reduced efficiency of executive control abilities, and more broadly, problems with self-regulation (Hartshorne & Nicholas, 2017).

6.2 The Neuro-affective Developmental approach: theoretical foundation

Neuro-affective Developmental Psychology is the theoretical perspective applied in this project, and is a theory based on a combination of neuroscience, theory of attachment and developmental psychology. This theory was developed by the Danish psychologist Susan Hart and occupational therapist Marianne Bentzen (Bentzen & Hart, 2015). We were inspired by their work to conduct this research project on arousal with adults with CDB and multiple impairments. Causes of deafblindness for this group of adults included Rett Syndrome, Cytomegalovirus (CMV) and Cerebral Palsy (CP).

Bentzen and Hart (2015) have developed a theoretical model based on the concept of the triune brain and knowledge from social and emotional neuroscience and developmental psychology. In this model, three compasses describe different stages of mental organisation and development: 1) the autonomic brain describes the sensory level of organisation, 2) the limbic brain describes the emotional level of organisation, and 3) the prefrontal brain describes the rationally mentalizing level of organisation.

Connected to the sensory organisational level of the autonomic brain is the model of the autonomic compass. This compass describes bodily reactions of arousal along a continuum from pleasure to displeasure combined with high to low energy. We will explain this compass further in the Methods section.

"Connected to the sensory organisational level of the autonomic brain is the model of the autonomic compass."

6.3 Ethics

The people involved with this project were unable to give consent to participate, so we applied for consent from all the legal guardians. All information collected - videos, written information and documents etc, were stored securely in the residential home or anonymised when used in our presentations of the project at conferences and seminars as well as for this publication. We have obtained written consent from the legal guardians on each occasion of external use.

Date	Tasks and documentation
Early 2017	The project commenced: information (data) collection, formal structured testing and planning activities.
Spring 2017	Activities were carried out and documented daily.
Spring 2017 until Summer 2017	Written reports of our work with the daily activities were completed, and a chart filled out according to the indicator-points. We occasionally filmed the activities on residents' personal iPads and made videos that served as guidelines for the activities. These were part of our naturalistic observations (see introduction chapter 1).
Summer 2017	The activities continued daily, but without documentation.
Autumn 2017	The activities were conducted and documented daily.
January 2018	Evaluation of the project.
Summer 2019 -	Some of the activities are still being used on a regular basis.

Figure 1. Timeline and documentation

6.4 Preparations

We are a team of pedagogues in the residential home and we were able to work on this project in close cooperation with multi-disciplinary teams, which included an occupational therapist, a neuropsychologist, and two consultants who helped us to coordinate the project. In the beginning, we ensured that all staff members developed a common knowledge of arousal through attending a lecture given by Susan Hart, reading selected literature on the subject, and group discussions.
In preparation for the project, we were very aware that we had limited funds and time on a day-to-day basis. When we planned any project activities, we always prioritised those we could connect to the performing of daily chores.

6.5 Case presentation

In this chapter we will report on the neuro-affective project involving four people who live at the residential group home with focus on the experiences of one man,

Simon[5], who is in his early thirties. He is blind and has a hearing loss although he can distinguish sounds. He also has additional impairments: motor impairments, epilepsy, and psychological/cognitive and communicative challenges. He communicates by using non-verbal sounds, facial expressions and movements.

Simon was chosen as a participant in this project to see if we could help him to regulate his arousal level through offering arousal-regulating activities. Before this project began, Simon had great difficulty regulating his arousal levels. He easily became anxious, irritated and angry, all of which are acknowledged signs of an arousal level that is too high. This very often occurred in situations in which we did not understand him and thus could not support his needs quickly enough. When he became anxious and irritated, it was very difficult to help him balance his arousal level afterwards. We noticed that Simon often had difficulty staying awake in the afternoon, and subsequently, trouble falling asleep at night. We interpreted these behaviours as possible indicators that he had difficulty self-regulating his arousal level.

6.6 Methods

In order to assess each participant's abilities within the areas of attention, memory, language, communicative and social skills as well as the ability to self-regulate, the pedagogues and the neuropsychologist used the DPU (Danish Developmental Profile)[6]. This is a formal assessment tool which can measure skills in a standardised way. This profile was completed both before and after the project, to see if it was possible to measure any improvements in arousal regulation for each participant.

We used the model of the autonomic compass (Bentzen & Hart, 2015) to make semi-structured observations (see Introduction to this book). Based on our observations and knowledge about each participant, we have used the compass to describe each participant's bodily reactions as signs of the different states of arousal. With this information, it was possible to see when we needed to intervene to help the person obtain a more balanced level of arousal and create a greater level of attention and readiness for interaction.

In the compass the vertical line represents the arousal regulation axis. This shows the level of activity of the person and whether the arousal level is high or low. The horizontal line represents the axis of hedonic tone and this shows levels of displeasure and pleasure. All four quadrants reflect autonomic and bodily sensations and reactions, based on general perspectives. A person who has

5 The name Simon is an alias.
6 https://dpf.dk/produkt/proeveevaluering/dansk-paedagogisk-udviklingsbeskrivelse-voksne-2-udgave

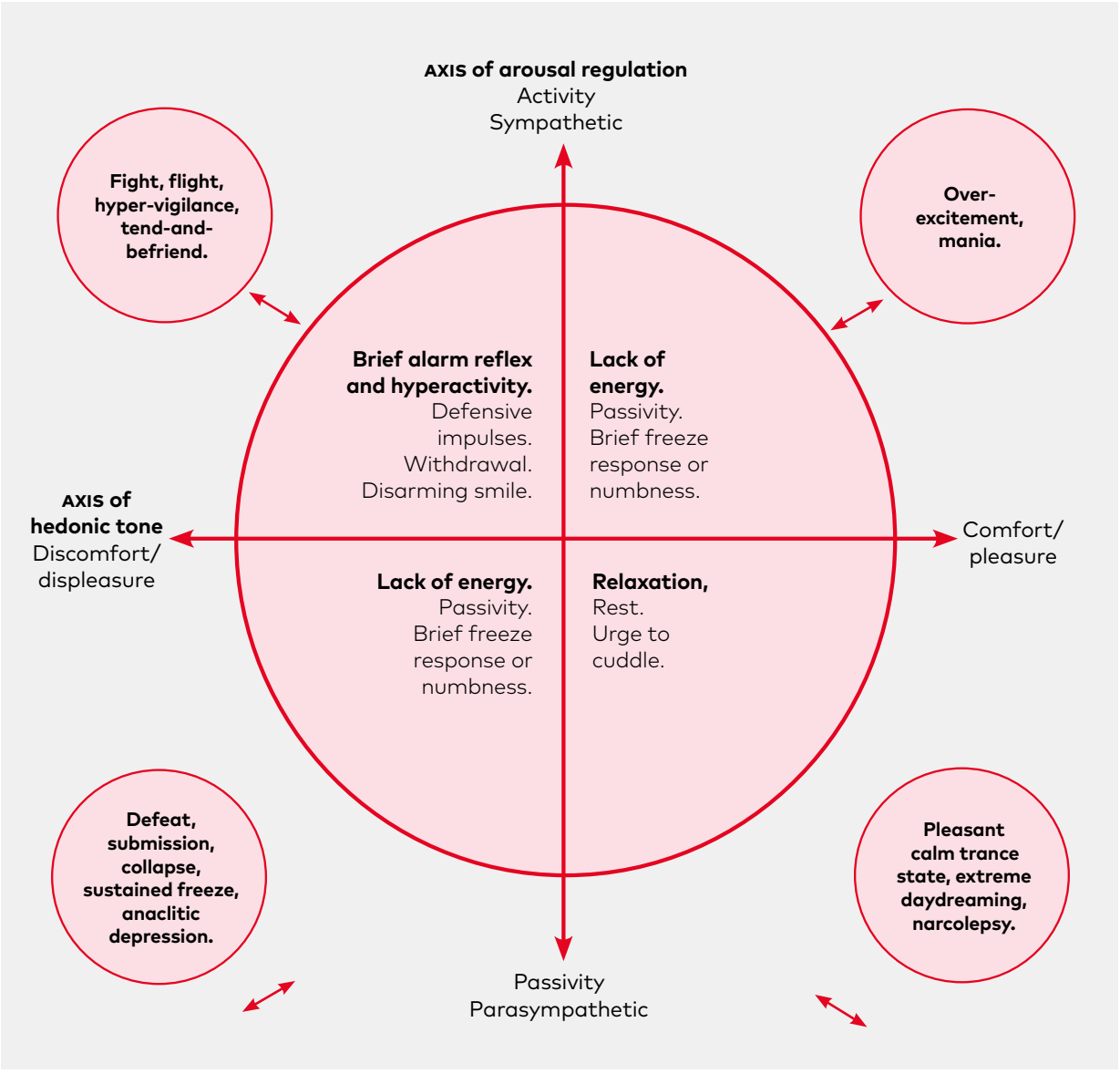


Figure 2. The autonomic compass with self-protection strategies (Bentzen & Hart, 2015).

learned the ability to self-regulate is able to stay in the centre, or to regulate back towards the centre. In this way, they can maintain a balanced arousal level. In addition, a person functioning with well-developed autonomic regulation is acquainted with the different states of arousal represented in the compass and can shift between levels with relative ease (Bentzen, 2018).

CDB will often influence the capacity of the person to engage in synchronized interactions because of frequent difficulty in following and imitating the actions of the caregiver. This is because impairments of sight and hearing

will influence the person with CDB's ability to read facial expressions, perceive emotional expressions in others or to use hearing to interpret and understand interactions. It is crucial that the communication partner has a comprehensive knowledge of how to interact and communicate with a person with CDB to ensure development in different areas, and to secure the wellbeing for the person with CDB.

If a person with CDB has a vulnerable nervous system, the caregiver must provide a greater level of support to navigate within the compass. The nervous system may be stuck in one of the quadrants as a self-protection strategy, or flip between them without achieving a balance. Self-harm, repetitive behaviour and sucking/biting are autonomic self-protection strategies.

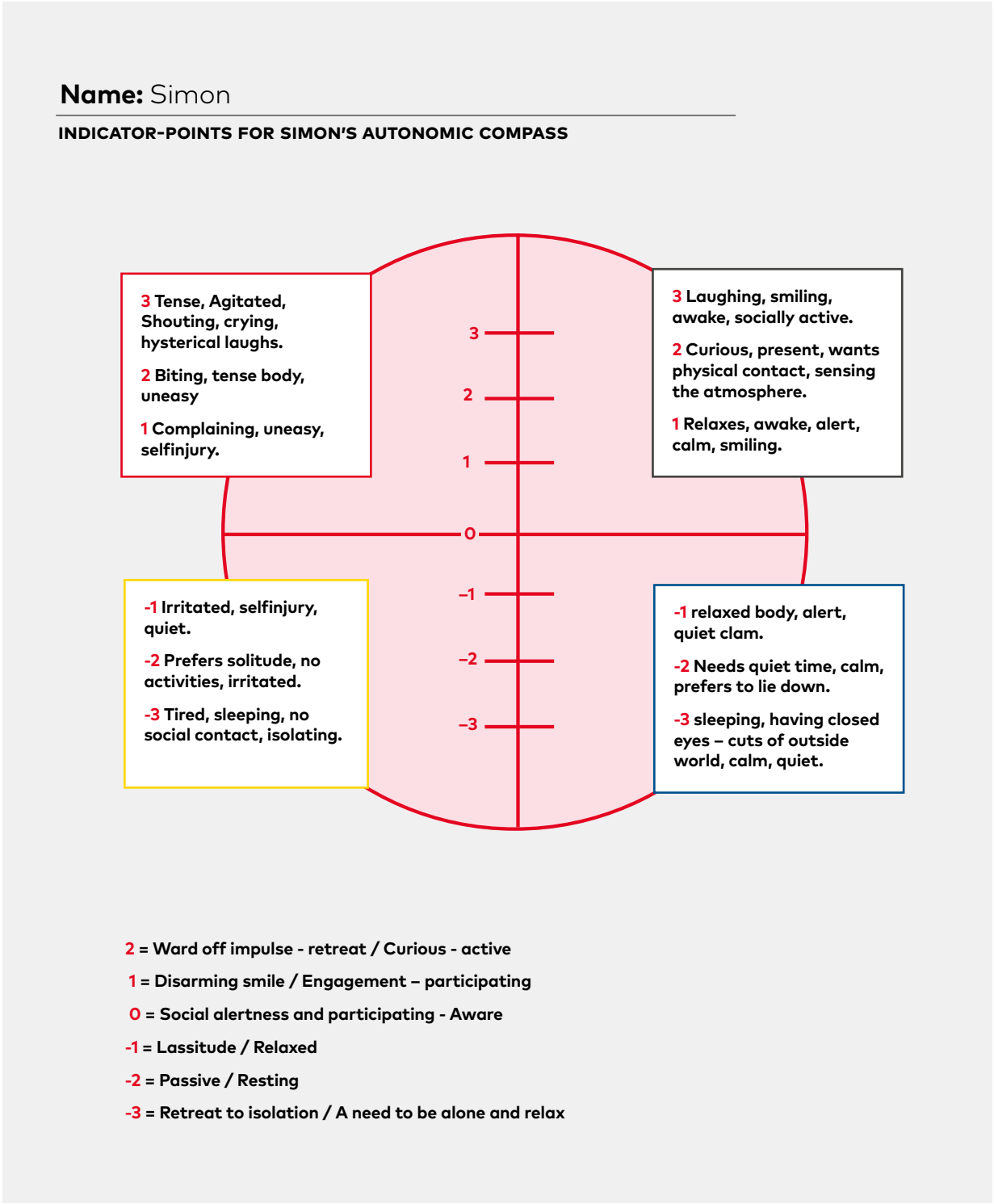
Some people with deafblindness may have lacked opportunities to develop these everyday response patterns due to sensory deprivation or stress, as well as biological factors. These contribute to making their nervous system vulnerable, leading to an under-developed autonomic system. Such a person may be challenged in their ability to self-regulate within the autonomic compass and they may "drop out" of the compass into self-protection strategies. In order to retain a balanced arousal level, they need help to regulate back into the circle of the compass.

The autonomic compass and indicator points

In this project, the autonomic compass served as a guideline to determine and assess the arousal level of each participant. In contrast to the four quadrants in the autonomic compass, we have also described indicator points. These are individual indicators of behaviour, such as body and facial expressions and sounds that we can use to read the expressions of arousal level. For this project we designed an indicator-point compass in cooperation with the neuropsychologist and the consultant. Each participant was provided with their own personal indicator-point compass. In figure 3, we show the personal indicator-point compass for Simon.

When we were interacting with or just observing Simon's behaviour, we used the indicator-point compass to determine what state of arousal Simon was in, at any given time. The optimal state of arousal for Simon in which he was attentive and ready for interaction, occurred when his arousal level was in the upper right quadrant (sympathetic and expressing pleasure, shown in blue in figure 3). Here he was relaxed, awake, mildly alert and accepted social or tactile contact. When he was in the quadrant indicating sympathetic and displeasured (red box), he was tense, agitated, biting or crying and needed our help to calm down. This was also the state in which it was most challenging for caregivers to find a way to help him. Simon reacted to our interactions, and if his behaviour or expressions changed, we could determine if his arousal level was moving up or down in intensity, or just becoming more balanced. We could then adjust our support and level of intervention to meet his needs.

Figure 3. Indicator-points compass for Simon.



Providing arousal regulating activities

Originally the project had six participants, but together with a psychologist and an occupational therapist, we learned that two of the participants were capable of self-regulating their arousal level and therefore did not need to participate in this project. We continued with the remaining four participants and tailored an activity for each according to needs and interests. During the process, we evaluated and altered the activities when required. The four participants had very different needs, which made it important for us to customize the activities for each person. It was a challenge for us to construct activities that were meaningful and effective, and this made the process of planning take longer time than expected.

We used a lot of time to develop activities that either raised or lowered arousal levels. The activities needed to be accessible and easy to manage, so that they could be incorporated into our daily practice. If an activity was too time-consuming and complicated, it would not be conducted on a busy day when there already were many other tasks to complete.
At the start of the project, we did not have a great deal of funds or time which encouraged us to be creative when developing activities for the participants. For example, we could use activities that were already part of the participants' everyday routines and make activity boards ourselves. We were conscious that others could develop similar projects since it does not require any special equipment nor are the activities time consuming.
For Simon, it was our aim to regulate his high/negative arousal levels in the quadrant of sympathetic and displeasure (red box in figure 3) to a more balanced level. We knew that Simon loves tactile stimulating activities conducted on his chest, hands and mouth, and this was our starting point in creating his activities.

Simon participated in arousal activities every day during the project. The aim was to regulate his high arousal by clapping intensely on his body/chest to match his arousal level, then altering our clapping to a slower clap before finally slowing to a gentle pace. We were attempting to influence his arousal level with the intensity in our clapping and thereby help him to achieve a lower arousal level. He also had an activity board to stimulate his senses as he mainly uses his mouth to obtain and access tactile stimulation on his own. The activity board was made from a chopping board with different objects attached to it. The board was attached to a tripod to make it easier for Simon to reach it with his mouth. The different objects had different textures, smells, sizes and tastes. Because of his physical impairments, Simon was only able to move his head from side to side and explore the different objects with his lips and mouth. This activity was meant to heighten his arousal level as the board offered different sensory stimulation to stimulate his brain. This activity was conducted in the evening after dinner. The following pictures give some example of different tools/equipment that were used to provide arousal regulating activities:

Pictures 1 and 2. Picures of Simon's second activity: Homemade sensory board, made from a kitchen cutting board, placed on an iPad holder/tripod on a table.

6.7 Outcomes from the arousal regulating activities for Simon

For Simon the arousal regulating activities proved successful. The activity of clapping Simon on his body and chest is still used today and can take up to half an hour. In our experience, this has helped Simon considerably, and helps to avoid his becoming so frustrated and distressed that he needs sedative medicine to calm down. He enjoyed the activities and we noticed that he recognised the activity even when he was agitated which helped us lower his arousal level from high/negative (sympathetic and displeasure) to a more pleasant and positive arousal level (sympathetic or passive/ pleasure see figure 1). During the project, Simon appeared largely content and had very few episodes where he was upset, angry or agitated. At the start of the project, Simon was able to concentrate on the board for approximately 15-20 minutes. By the end of the project, he was able to concentrate for about 30-45 minutes. We found that he understood what the board had to offer and how he could explore this.

The indicator-points in figure 3 were a great help in enabling us to read and understand Simon's bodily sensations and reactions as indications of his level of arousal. Over time, our ability to distinguish Simon's communicative signals has improved greatly. Together with the increased amount of structured sensory input, Simon has become more balanced in his arousal levels, because we have become better at helping him before his arousal becomes either too high or too low. As a result, it is our impression that his ability to self-regulate his arousal level has improved. Furthermore, it has been possible for us to raise his level of readiness for interaction and such interactions have improved our communication.

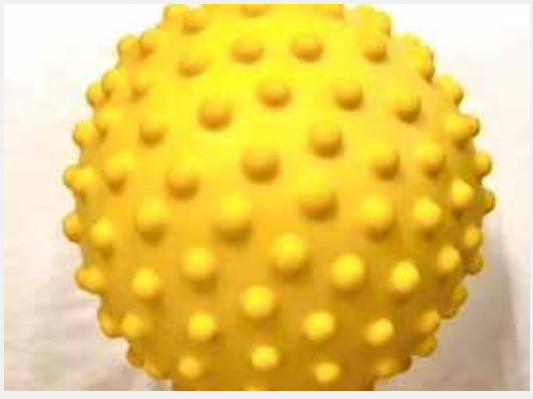
6.8 Outcomes from the arousal-regulating activities for all four participants

Throughout the project, we kept regulating and adapting the activities to make them more meaningful for individual participants. We will share some examples of activities for the other participants to illustrate how simple items can be used in arousal-regulating activities:

Picture 3, 4 and 5. Handysling (walking aid for a personal lift in the ceiling) and moving disco lights.

One person with a visual impairment walked into a dark room, searching for a coloured light. In combination with the physical stimulation, this activity seemed to help awaken her body and mind, and thereby heightened her arousal level from the quadrants parasympathetic or sympathetic and displeasure, to sympathetic and pleasure.

Picture 6. Sensory stimulating massage ball.



This ball was used in an activity in which an individual with high arousal (quadrant sympathetic and displeasure) needed help to lower his arousal. This activity was altered to that of a massage for which hands were used instead of the ball. Over time, this had the positive effect of helping us to lower his arousal to the quadrant of parasympathetic and pleasure.

Picture 7. Sing-a-long book.

We combined singing with physical gestures and signs. By doing this half an hour before dinner time, we could help one woman regulate her arousal level from very low (parasympathetic and pleasure) to a more balanced level (sympathetic and pleasure), to help her stay awake during mealtimes. By performing this activity every day for two to three years, she has slowly altered her internal energy level – basic level of arousal - from passive to active and is able to remain more awake during the day.

After a certain period we evaluated the individual activities, we learned that they all appeared to be meaningful for the participants as well as useful for regulation of arousal levels. We realised that the four participants had been thriving and developing new communicative skills over the course of the project and in the time following its conclusion. Thanks to this structured method of using activities and documenting results, we could follow and enhance the development of each person. We are still using the activities and documenting the development of participants. In this way, we will be able to see if there are long-term effects of the arousal activities for all four participants in this project.

6.9 Conclusion and discussion

The combination of neuropsychology and our fundamental knowledge and practical experience in the field of CDB has increased our attentiveness both to the issue of arousal and the expressions of the residents. We have become more aware of how every little sound or gesture from a participant can have a purpose. They can be understood as communicative expressions as well as indications of arousal level. In our project, communication partners and the participants succeeded in improving their communication in a reciprocal way. It is vital for each person that all their communication partners share knowledge about how to communicate with them.

In our view, the theory of arousal regulation is transferable to other similar projects. When using the autonomic compass with the indicator-point compass, it is possible to work with people with CDB who might have arousal-regulating problems. The indicator-point compass allows the caregivers to describe their knowledge of the person's bodily expressions in order to emphasise and interpret the corresponding state of arousal. This gives a clear idea of how to spot arousal irregularities and when to give support.

We would like to emphasise that the tools derived from the theory of arousal and the autonomic compass are extremely useful in work with adults with non-verbal communication and developmental delays. We found that for all four participants, these varied and sensory-stimulating activities helped to minimize autonomic self-protection strategies. We experienced and learned how we could create activities and use sensory stimulation in our interactions with the participants to influence their arousal levels in a positive way. Through our new knowledge of arousal, we continue to explore new possibilities for minimizing self-stimulating activities. Our experience has shown that it is possible to ensure a greater level of attention and readiness for interaction and communication by supporting arousal regulation.

The participants need continuity and repetition to understand and develop. They need time to connect gestures and sound with communication and to understand that their partner is trying to interpret their communicative attempts. We have been working on this project for a year and it took time before we experienced progress within the arousal activities. We found that starting a new project can be rather difficult, especially when progress is not seen right away, and it seems as though all the hours of work have been for nothing. However, in work with people with CDB and multiple disabilities, it is important to show patience and remember that you cannot force progress. Development will occur in its own time. Our patience and dedicated work have been rewarded, and we are now working well using the results of a successful project.

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"We would like to emphasise that the tools derived from the theory of arousal and the autonomic compass are extremely useful in work with adults with non-verbal communication and developmental delays."

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Chapter 7

Waterplay: taking the role of cognition partner to see and support exploration and learning in a child with congenital deafblindness

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Eline Falch Melhuus

In this chapter, we describe a qualitative, semi-structured practice-based project involving assessment of cognition in a child with congenital deafblindness (hereafter CDB). The project was conducted by the two first authors, teachers at a school for children with CDB, and influenced by supervision from the third author, an advisor within the field of CDB.

This project is an example of semi-structured assessment in a practice context of the cognitive functioning and progress of a pupil by two teachers. As a qualitative, interpretive project, the structure of the assessment situation and the actions of the partners facilitating it changed as preliminary analysis led to new perspectives on the assessment situation (for example, see Corbin & Strauss, 2015). This circular process of framework – implementation – analysis – evaluation followed by further implementation based on evaluation is common to most forms of qualitative, interpretive research.

In encounters with children and youth with CDB, we often ask questions such as "How can we contribute to increase the child's exploration of the world?", or "What does the child comprehend?" When communication has low readability and the child has few or no linguistic expressions in the form of signs as well as non-typical ways of showing attention, it is often difficult to hypothesize about what he has noticed and understood. Therefore, there is the risk of underestimating the child's cognitive level and potential. Though we may suspect that this is the case, concrete and objective points of reference for assessment are often lacking. As teachers at a school for pupils with CDB, we know that underestimation can have unfortunate consequences for how teaching is planned, the aims we set for the pupil and, not least, the expectations we have for further development and learning.

To gain a better understanding of the cognitive potential of one of our pupils, we created a project we called "Waterplay". This project employed a general perspective on cognition as embodied and was pragmatically defined as learning and exploration. As the project progressed, the third author (Costain)

introduced an elaboration of the communication partner relations described by Nafstad and Rødbroe (2015) and suggested the parallel role of cognition partner as defined in a set of partner attitudes. These theoretical perspectives are described next.

7.1 Theoretical perspectives

7.1.1 Cognition: a practical definition

It is perhaps most practical for partners of people with CDB to view cognition as exploration and learning (the latter is most easily seen in the transferral of skills or knowledge from one situation to new settings or situations). When we view the child's general interaction with ourselves as communication partners, we are interested in such embodied aspects as the type and extent of both responsive and self-directed activities and the emotional and communicative expressions of the child, as well as in the qualitative characteristics of this activity and these expressions ("hard" <-> "soft" touch, or "fast" <-> "slow" arm movements, for example). Of general interest are any patterns in what the person with CDB does. For example, shifts in self-directed activity to "listening." Other features of interest can include:

- Mimetic expressions
- "Doing it over again", such as repeating an activity or aspect of an activity in the form of re-enactment
- Directing attention (including pointing and other bodily indications of attention- directing and intentionality).
- Categorisation activity: exploring, for example with reference to schematic structural pairs (in and out, up and down, for example). Another fundamental schema is that of Source – Path – Goal. All actions and events have a start (source), a route or series of smaller actions (path), and an endpoint (goal). Understanding and using these basic schematic structures to categorize our experiences is something we begin to learn from birth through our embodied experience, on our own and with others (Johnson, 1987).

Embodied cognition can be thought of as thinking with and through the body (including, but not restricted to, the brain), and through bodily experiences. These function as the basis for cognitive schema such as those described above, which then become tools for thinking and learning about further experiences with and in the world. In taking this embodied cognition approach, we can say that there is no thought or thinking and no communication without the body.

7.1.2 Viewing the child with CDB as a cognitive subject: the YOU position

By viewing the person with CDB as a subject we can (temporarily) distance ourselves from the intersubjective orientation of the partner-person couple and facilitate, observe and assess cognitive activity in a clearer way. To achieve this, (a) we need to be aware of the expansion of our support or partner role from communication and social interaction partner to include a cognition partner role in seeing and supporting the child's learning and cognitive development; and (b) the partner of the person with CDB needs to take a YOU perspective toward the person with CDB. Nafstad and Rødbroe (2015) describe the three perspectives of the partner in terms of the I or first-person perspective, the YOU or second person perspective, and the IT or third person perspective. The I perspective is the perspective of the partner him/herself, sometimes projected onto the subjectivity of the person with CDB. There can be good reasons for taking this perspective in trying to identify what the person with CDB is feeling or interested in communicating, though it is also important to identify and 'own' one's own partner perspective by clearly indicating that it is a perspective on the thoughts and feelings of the person rather than those thoughts and feelings themselves.

The IT perspective also has its place, but can very easily become dominant, and can lead to objectification of the person with CDB. This is the opposite of treating the person as a subject. The IT view is often signalled by use of the third person pronoun (he/she) as in, "He always does that when we go out"; "She doesn't like to use signs" or "He loves loud music". The IT perspective involves ideas about what the person likes/does not like, and can and cannot do, for example, and these ideas tend to become somewhat fixed if they are not reassessed through reflections on practice. In the YOU perspective on the other hand, the partner's focus is on the person with CDB as a subject. A subject is a someone who understands and thinks, who expects something from the environment, who is cognitively and emotionally present, and who has her or his own perspective. When a person is regarded as a subject, he or she feels something, whereas when the person is objectified, he or she is perceived as an individual who merely reacts. For example, a subject acts whereas an objectified person merely demonstrates behaviour. When we take a YOU perspective as partners, we become more conscious of people with CDB as individuals with their own agency, or ability to act based on a cognitive-emotional perspective of their own.

Taking the role of cognition partner

Taking this more dynamic perspective can be described in terms of (also) being a cognition partner, as the focus is on the person with CDB as an experiencing and learning, thinking subject who needs support in their exploration of the world. Being a good cognition partner can be helped by cultivation of certain partner attitudes that emphasise the YOU perspective. Here is a suggested list of such attitudes:

- Wondering (including taking what in therapy is called the "not-knowing position" (Andersen, 1994) as an active position, or suspending one's own knowing).
- Listening (being a listener as much as one is a speaker) and thus supporting participation in dialogue and communicative agency. Treating the person with CDB, regardless of formal linguistic ability, as a contributor to as well as recipient of, communication.
- Being expectant (expecting something from the person with CDB as part of an active way of being with the person).
- Following the person with CDB (following his/her initiative).
- Mirroring the person's actions or initiatives (reflecting them back to the person with CDB in an attuned manner, not merely using mirroring as a technique).
- Confirming (for example by speaking out loud about what one as a partner sees that the person with CDB is doing, is engaged in or attempting to do).
- Being addressed to (also without directly addressing) the person with CDB.
- Allowing things to happen (suspending intervention and permitting the person with CDB to act and express; making space for new things to occur through an attitude of allowing this to happen).
- Refraining from doing, saying or meaning something in the moment (as above, allowing for a space to enter in between our perceiving and then acting on our perception; taking our time. This space can be very potent for both the partner and the person with CDB).
- Being informative (not necessarily only through language, but through an orientation, also bodily, of providing the person with CDB the best access to context through information. The word in-formation suggests meaningful gestalts or wholistic units of meaning, not merely isolated facts or directives. An informative attitude takes this into account.)
- Observing the child as a subject in a fresh and inquisitive manner (also more than merely being observant; suspending our urge to categorise as we do this, as that is for later when we are not actively partnering, rather reflecting over our practice)
- Being with the person with CDB (in Norwegian, the phrase is "being together with", and this is closer to the meaning suggested here - accompanying the child in an engaged side-by-side manner).

These ideas about the YOU position, and the role of cognition partner became part of the project presented below and provide necessary context for interpreting the results. They can also be generally useful in partnering children with CDB with the aim of supporting learning and exploration in cognitive development.

7.2 Ethical considerations

In this project, we made use of video as a tool for assessment of cognition in a pupil with CDB. We wanted to reflect on our own practice and to be able to see details of the pupil's actions that might otherwise escape attention in the practice situation.

The use of video recordings involves several ethical considerations such as consent, storing of data, duplication, distribution, anonymisation and sensitivity in how the person is presented. In our practice, video recordings of interactions between pupil and partner are routinely used for team discussions. Video technology enables us to discover the person's communicative expressions, which is important for further intervention. To begin with, this project (Waterplay) was planned solely as a base for discussions among colleagues, not for sharing publicly. The parents had already given general permission in verbal and written form to use video recordings within our institution. As the project evolved into a presentation held outside the school, we asked for a more specific, written consent from the parents, regarding both the video clips and use of the material presented in this chapter.

In this article, the pupil is anonymised, and all the material has been stored on an external hard drive, not connected to the internet and kept in a locked cabinet, in accordance with our institution's strict regulations. We have given attention to this issue, as identification of a pupil can be relatively easy in a school with few pupils.

We had to have in mind that video recordings, especially edited clips, only show a partial representation of the person and his or her capacities. This, and the fact that the boy himself may not be capable of understanding that he is being recorded and therefore could not give consent himself, made it important for us to be conscious of our responsibility in presenting the pupil and his capacity in a positive manner.

7.3 Case description

Our pupil, we can call him Daniel[7], is a boy with CDB who attends a school for the CDB. He was twelve years old at the time our project was carried out. Daniel has residual vision and hearing, but it is not clear to what extent and how these senses are used. He is very tactile in his general approach to the world and often shows attention by exploring in a tactile manner with his hands or feet while closing his eyes. Sometimes he even removes his hearing aids while being tactilely attentive.

1 Daniel is an alias.

In general, we consider Daniel to be attentive and curious towards people within his visual field and tactile reach. However, we experienced challenges regarding joint attention towards a third thing – YOU – ME – SOMETHING. In order to communicate about something-in-the-world, attention needs to unfold in a triadic dynamic structure (Nafstad & Rødbroe, 2015). Daniel has few linguistic expressions in the form of signs and his ways of communicating have low readability for the people around him. Knowing where or towards what he is directing his attention is sometimes difficult and thus it is challenging for partners to understand what he comprehends. Therefore, there is a risk of underestimating his cognitive level and potential.

Through this project, we wanted to gain a better understanding of Daniel's ability during interactions with the partner involving a third thing, to show curiosity toward something (other than the partner), to take the initiative to explore something (other than the partner), to use memory (using previous experience) and to be attentive over time (toward something other than the partner). During the project, we chose to focus on aspects of cognition other than the communicative-linguistic activity of the pupil, although this was also of interest. A focus on sign use is relevant and appropriate; however, our view is that learning and cognitive development should be assessed using more variables than comprehension of signs and sign production alone.

7.4 Methods and procedure

Video analysis

The use of video as a tool of analysis is central in human interaction studies. Video enables the study of social interaction in detail at a micro level (Hansen, 1991). It gives us the possibility to watch sequences repeatedly and to discuss observations with others in the pupil's network. Video recordings allow us to see and become aware of actions and expressions that might otherwise have been overlooked in the situation. Our observations made from reviewing the video recordings have been transcribed into a table for further analysis (Table 2).

The didactic plan

Throughout the project, we used a didactic plan as a tool for planning, completion and evaluation. Didactics is a central aspect of pedagogy and described as the "practical-theoretical planning, completion, assessment and critical analysis of teaching and learning" (Hiim & Hippe, 1998:9 cited in Lyngsnes & Rismark, 2007, p. 26). As a partner, you must ask yourself what, how and why: what do we want the pupil to learn, in what way should the pupil learn this, and why should the pupil learn this? The pupil's prerequisites for learning and development in the activity and environmental factors should also be part of didactic planning.

Procedure

Waterplay was a series of weekly sessions over two months in which Daniel stood in a standing frame with a washbasin in front of him. The partner then poured cold and warm water from several jugs interchangeably into the basin. Initially the partner also presented two different objects to explore in the water. These objects were later omitted because Daniel showed significantly more interest in other aspects of the activity. Our aim was to stimulate and encourage him to engage in greater exploration of the activity, together with the partner.

Table 1. Excerpt from the didactic plan for the activity Waterplay.

CONTENT (What)	ACTIVITY (How)	AIMS (Why)	PRECONDITIONS AND ENVIRONMENTAL FACTORS
Playing with water	Daniel and partner are to pour cold/warm water interchangeably into the basin	Stimulate cognitive processes such as curiosity, initiative taking, exploration, memory and attention.	Daniel is acquainted with the standing frame and playing with water in other situations.
Exploration of the water and objects in the water.	Partner and Daniel are to explore together two different objects in the water.	Experience excitement in playing with water.	Partner needs to ensure that Daniel is shielded from visual and auditory distractions.
Repeated once weekly over two months.	Daniel is to be encouraged to be participative and explorative.	Opportunity to use all the senses to experience water.	Equipment we need:
All the sessions are to be filmed.	All the sessions are to be filmed.		
EVALUATION			

We wanted the activity to have a certain choreography, a structure, but with the flexibility to make changes as we progressed. There was to be a setting around the activity and several elements Daniel could recognise from session to session, but we also wanted there to be room for improvisation by both Daniel and the partner.

Continuous evaluation

We recorded each session and reviewed the videotape afterwards, looking for cues that suggested engagement, exploration and initiative-taking. We also examined critically how each partner (the first and second author) engaged with and contributed to the activity. We noted what we saw and tried to analyse

and reflect on this by asking ourselves questions about what we had seen, the context for our interpretation and why something might have happened.

Following the use of a didactic plan as described above, we made notes on every session. After the first session, for example, we wrote "Daniel seemed quite interested when I poured the water from the jugs into the basin, reached out to the stream". After the next session we noted "... even more interested when I poured water from the jugs into the basin. He took hold of the jug, felt the stream of water and banged down into the basin with his hands. Speaking about where the water was headed? (...) next time I'll take even more time for this part of the activity (...) is he maybe more interested in the pouring than the objects? Are there too many elements?" Some weeks later, we had even more questions: "uncertain about whether we give him enough time to explore. Do we interfere too often? Interrupt him? What parts of the activity led to extra engagement/interest? Can we use even more time (at least 5 minutes!) to pour the water into the basin?".

These questions led to an evaluation followed by adjustments mid-way in the project.

7.5 Analysis and results

7.5.1 Midway evaluation and subsequent adjustments

We discovered that there was one part of the activity about which Daniel showed special interest. Originally, we thought that exploration of a toy plane and a tin lid in the water would be the main activity, but pouring the water seemed to be more interesting and stimulating than the objects. We chose therefore to respect his contribution and interest and made changes in the activity by using more time to pour the water.
Another, perhaps the most important, observation we made was that the partner had quite a brisk tempo. Daniel was attentive nonetheless and partially exploratory throughout the activity, but we started asking ourselves whether a slower tempo could act as a type of friction, or obstacle to stimulate further and more independent exploration. What would Daniel do if the partner waited a bit longer before encouraging him or placing further conditions on the activity? In trying to find out, we decided to change our approach to be more expectant, allowing and refraining (from doing), cf. the partner attitudes described above.

7.5.2 Video transcription and analysis

After completing all remaining sessions with the adjustments made after the midway evaluation, we chose to make transcriptions of the videos from the first and last sessions. The transcript was based on the following questions:

A. When does Daniel make tactile contact with partner (tactile addressivity)?
B. When can we see that Daniel explores something (or someone) without direct tactile and/or verbal instruction from partner?
C. When do we see that Daniel comments on something, asks for something, or answers partner?

Table 2. Except from the transcription/coding table for the last session of Waterplay.

Time	Event preceding Daniel's action	Description of Daniel's action	A, B, C
00:39	Partner supports Daniel's wrist and leads him to the edge of the jug for the second time.	Daniel feels the edge with his fingertips (his tactile acute vision). Notice hand position!	B
00:40	Partner begins to pour water from jug.	Mouth movements: Daniel changes sucking-smacking to chewing-smacking sounds.	C?
00:47	Partner pours water from jug.	Daniel lifts his hands up from the jug, puts them in the stream and feels it with the back of his hands with fingers spread.	B
00:55	(Daniel withdraws briefly.)	After a brief withdrawal Daniel continues his exploration as above.	B
01:06	Water runs down into basin.	Daniel moves his hand from the stream into the basin.	C (SPG*)
01:27	Partner leads Daniel's hand into the jug; shows that it is empty.	Daniel stops mouth movement (chewing-smacking).	C
01:36	Partner makes contact by stretching out hands in speaking position towards Daniel.	Daniel immediately places hands in listening position up onto his partner's hands.	C
01:45	Partner splashes with fingers in the water.	Daniel instantly dips right hand into the water.	C
01:54		Daniel places his hands (flat, splayed fingers) in listening position on top of partner's hands, with little encouragement from partner.	A
02:03	Partner fetches a new container, a carafe, from the shelf.	Daniel stretches hands toward new container and touches it with both hands; uses fingertips to feel the carafe.	B
02:11	Partner says WATER (vocally and tactilely).	Daniel moves his hands down into the basin.	C

Based on information from the transcriptions, we made a more structured comparison of how Daniel's engagement, initiative-taking, and communicative expressions had shifted following the change in partner attitudes. We could not know what caused what, but we saw a distinct change after the alteration.

7.6 Results

In phase 1, our frequent interference and fast pace appeared to disturb Daniel's independent exploration. We could have had greater confidence in Daniel as one who is able to understand, who expects something, who is cognitively and emotionally present and who has his own perspective by taking a more consistent and complex YOU-perspective. We could have been more conscious generally of how we performed the role of cognition partner: a partner who sees and supports cognitive processes (in terms of the partner attitudes described above). In our eagerness to show and help Daniel to explore in the way we expected the exploration to proceed, we might have interrupted his independent exploration. In the second half of the project therefore, it was important for us to be more expectant and allowing, more curious and more listening regarding his exploratory initiatives.

During phase 2, Daniel did not lose interest, as we had expected, when we changed our approach and gave him longer to respond. Rather, he demonstrated ways of exploring that were completely different from those seen at the beginning of the project. The first time he engaged in Waterplay, his exploration looked relatively uniform throughout the session. He shifted between reaching his hand into the stream of water when the partner poured from the jug and splashing his hand in the basin; there was little variation during the half-hour session.

Daniel shifted between reaching his hand into the stream of water when the partner poured from the jug and splashing his hand in the basin.

In the final session, the partner was more restrained, stopped more often and waited longer for Daniel to take the initiative (taking an allowing position as cognition partner). Daniel began early in the session to explore the partner's exploration: the partner splashed with her fingers in the water in the jug. Daniel felt the partner's wrist with his pointing finger. He consistently shifted between using tactile acute vision (fingertips) and tactile overview (scanning with whole hand) and showed increased and more varied tactility compared with the first session. When the partner paused in her exploration of the water, Daniel set the partner in motion again in a variety of ways. Later in the session, we saw that he progressed from getting the partner to resume the pouring, to starting the pouring again himself; for example: the partner pours a bit, then stops and repeats this. Daniel leads the partner's hand quickly up to the jug and clearly pushes it downwards so that the water can begin to run again. This is repeated several times. In this session, we also observed an example of how Daniel made use of what can be described as a source-path-goal schema. This is also an example of using former experiences (suggesting learning and working memory; see chapter 8 in this book) as a base for exploring something familiar in new and more varied ways.



It seems that the partner's increased awareness of taking the YOU-perspective to show that she really believes Daniel has the capacity to contribute to the situation and interaction, appears to have been important for giving him opportunities to initiate, vary and reflect upon his exploration - to learn, and become more active cognitively. Although we chose to focus on other aspects of cognition than the communicative-linguistic activity in terms of signs or sign-like expressions made by Daniel, we could observe a doubling of such expressions in the final session. This suggests that a more consistent and significant YOU-perspective from the partner had influenced Daniel's ability to address the partner and to express himself, and his expressions appear to reflect greater cognitive engagement.

7.7 Discussion and conclusion

We began the project with the aim of increasing the pupil's interest in exploring, and to stimulate his independent contributions within a specific activity. At the mid-point of the project, we discussed the perspective of cognition partner, and how the notion of the YOU-perspective (Nafstad and Rødbroe, 2015) and partner attitudes could be implemented in practice. Phase two of the project was informed by this perspective and led us to adjust elements of our actions as partners as well as the content of the activity.

The concept of cognition partner made us more attentive towards the YOU-perspective. Our experience is that in partnering people with CDB, it is easy to fall into over-emphasis of an I-perspective no matter how good one's intentions are to avoid this. In this project, we did not find ourselves in the IT-perspective to any great extent. However, in our eagerness to help and understand we can sometimes take over the voice of the person with CDB. This can create confusion about what is the voice of the person with CDB versus the voice of the partner.

Increased focus on following the cognition partner attitudes was helpful in taking a more distinct YOU-perspective:

- Be listening (do less talking/acting)
- Be expecting (expect something from the pupil; expect the unexpected)
- Be following (follow the pupil's initiative)
- Be refraining (take your time)
- Be accompanying (be together-with)

In other words, we showed greater confidence in the person with deafblindness as someone who can understand, who expects something, who is cognitively and emotionally present and who has his/her own perspective. Practitioners may find it useful to increase their awareness of taking the YOU-perspective and actively reflect upon this in encounters with a person whose communication has low readability, as this perspective can open new ways of viewing the person and identify aspects that can be easily overlooked.

We feel it is unfair to assess cognition only based on observations and analyses of the person's communicative skills when this communication has low readability. The feeling of not being able to understand one another can make the partner feel uncertain about her efficiency as a communication partner - a partner who can maintain a communicative relation with the person with deafblindness according to his or her abilities and capacity. It can also make the partner question their own ability to be an understanding and supporting partner. A focus on signs and other linguistic practice is indeed important. But in our experience, low readability can mask other cognitive processes such as initiative-taking, active exploration, working memory and attention. In Waterplay, we did not abandon the communication partner perspective but expanded our focus to contain two

ideas at once and to observe both the child's and our own communicative interaction, as well as cognition defined as exploration and learning.

We found that what to us appeared to be one activity was composed of several parts. The partner's agenda was not initially in compliance with Daniel's interest. From the beginning we wanted the activity to have a certain choreography, but it was important for us to have the opportunity to make changes and adjustments along the way. Adjustments made after the mid-way evaluation proved to be beneficial.

Experiences from Waterplay strengthened our perception of how disciplined one must be when interacting with persons with CDB, as the challenges of reducing the tempo of the partner and waiting for the pupil's initiative illustrate. When we earlier referred to a brisk tempo, it must be kept in mind that the partner felt that she was slowing down from the start of the project, but the videos made us see that we could proceed even more slowly. As a partner, one must be prepared to constrain oneself in the situation in ways that can feel awkward and uncomfortable.

"Experiences from Waterplay strengthened our perception of how disciplined one must be when interacting with persons with CDB, as the challenges of reducing the tempo of the partner and waiting for the pupil's initiative illustrate."

After working with Daniel for many years, we continued to feel that he was quite an enigma. Low readability made it difficult to guess about what he might be feeling or thinking. However, the insights we developed after analysing the Waterplay videos inspired us to see him in a new light. When we adjusted our tempo and implemented the partner attitudes outlined earlier, we were able to provide better conditions for him to demonstrate his cognitive competence. A clearer understanding of this competence allowed us to facilitate the

tuition and support his development and learning in a more targeted way. Our systematic analyses and the use of the partner attitudes in taking on the role of cognition partner, led us to give the pupil the opportunity to express himself in a more exploratory and communicative-linguistic manner. The approaches taken in this project to the task of cognitive assessment are easily replicable in the school/institutional setting. We hope that this chapter will serve as an inspiration to professionals to pursue ways of developing awareness and assessments of cognition in a semi-structured manner in their practice.

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Chapter 8

The Tactile Working Memory Scale

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The Tactile Working Memory Scale (hereafter TWMS) is an itemized rating scale for structured observation of working memory in the somatosensory (bodily-tactile) modality, identified by patterns of observable behaviour in everyday occurrences and during social interactions (Nicholas, Johannessen & van Nunen, 2019). The TWMS has been developed for professionals to undertake structured observation, facilitate identification and promote effective interventions of working memory in the bodily-tactile modality in people with congenital deafblindness (hereafter CDB). It is primarily a tool for enhancing the effectiveness of bodily-tactile working memory, with respect to the competencies and potentials of the individual. The TWMS not only identifies how a person with CDB uses their cognitive and social cognitive capacities in everyday life, but also assesses the individual's propensity to learn from new learning opportunities (learning potentials) or the individual's ability to change his or her own cognitive processes while the assessment is underway (cognitive modifiability). This chapter will describe the theoretical and clinical assessment approaches that provide a basis for assessing tactile working memory. The chapter will also highlight a framework model for planning and evaluating the TWMS assessment.

8.1 What is working memory?

Working memory is the mental workspace that keeps track of and works with information according to the needs of the moment. It is a core property in information processing that enables us to organise information and deal with daily functions. It can be used flexibly to support a wide variety of tasks performed in daily life and is widely thought to be one of the most important mental faculties, critical for cognitive abilities such as planning, problem solving, understanding complex topics and language. Working memory is a critical aspect of our cognitive capacity because it provides the ability to retain task-relevant information in a highly activated and accessible state over time (Hambrick, Kane, & Engle, 2005).

Furthermore, working memory is involved in understanding our social world. Working memory in social contexts is referred to as social working memory and it is involved when we try to interpret other people's feelings and emotions and when we attempt to navigate a broad range of interpersonal interactions that we encounter daily. The purpose of social working memory is to build up and maintain an internal model of the immediate social environment and what has been happening in our social world (Meyer, Spunt, Berkman, Taylor, & Lieberman, 2012). Social working memory includes the mental processes of encoding moment-to-moment maintenance and manipulation of social cognitive information during interpersonal interactions (Meyer & Lieberman, 2012). Managing the demands of social cognition engages social working memory (Meyer, Taylor, & Lieberman, 2015).

8.2 What is tactile working memory?

Tactile working memory is likewise the ability to hold bodily-tactile information actively in mind and to keep the information available for further processing. While mechanisms underlying working memory processes in the visual and auditory modality have been studied intensively, studies of the principles underlying working memory in the tactile modality are scarce. However, in the last decade there has been an increase in the number of research studies directed at understanding working memory in the tactile modality. Several studies have examined tactile working memory in typical subjects (Bliss & Hämäläinen, 2005; Bonino, et al., 2008; Savini, Brunetti, Babiloni, & Ferretti, 2012). Furthermore, a research study demonstrated enhanced tactile working memory functions in blind subjects compared with sighted subjects, indicating that modality-specific experiences play a crucial role in shaping tactile working memory (Cohen, Scherzer, Viau, Voss, & Lepore, 2011).

An important topic for assessment and a specific focus for cognitive assessment is to see how a person with CDB encounters the world using her or his tactile sense (Ask-Larsen & Damen, 2014). It is generally agreed upon that the bodily-tactile modality is the main (but not the only) modality on which to perform assessment of cognition in relation to CDB (Damen & Ask-Larsen, 2014). Based on the assumption that the person with CDB may be better equipped to perceive the world from a bodily-tactile perspective, we must be willing to move towards a framework that could guide us to assess cognitive and social cognitive working memory potentials in the bodily-tactile modality.

8.3 A framework to guide the assessment of tactile working memory

The following theoretical and clinical assessment approaches provide a basis for identifying tactile working memory in persons with CDB.

a) The information processing theory

Working memory in information processing is the capability to keep track and work with cognitive or social information according to the needs of the moment. Working memory includes the distinct processes of encoding (initial interpretation /perception), maintenance (temporarily retaining) and manipulation (controlling attention). It also supports the inhibition of irrelevant information and instant retrieval of stored information in long-term semantic and autobiographic memory. In view of this description, tactile working memory requires our ability to encode relevant bodily-tactile sensory information, maintain the new information, and then take that novel information and manipulate it to produce a desired result during problem solving, language acquisition and social interactions.

"To understand our social world, we must continuously update information about the other person's current intentions and motivation and adapt our own behaviour accordingly."

To understand our social world, we must continuously update information about the other person's current intentions and motivation and adapt our own behaviour accordingly. This social dynamic process that engages working memory by distilling social experiences into meaningful and flexible representations for the purpose of navigating the social world is referred to as social working memory. The purpose of social working memory is to keep track and work with the multiple complexities of social information and to support mental effort in a social context (Meyer, Spunt, Berkman, Taylor, & Lieberman, 2012).

The information processing approach also describes capacity limitation within the processing system. This means that the amount of information that can be processed by the system is limited or constrained in some very important ways. Restrictions in the flow of information occur at very specific points and are often referred to as resource-limited processes (Norman & Bobrow, 1975). Nevertheless, the information processing approach emphasises learning strategies to overcome these limitations.

b) Understanding the development of tactile working memory through transactions

The fundamental assumption of the transactional approach to working memory is that development is facilitated by a bidirectional, reciprocal interaction between the person and his or her environment. A change in the person may trigger a change in the environment, which in turn affects the person and so on. In this way, both the person and the environment change over time and affect each other in a reciprocal fashion, and early achievements pave the way for subsequent development (Sameroff & Chandler, 1975; Sameroff & Fiese, 2000).

The transactional approach conceptualizes the development of working memory as a function of bidirectional and reciprocal exchanges between the person with CDB and context over time. It emphasizes that the development of working memory must be seen in the relationship between the person and the context, and not only in the person.

c) Understanding the development of tactile working memory within the dynamic assessment approach

A dynamic assessment approach highlights the general principle that guided learning can make a valuable contribution to the assessment process (Jitendra & Kameenui, 1993). The dynamic assessment approach emphasises the learning or cognitive potentials and accounts of the amount and nature of the mediator investment. Generally defined as an interactive, test – intervene – retest model of psychological and psychoeducational assessment (Haywood & Lidz, 2007), dynamic assessment links assessment with intervention, and is viewed as an approach that enables examiners to move beyond merely testing current levels of performance (Boers, Janssen, Minnaert, & Ruijssenaars, 2013).

The essence of assessing tactile working memory applying a dynamic assessment approach is that a person with deafblindness might perform above the limits of their optimal level of performance (specific level of competence), when supported by a partner who is able to facilitate social interactions and mediate individualized working memory strategies within the assessment.

d) Understanding the development of tactile working memory within an ecological assessment approach

The ecological assessment approach is an asset-based assessment that considers the person's competencies and potentials, as well as the systems within which he/she interacts, when assessing and intervening (D'Amato, Crepeau-Hobson, Huang, & Geil, 2005). An ecological assessment implies the examination of the individual's naturally occurring behaviour, the environment immediately surrounding the behaviour, and the individual-environment link. The essence of assessing tactile working memory in the application of the ecological assessment approach is to identify the behaviours of the person with CDB which are appropriately related to working memory functions from less

structured and more naturalistic learning situations. The TWMS is based on these theoretical and clinical assessment approaches.

8.4 The Tactile Working Memory Scale (TWMS)

The main purpose of the TWMS assessment is to promote a high level of working memory potentials in a person with CDB through accommodation of the environment (environmental interaction/social interaction), for instance by optimizing the physical and social environment of the person and by mediating effective bodily-tactile working memory strategies within the assessment. Accordingly, a learner will use different learning strategies such as perceptual, cognitive and/or social cognitive strategies in order to gather information, attend, problem solve, remember, or socially interact more successfully. For further details regarding the different bodily-tactile learning strategies, see the professional manual of the Tactile Working Memory Scale (Nicholas, Johannessen & van Nunen, 2019).

Furthermore, the assessment can help us identify the person's level of understanding of these strategies as well as their transferral value to other activities or tasks of increased levels of complexity or novelty and thereby provide insights into the emerging working memory capabilities of the person with CDB. To promote construct validity, the domains, subscales and items of tactile working memory are identified and conceptualized based on theory, clinical practice and the research literature.

Research suggests that the concept of working memory not only refers to short-term storage of information, but also to attention and executive control, and is reciprocally linked to long term memory (Miyake & Shah, 1999). Furthermore, it involves a great deal of social information processing and engages social working memory (Meyer, Taylor, & Lieberman, 2015).

The TWMS has been formulated in three steps: the first step was a literature review focusing on studies addressing tactile information processing (i.e., (Gallace & Spence, 2009; Song & Francis, 2013; Katus, Müller, & Eimer, 2015). The second step was to take into account theoretical models of working memory (i.e., (Baddeley & Hitch, 1975; Miyake, et al., 2000; Baddeley, 2003; Cowan, 2008)) and a tactile spatial model of working memory (Cohen, Scherzer, Viau, Voss, & Lepore, 2011). This tactile spatial model of working memory especially considers the crucial role of tactile experience in shaping working memory. During the second step, particular emphasis was given to two specific working memory models: the model as suggested by Daryl Fougnie, in which working memory is the ability to retain information in an accessible state and includes the distinct processes of encoding, maintenance and manipulation of information (Fougnie, 2008); and the model of social working memory proposed by

Meghan Meyer and Matthew Lieberman, that social working memory is working memory for social cognitive information and includes the mental processes of accessing, maintenance and manipulation of social information (Meyer & Lieberman, 2012).

During the third step, the items within the working memory domains were collected and selected from observations of the interactions between individuals with deafblindness and their interaction partner(s). Based on the scientific literature, video analysis and clinical experience, an initial conceptualization was constructed (Nicholas & Johannessen, 2014). After this, a first trial was conducted in collaboration with several professionals within the deafblind field which resulted in the current version of the TWMS.

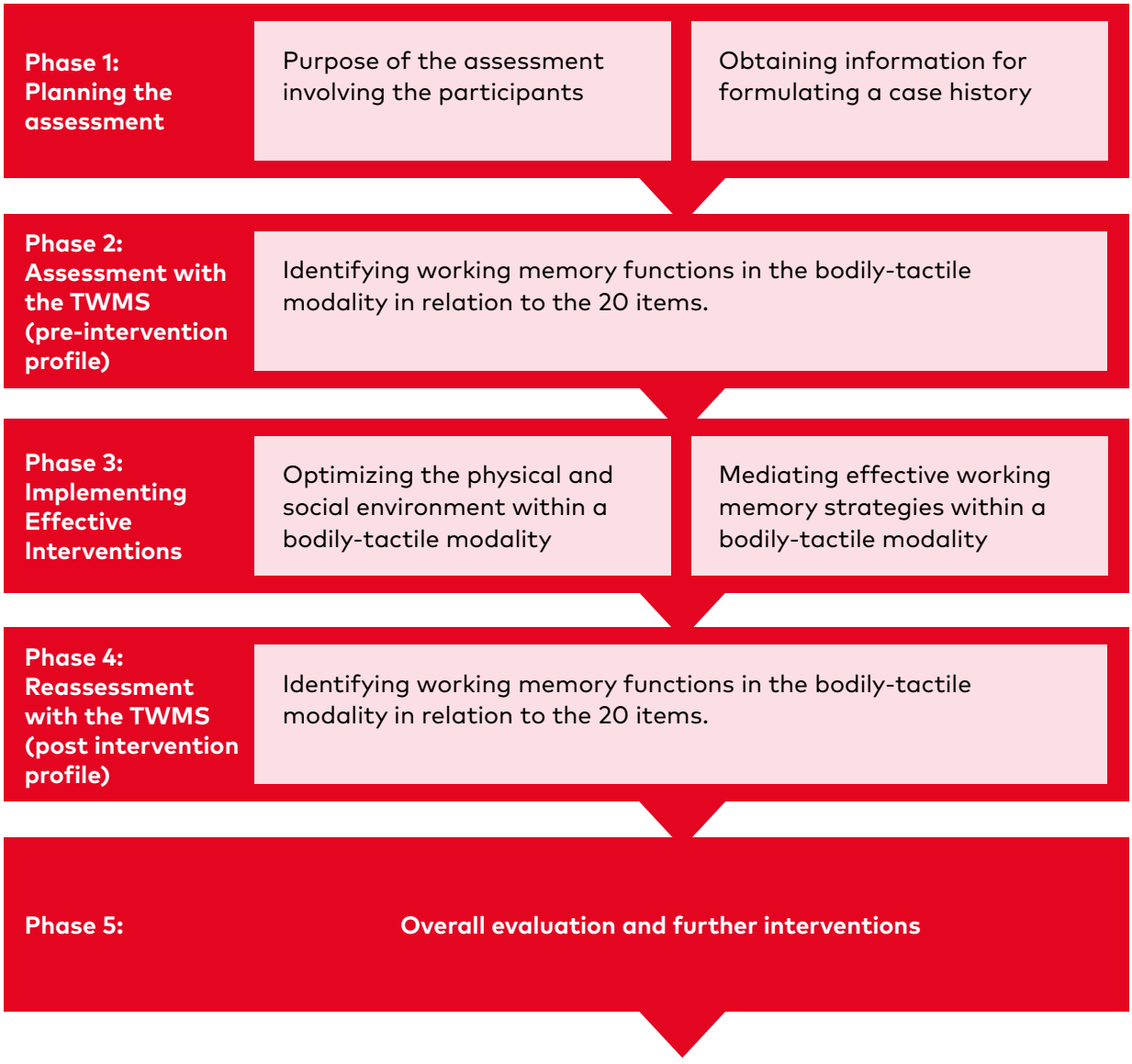
The form of the TWMS contains 20 items within 3 theoretically derived domains that measure the different processes of tactile working memory: initial interpreting /perceiving (ENCODE), temporarily maintaining (MAINTAIN), and actively manipulating (MANIPULATE) bodily-tactile information in the everyday environment and during interaction in an efficient way (see figure 2 for an overview of the 20 items).

8.5 Analysis of the TWMS assessment exemplified through a practice example

The following model shows a framework to use in planning and evaluating the TWMS assessment. The model describes five distinct phases. The design of the overall evaluation will be based on a pre- and post- intervention comparison in a dynamic assessment format (see figure 1).

Phase 1 – Planning the assessment: Case and purpose of assessment
Sue is a ten-year-old girl. She was premature at birth and had a very low birth weight. A magnetic resonance imaging (MRI) scan of the brain showed a cerebral hemorrhage, but a shunt treatment was not needed. The brain scans also showed some focal atrophy in the cerebellum. The consequences of the cerebral hemorrhage and the cerebellar dysfunction were bilateral neurogenic hearing loss, vision impairment and motor impairments.

When she was one year old, she received a unilateral cochlear implant and there were indications of some residual hearing. Although her optic nerves were intact with positive results on flash Visual Evoked Potentials (VEP), her functional vision was impaired. Her motor impairments made it difficult for her to move around on her own. However, she was able to use her arms and legs actively in exploring her surroundings. During communication, she used some tactile signs, gestures, bodily movements, emotions and vocalizations to express herself.



Several educational reports described her communicative and learning abilities as extremely limited. An objective assessment was not performed due to her complex sensory impairment. However, her parents and some of her teachers reported that Sue was showing elements of communicative and learning potentials within the bodily-tactile modality. The parents were concerned that Sue would not receive the appropriate interventions needed to stimulate or support her cognitive and communicative potentials. They requested an assessment that would capture Sue's cognitive and communicative abilities in the bodily-tactile modality.

Figure 1. Framework model for planning and evaluating the TWMS assessment (Nicholas, Johannessen & van Nunen, 2019).

The primary purpose of this assessment using the Tactile Working Memory Scale (TWMS) was to obtain a comprehensive picture of Sue's functional ability and to identify her cognitive and social cognitive potentials in bodily-tactile modality. The assessment was conducted on transactional, dynamic and ecological principles.

A dynamic assessment requires a pre-intervention assessment, an intensive intervention period and a post-intervention assessment. Accordingly, an initial meeting was held with all the involved participants (parents and teachers) to discuss different focus areas such as the purpose of the assessment, the assessment tool, the intervention procedure and the evaluation of the assessment. The time frame for the entire assessment period was also presented during this meeting. Six intervention meetings were planned with parents and teachers. These meetings would focus on video analysis of social interactions and specific tasks related to obtaining a pre-intervention profile (baseline) based on the 20 items (see table 1).

Phase 2 – Pre-intervention phase
Past medical history and earlier assessment reports were obtained. Interviews with parents and teachers were also conducted. A case history was made based on this information. Topics concerning the bodily-tactile modality were

"A dynamic assessment requires a pre-intervention assessment, an intensive intervention period and a post-intervention assessment."

emphasised in the interviews, for example in how they recognised her bodily-tactile expressions, attention directedness within the bodily-tactile modality, how she used her bodily-tactile modality when exploring surroundings, their experience of how to interact within the bodily-tactile modality, among others. The case history was used as a framework for implementation of the assessment strategy and was useful in preparation of the first observation.

During the first observation, interactions between Sue and her partners were filmed during different activities at school. There was also a session with the assessor interacting with Sue. This was necessary for the assessor to get an idea of how Sue used bodily-tactile modality during interaction. Interacting

with Sue in the bodily-tactile modality gave us important information about how to plan the intervention, for instance how to use talking/listening positions, how to recognise and confirm her bodily-tactile expressions, and how to capture her attention in a bodily-tactile manner. After the observation, the videos were analysed according to the items of the TWMS, to form the pre-intervention profile.

The pre-intervention profile of the TWMS (see table 1, blue line) was presented to the participants at the second meeting. During this meeting, two major intervention strategies were discussed: (1) how to be an interaction partner in a bodily-tactile manner, and (2) how to mediate effective cognitive strategies in the bodily-tactile modality.

Phase 3 – Implementing effective interventions
Based on the pre-intervention profile there were several areas that needed focus during the intervention period. Some of the items of the scale were scored as 1 (absent) because it was not possible to observe behaviours related to the items during the first observation. This may have been a consequence of the social environment not being optimized for Sue to show her working memory potentials within the bodily-tactile modality. Hence, to optimize the social environment and for interactions in the bodily-tactile modality, parents and teachers were guided to engage with Sue in a bodily-tactile manner. The main intervention measures were enabling Sue to take both an overhearing role (to hear a conversation without being part of it) and a listening role (selectively concentrating on what is being said), exploring the world together in a bodily-tactile manner, being a narrative partner in the bodily-tactile modality, recognising and acting in response to Sue's bodily-tactile expressions, negotiating meaning in a bodily-tactile manner and supporting cognitive strategies in a bodily-tactile manner.

The intervention began with focus on her tactile perceptual learning strategies. For example parents and staff were advised to adapt a learning environment that provided possibilities for shared tactile exploration and opportunities for supporting tactile perceptual strategies and exploratory procedures. Sue and her partners were advised to explore different materials/things in the surroundings and to feel the similarities and differences between objects. Together they explored different materials/things/objects in a bodily-tactile manner, emphasising changes in structure and other features. This gave Sue the possibility to recognise reference points in the object using touch and movement. After exploring, they talked (using gestures, narratives, emotions, body positions, signs, etc.) about the different structures and features and how they had explored them together in a bodily-tactile manner. They also tried to share their experiences with another person (who did not take part in the exploration event) through multiparty conversations. There are several approaches to achieving a bodily-tactile multi-party conversational practice in which one joins

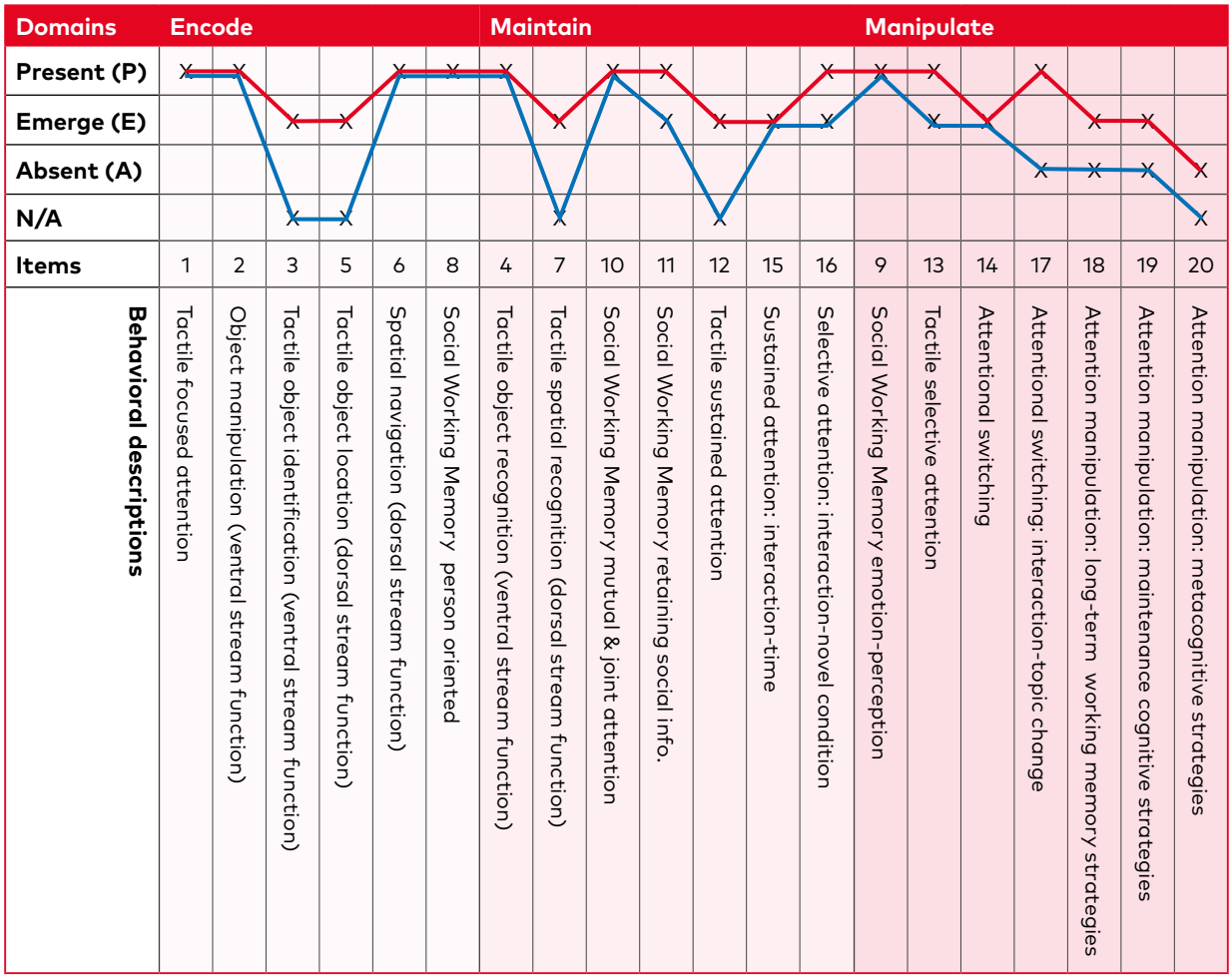
a conversation with at least two others: (1) a bodily-tactile contact between three or more partners in which the communication code is mainly movements and gestures; (2) switching of hand positions from a listening role to a talking role (using hand over hand tactile conversational turntaking methods) during the conversation.

Multi-party conversational practices that require the interaction partner to engage in conversations that involve equal participation in the bodily-tactile modality are necessary not only for developing communication but also for managing demands to social cognition and improving social working memory skills. These are referred to broadly as social cognitive strategies. When implementing social cognitive strategies to enhance the quality of social working memory in a person with CDB, it is necessary for the interaction partner to be sensitive to the persons attention focus, foster a sense of togetherness, support the social forms of attention, provide scaffolding, stimulate reciprocity/turn-taking and establish conversational practices in the bodily-tactile modality.

The interaction partners learned quickly how to interact with Sue in a bodily-tactile manner and they were also able to mediate different cognitive strategies (e.g. long-term working memory strategies, maintenance cognitive strategies and metacognitive strategies) during the interaction or ongoing activity. For a more detailed description of how these cognitive strategies are implemented in practice, see Nicholas, Johannessen, & van Nunen (2019).

The TWMS assessment gave a clear indication of how Sue maintained her attention within the bodily-tactile modality. For example, how she used her touch and movements in a purposeful manner to explore the similarities and differences in objects, how she managed to maintain social working memory while she explored different objects and shared them with her partner in a bodily-tactile manner and how she shifted attention between exploring an object and recognising her partner's emotions through touch and movement. Furthermore, when her teachers mediated different cognitive strategies through the bodily-tactile modality, she was able to sustain her attention for a continous period of time and she took more initiatives to explore objects in the environment. She was now taking the initiative to engage in conversations in the bodily-tactile modality.

After the first intervention period, the participants could recognise more of Sue's tactile working memory potentials in the bodily-tactile modality, especially when the situation was optimized. The next steps during the intervention period were to stabilize the interaction pattern between Sue and her partners and to transfer her working memory skills to other situations or activities of increased levels of complexity.



Domains	Encode						Maintain							Manipulate						
Present (P)	X	X			X	X	X		X	X			X	X	X		X			
Emerge (E)			X	X				X			X	X				X		X	X	
Absent (A)																	X	X	X	X
N/A			X	X				X			X									X
Items	1	2	3	5	6	8	4	7	10	11	12	15	16	9	13	14	17	18	19	20
Behavioral descriptions	Tactile focused attention	Object manipulation (ventral stream function)	Tactile object identification (ventral stream function)	Tactile object location (dorsal stream function)	Spatial navigation (dorsal stream function)	Social Working Memory person oriented	Tactile object recognition (ventral stream function)	Tactile spatial recognition (dorsal stream function)	Social Working Memory mutual & joint attention	Social Working Memory retaining social info.	Tactile sustained attention	Sustained attention: interaction-time	Selective attention: interaction-novel condition	Social Working Memory emotion-perception	Tactile selective attention	Attentional switching	Attentional switching: interaction-topic change	Attention manipulation: long-term working memory strategies	Attention manipulation: maintenance cognitive strategies	Attention manipulation: metacognitive strategies

Table 1. Pre-intervention (blue), Post-intervention (red) profile

Phase 4 – Reassessment with the TWMS: post-intervention profile

A reassessment was performed after approximately one year. Different optimized daily activities in which Sue interacted in a bodily-tactile manner with her partners and her surroundings were filmed. The videos were analysed and scored according to the items of the TWMS. A post-intervention profile based on the 20 items was obtained (see table 1, red line).

When comparing the pre-intervention profile with the post-intervention profile, we could see a significant change, suggesting that the recommended interventions had a positive impact on Sue's working memory functions in the bodily-tactile modality.

Phase 5 – Overall evaluation and further intervention
By optimizing the social environment and supporting the use of effective learning strategies (perceptual, cognitive, social cognitive) Sue was able to enhance her working memory functions in the bodily-tactile modality. This assessment was able to identify Sue's cognitive/social cognitive potentials (working memory in the bodily-tactile modality) and learning potentials (her ability to respond to bodily-tactile interventions). There was likelihood that Sue could develop her potentials further and there was a need for further interventions in the bodily-tactile modality. Supervision of the staff and parents was highly recommended. In addition, staff and parents needed to learn more about the different cognitive strategies in the bodily-tactile modality and how to mediate these strategies in an effective and smooth manner.

8.6 Conclusion

The TWMS is an itemized rating scale for assessing cognitive and social working memory in the bodily-tactile modality identified in patterns of observable behaviour in everyday occurrences and during social interactions. This chapter has briefly described the TWMS as a tool to facilitate identification and promote effective interventions for working memory in the bodily-tactile modality, especially for persons with CDB. By explicitly seeking their participation in the TWMS assessment process, we hope to build a bridge of communication through mutual understanding of their everyday experiences. Such a collaborative partnership in the assessment process provides a starting point for a more comprehensive evaluation of cognitive potentials, as well as a more successful intervention in the world of people with CDB.

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Chapter 9

Psychological assessment of individuals with deafblindness

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9. 1 The "Who", "Why", "How" and "What" in psychological assessment

The authors of this chapter are clinical psychologists in the professional field of deafblindness in Sweden, Norway, Finland and Denmark. We regard psychological assessment as an important tool for promoting learning, health and development. At the same time, we all understand the shortcomings when it comes to implementing a medical perspective in the specialized services for people with congenital deafblindness (hereafter CDB) in our everyday practice. The person in question, the parents and professionals in the health and social care and educational systems raise many questions and concerns about how psychological assessment and other medical disciplines can help to increase knowledge. Our original working document tries to address such issues by presenting four different sections with the headings "Who", "Why", "How" and "What"[8]. Thus, we aim to guide the reader through the procedures of doing cognitive assessment from a health perspective. This chapter is an excerpt from a fuller article on psychological assessment of individuals with CDB, which you will find in its entirety on the website of Nordic Welfare Centre. The full article is published as a report, with the title Psychological assessment of individuals with deafblindness.
nordicwelfare.org/publikationer/psychological-assessment/

In the following pages, you will find the first part of the "What"- section from the fuller article, which refers to the type of information psychological assessment of cognitive domains can present. As in the more detailed article, small vignettes illustrate accommodations of test procedures and other individual adjustments. At the end of this chapter some excerpts from our original discussion are included.

8 "Who" refers to the person with CDB undergoing the assessment as well as the clinician doing the assessment. "Why" refers to the purposes of doing cognitive assessment, for example, supporting development. "How" refers to the assessment procedures of information gathering. "What" refers to the information cognitive assessment can provide.

9.2 What? – The types of information psychological assessment can provide

Psychological assessment is a process that uses a combination of methods to evaluate an individual's behaviour, personality, capacities and challenges. The results are often depicted in a cognitive profile, which provides information about what kind of interventions can scaffold the individual's development. In this section, a description of the most central cognitive domains is given. To add clarity, we have also included anonymised vignettes as illustrations.

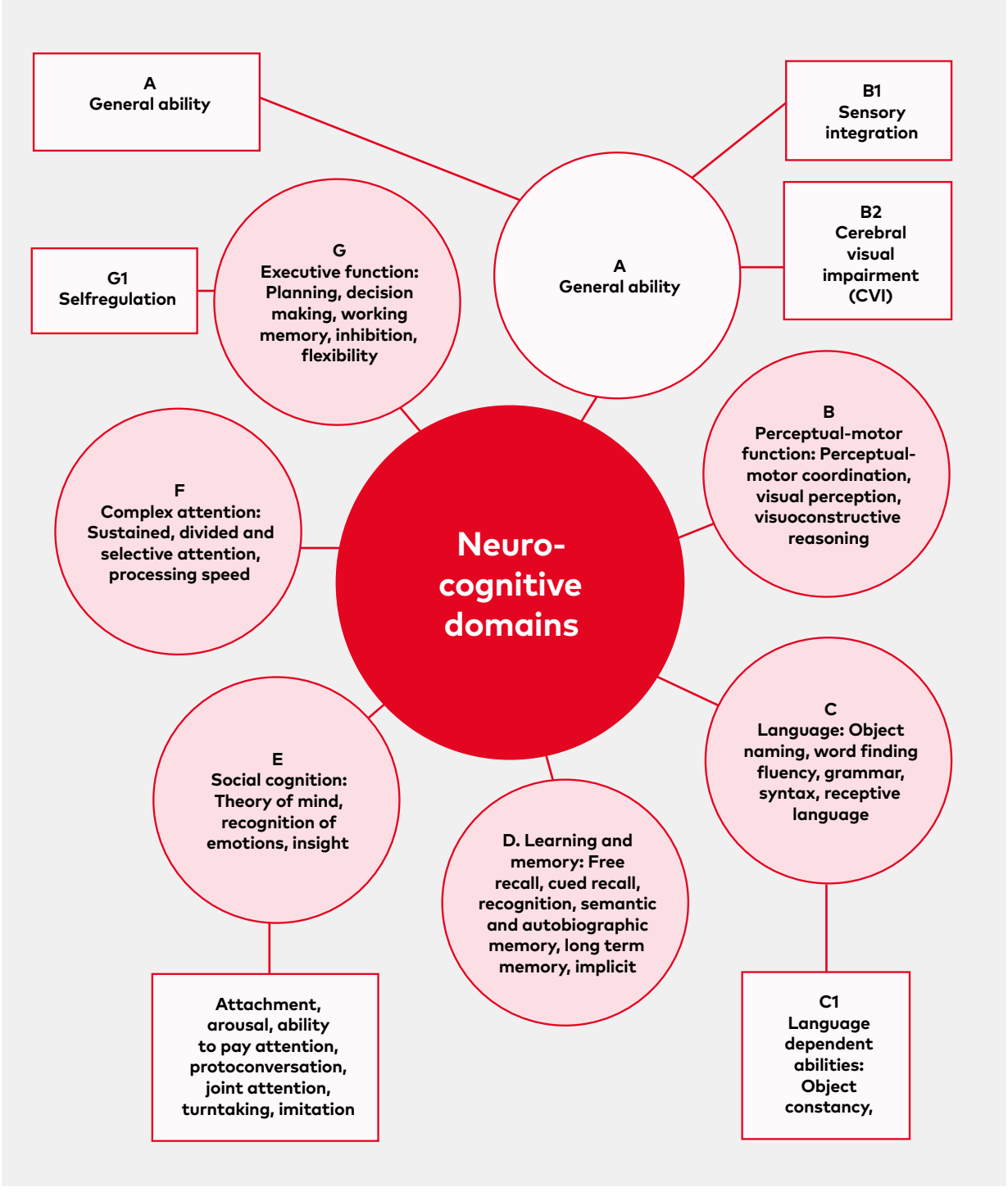
In psychological assessment, what we get is co-dependent on how we get it. In this respect, this chapter and the fuller article supplement each other.

9.2.1 Central neurocognitive domains in assessment

We have used Sachdev's model (2014) as a starting point to illustrate some of the domains that are included in psychological assessment, for example, perceptual-motor function, language, learning and memory, social cognition, complex attention, and executive function. All psycho-motoric tests, scales and batteries primarily based on these domains, provide domain specific information as well as insights into general ability. We have adapted the original Sachdev model to include other domains and subdomains that we find important in psychological assessment of individuals with multiple disabilities. These include general ability with the subdomain adaptive function, the subdomains sensory integration and cerebral visual impairment, and the subdomain language dependent abilities (see figure 1). the different domains and subdomains are numbered for clarity.

The Sachdev model can be useful by directing the assessment focus so that one can obtain insights into the individual's levels of function across specific domains; a set of domains transferrable to a functional profile; and general ability. Getting information on an individual's functional profile makes it easier for the network to support the individual's development socially, communicatively and emotionally.

Figure 1. Model of neurocognitive domains; modified after Sachdevs model (2014).



A. General ability

The functional domains are very much intertwined as no part of the brain works alone. When assessing children and adolescents with multiple disabilities, our focus of interest is mainly on the individual's baseline, which serve as a reference for the evaluation of progress after implementing specific interventions. Another focus of interest is how the individual achieves his or her results, such as the strategies used, and how the individual profited from scaffolding, for example. By analysing elements behind the performance or achievement one obtains access to valuable information that can make future interventions more successful. In this respect, a measure of the individual's general ability, often referred to as IQ, is less interesting.

However, psychologists often receive referrals from health care professionals, and with respect to legal aspects of health. These can be cases in which there are questions about an individual's general intellectual resources if he or she fulfils the diagnostic criteria of an intellectual disability (ID, DSM-5; ICD-11), and if so, to what degree. Even though we can experience reluctance in some parents to an ID diagnosis, this often passes when they observe positive developmental changes due to better adjustment between demands and ability, as well as ensuring access to different support in the future. In addition, one of the most common questions from schools when a pupil's educational progression is slow or atypical concerns her or his intellectual capacity.

With reference to individuals with CDB, special care must be taken to validate the assessment findings. In addition to including parents and professionals who know the individual well, cooperation with another psychologist in the assessment process may be necessary in relation to preparation, implementation and evaluation. When consent is given, video recordings of the assessment are used. The results and performance can then be analysed and discussed with others, such as professionals and parents, to increase the validity of the assessment. Video recordings will also provide opportunities to evaluate the individual's degree of engagement and compliance and reveal the failures of test administrators.

A1. Adaptive function

An individual's level of adaptive functioning provides valuable information to the support network on accommodations needed in the present, but also serves to guide intervention to specific functional areas. It can also serve as a reference when measuring progress following targeted interventions. According to the diagnostic manuals DSM-5 and ICD-11, adaptive function must always be evaluated before diagnosis of intellectual disability. The Vineland Interview and ABAS self-report (appendix C) are widely used and recognised tools for analysing adaptive behaviour. The authors define adaptive behaviour as the performance in daily activities necessary to maintain personal and social well-being. There are four essential principles attached to this definition of adaptive behaviour: (1) adaptive behaviour is age-related, (2) adaptive behaviour

is defined by other people's expectations and norms, (3) adaptive behaviour is changeable, and (4) adaptive behaviour is about a person's typical behaviour.

Vignette 1: Beth is a 19-year-old young woman with deafblindness

Beth was referred for psychological examination because she wanted to move out of her parents' home to live in her own flat. Her mother and father were cousins. Only the mother participated in the interview, as the father did not speak the native language. The father's communication with his daughter was limited as they did not speak the same language.

ANALYSIS

The profile was evenly indexed with an index score two standard deviations below average. At the subdomain level, strengths were identified in relation to adaptability and ADL skills at home, which were assessed as average. Other subdomains had low scores. Overall, Beth's general adaptive skills were significantly limited, but matched her intellectual level. She was tested with Wechsler Nonverbal Scale of Ability. The findings showed that she needed extensive support to gain more independence. A residential placement was assessed as more appropriate than independent living.

B. Perceptual, motor, and sensory function

Fine motor functions and social competence are generally used as indicators for the child's developmental level (Fenichel, 2009). The matrix found in appendix A is adapted from the chart displayed on Kid's Sense Child Development (2018). It is designed to serve as a functional screening of fine and gross motor milestones in reference to typical developed children. However, it is also useful as a reference to evaluate delays and specific ability peaks, as is often the case in CDB.

Assessment of nonverbal abilities are not as straightforward as many might believe. Besides sensory loss, the influence of various requirements such as speed, eye-hand coordination, motor control, attention and executive function must all be considered. Motor and sensory-perceptual data are extremely useful in the assessment procedure. Along with an updated functional assessment of vision and hearing, careful observation by both a physiotherapist and an occupational therapist (Sensory Profile) is recommended prior to psychological assessment.

Poor performance in some aspect of a person's motor and/or sensory assessment can highlight a persisting impairment that may be functionally intrusive but subtle enough to remain undetected to the casual observer. An example can be apraxia, which refers to an inability to perform learned skilled movements that is not explained by weakness, lack of coordination, sensory loss or inability to understand instructions. Praxis assessment involves trying to get the child to mimic actions such as brushing their teeth or using scissors and performing familiar gestures such as waving goodbye and giving a high five. The Vineland and other tests of Adaptive function and the 5-15 include items that tap into these abilities.

Handedness is an important component of cerebral lateralization in humans and is generally firmly established by age 9. Anomalous early or late hand preference suggests neuro-motoric dysfunction. Prolonged ambidexterity, that is, no sign of hand preference by age 3, is another marker of a possible neurodevelopmental problem. To examine this, it is valuable to ask the child to perform a series of actions and to observe directly and quantify hand use and praxis (Baron, 2018).

Visuo-perceptual, visuo-spatial and visuo-constructional functions comprise the ability to evaluate visual details and understand visual-spatial relationships in order to construct geometric designs from a model. This skill requires visual-spatial reasoning, integration and synthesis of part-whole relationships, attentiveness to visual detail, and visual-motor integration. Visual-spatial ability involves skills such as finding your way around, understanding things by looking at them and picturing how details fit together to create a bigger picture. Face recognition gradually develops from the infant's innate attraction to the human face, which kick-starts social development (Meltzoff, 2005).

These skills are important to academic success because they may help the child understand how individual parts are related to complex wholes. They may also assist in the acquisition of early reading skills. Equally important, these skills are also relevant in the social domain, where the ability to form an overview of a situation, "the gist", is more helpful than attention to certain details. People with visuo-spatial problems often experience anxiety in being unable to have a quick overview of a situation. Instead, they experience the world as a fragmented place, and this can be stressful with or without sensory loss.

The ability of visual-perceptual reasoning ability allows the underlying conceptual relationship among visual objects to be detected, and reasoning can be used to identify and apply rules. Identification and application of conceptual relationships requires inductive and quantitative reasoning, broad visual intelligence, simultaneous processing, and abstract thinking. Individuals who have relative difficulty with fluid reasoning tasks may have difficulty solving problems, applying logical reasoning and understanding complicated concepts.

Vignette 2: Charles is an 11-year-old boy with a rare genetic condition in the SOX6 gene

Charles was a student in an ordinary school, where the teachers found him lazy. For example, he was often late for class because he could not find his way and failed to start working on his worksheets in class.

After assessment, Charles showed a distinct developmental profile on the WISC-IV with an above-average score for verbal ability: Verbal Index of 130, and subnormal perceptual reasoning: Nonverbal Index of 65 (average index score is from 85 to 115). A comprehensive neuropsychological examination showed that he had apraxia, nystagmus and cerebral visual impairment (hereafter CVI) as well as a minor hearing-loss.

ANALYSIS

Charles' extraordinarily good verbal skills had masked his disabilities. For example, the CVI was not considered as needing special intervention in school. He was an only child with exceptionally capable parents who provided good conditions for his upbringing, and this had masked the degree of difficulties further.

B1. Sensory integration

Sensory integration is a subset of sensory processing and involves our ability to flexibly use the sensory apparatus to learn and understand the environment. Thus, it is a prerequisite for learning and development. Sensory integration occurs when the brain tries to synthesize and process information gained from various sensory systems in the body, and to respond intentionally.

Individuals with impaired sensory integration may face challenges in perceiving, processing, and responding as expected combinations of sensory impressions related to vision, hearing, smell, taste, tactile, proprioception, vestibular, and chronoception. For example, maintaining a conversation at the same time as going down the stairs will be very problematic for an individual with deaf-blindness. Because the individual must compensate for the visual and auditory challenges of grasping the handrails, feeling his or her feet, looking for visual markers and concentrating on hearing, these ongoing cognitive processes will already occupy large parts of the mental capacity. Thus, the person will not be able to perceive or respond to elements of the conversation and, if sufficiently overloaded, may become passive, search for help, or have a mental meltdown.

Difficulty ignoring sensory impressions is another challenge that can occur with impaired sensory integration. Certain types of stimuli can then be experienced as overwhelming because the person is unable to ignore or tune out the impression. Due to the intensity, just one stimulus can steal all mental capacity, which then results in reduced mental availability for other information, although this is initially more important.

Vignette 3: Christian is a 14-year-old boy with deafblindness and gross motor impairments

His type and degree of sensory disturbance makes sensory integration difficult, which can manifest as a problem with attention, and those around him have problems contacting him even though the auditory conditions are adequate. The teacher has complained to Christian's parents that their son is being disrespectful by ignoring her.

ANALYSIS

In situations in which Christian's focus is directed toward something else in the environment that interests him (for example his Ipad) or inner impressions (for example pain), he can have difficulties perceiving additional stimuli (such as the teacher's voice). To get Christian's attention, it can be helpful to establish the same focus and try to share his experience. Another strategy is using the tactile modality (for example touching Christian on the arm) since tactile information has perceptual precedence in most of us.

B2. A special note on CVI

CVI is an umbrella term for many visual impairments that each have many ranges.

Vision is complex and is not limited to one segment of the brain, the visual cortex.

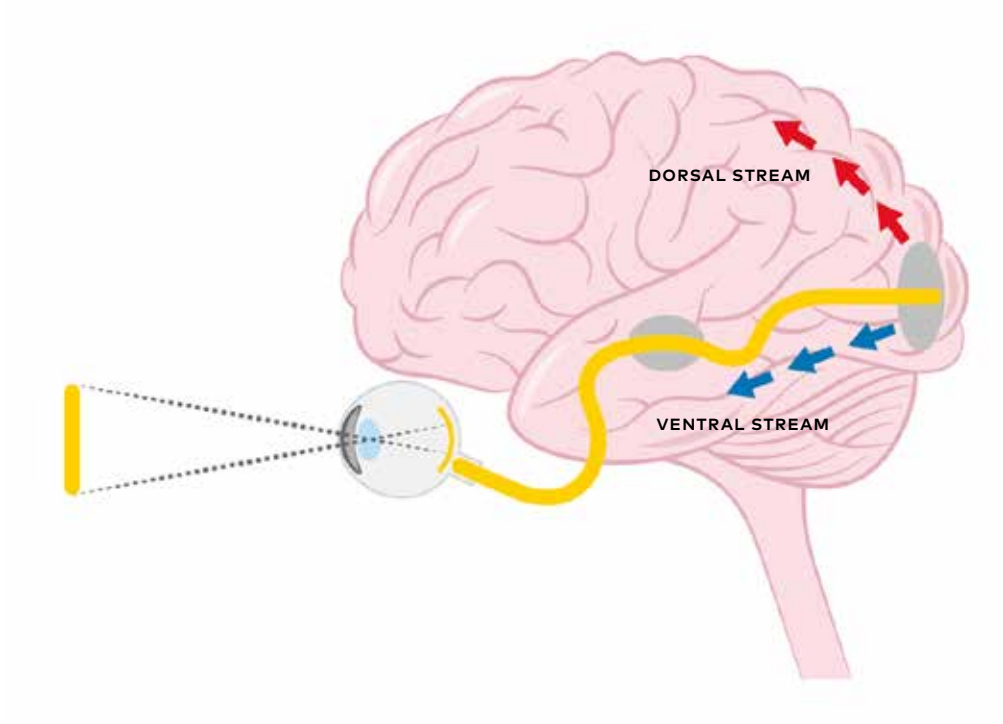


Figure 2. Effects of CVI on dorsal stream and ventral stream functions in the brain.

There are pathways from the visual cortex to other areas of the brain, and some pathways go to other areas of the brain before they even reach the visual cortex. Because of these intricate neural networks, if there is neurodevelopmental or brain damage, there may still be vision.

Researchers are now identifying complex neural systems and their effects. Zihl and Dutton (2015) described the effects of CVI in terms of dorsal stream (the "where" system) and ventral stream (the "what" system) functions (Se Figure 2).

Ongoing research has also examined the mirror neuron system, which has been shown to be involved in the observation and imitation of goal-directed action.

"There are pathways from the visual cortex to other areas of the brain, and some pathways go to other areas of the brain before they even reach the visual cortex."

Vignette 4: Victoria is a 38-year-old woman with early blindness, a moderate hearing loss and intellectual disability due to extreme prematurity

Victoria was referred for a neuropsychological examination. The staff thought she was "trying to get attention" by not doing her daily tasks although she herself verbally repeated what she had to do. In the test procedure, Victoria understood the instruction but was unable to place the blocks in their respective form-board hole. In other tactile form recognition tests, she was unable to determine whether the objects presented to both hands were different or similar.

ANALYSIS

Among other challenges, Victoria was not only blind but in addition had other neuro-motor perceptual difficulties. She was relatively verbal compared to the other residents. Thus, her difficulties in daily function had been undetected and interpreted as attention seeking.

The observations from visual-tactile testing raised the hypothesis of CVI, and Victoria was referred for further medical investigations. The CVI was confirmed.

There are many unanswered questions about CVI, and there is a need for a multidisciplinary approach along with greater focus on the topic, both in the deafblind field and more generally.

C. Language

Language is one of the most sophisticated expressions of cognition in action, and psychological assessment of the language domain is one of the most interesting but also challenging endeavours we encounter. To promote language development, all kinds of causal features must be detected, understood and addressed. However, in work in the field of deafblindness, there are many new aspects and concepts that must be considered which are not present when evaluating typical language development. In attempting to give an idea of the complexity of this domain, this section will touch on some of these issues. Despite unique contributing factors, we firmly believe that an understanding of the atypical is derived from knowledge of the typical, thus typical language development is always an important stance. You will find a summary of typical language development in appendix B of the full chapter, which is based on the work of Carr et al. (2016).

Social ability, motor function and language are intertwined during all stages of development but are especially significant in infancy. All the aspects and sequences of social cognitions, such as arousal, ability to pay attention, protoconversation, joint attention, imitation and turn-taking are prerequisites for language development. For example, protoconversation and joint attention are prerequisites for all early childhood language development. In addition, language is co-dependent on motor ability. For example, when mobility is compromised, consequences appear in verbal functioning (e.g. Thomas et al., 2017; Mody, 2017).

Regarding individuals with CDB, there are many sensorimotor barriers to be overcome to succeed in all these aspects. Establishing secure attachment to get access to the world is a prerequisite for language acquisition. There are many individuals with CDB who never acquire conventional language, spoken and/or signed languages, despite longitudinal follow-up with targeted interventions. Using Piaget's stages (1976), we can infer that many individuals stay in the sensorimotor stage for a prolonged period, and some will never reach the next level. However, we want to highlight that all individuals, regardless of disability, have a language and are communicative in their authentic way (Rommetveit, 1974). Authentic communication can be difficult to perceive and is easily misunderstood because of its uniqueness. The notion of authenticity refers to a language emerging from within the individual, formed from her or his personal experiences and immediate associations. Thus, authentic communication can be understood as "... human communication 'from within', i.e. in terms of the individual experiences and existential conditions of the 'I' actively engaged in the discourse." (Rommetveit, 1974, p.23). Authentic expressions are based on events that have had a meaning for the individual, i.e. emotional bodily experiences in specific situations. These meaningful events can be relatively different from what others perceive as significant, which can make authentic expressions and their basis inaccessible to others who do not have in-depth knowledge of the individual's personality, personal history and communicative mode.

An individual's authentic and unique communication mode can lead to issues of readability, which refers to how accessible an individual's language and communication is for the communications partner(s) (Nafstad, & Rodbroe, 2013). Individuals with CDB can have additional neurological challenges that compromise their communication to such an extent that low readability is the result. The cognitive assessment procedure must then also incorporate a prolonged getting to know each other phase during which the people involved develop a better understanding of each other's communication. In some cases, they might even develop a common conceptual framework and viewpoint. The professional must ensure a common conceptual understanding using a dialogic communicative approach in which one's own meanings and those of the other and the surrounding world are founded in a relationship. Depending on the degree of readability, i.e. high or low, the timeframe of assessment will vary greatly. However, it is important to emphasise that the cognitive assessment starts when the contact with the person in question is established. The professional approach to ensure a

common conceptual framework, and thereby trust, will serve as a very important part of the cognitive evaluation and should be documented.

As an extension of the concepts of authenticity and readability, languaging is also a relevant topic, one that can be traced back to Vygotsky's work on the critical role language plays in mediating cognitive processes (Vygotsky 1978; 1987). The foundations of this concept are the assumption that language is a way of making personal sense of the world, and the process of becoming conscious of oneself. It is a means of understanding the world as well as creating one's identity. In the simplest sense, languaging stands for an unbridled, natural way of using language beyond the normative constraints of a cultural language. Languaging underscores the dynamic relationship between thought and language, in which language ceases to be perceived as a mere conduit, but rather performs a function or "coming-to-know-while-speaking" (Swain 2006; 2009). We want to refer the interested reader to the website of the Nordic Welfare Centre where you will find publications and links to literature which specifically addresses different aspects and levels of interventions with reference to the language and communication of individuals with CDB.

Vignette 5: Eva is an 8-year-old child with deafblindness, motor difficulties and unclear intellectual disabilities

Victoria was referred for a neuropsychological examination. The staff thought she was "trying to get attention" by not doing her daily tasks although she herself verbally repeated what she had to do. In the test procedure, Victoria understood the instruction but was unable to place the blocks in their respective form-board hole. In other tactile form recognition tests, she was unable to determine whether the objects presented to both hands were different or similar.
Eva can suddenly hit and be rough with those who are near her. This usually happens when she experiences strong positive and negative emotions. The school personnel regarded this behaviour as unpredictable and without any connection to actions in the surroundings. Even though Eva had minimal speech, the school personnel was convinced that she understood all verbal information.

The child was observed in several settings by a psychologist, which put forth a hypothesis about Eva's verbal abilities, i.e. that her impressive verbal function was also subnormal. Eva was then tested with C-BiLLT, a computer-based test for impressive abilities. This confirmed the hypothesis showing impressive function 3 standard deviation below average.

The school personnel were given instructions to strengthen and support Eva's expressive and impressive abilities by incorporating augmented alternative communication, such as signs and symbols. After six months, school personnel could report that Eva's negative behavior was diminished.

ANALYSIS

Eva did not have conventional verbal abilities and the psychologist supposed that her negative behaviour was a way she handled and communicated strong emotions. Her verbal impressive difficulties seemed to aggravate these emotional reactions. By supporting Eva's verbal understanding and giving her an expressive mode of communication, her feelings of control and security were increased, making it less necessary for her to act out.

For children with CDB, it is a huge challenge for the environment to offer a stable and individualized linguistic input. Relatively few individuals develop functional speech or sign language, and if they do this is likely to have required longitudinal targeted interventions by dedicated professionals. Vignette number 9 illustrates the benefits of early interventions with extraordinary communicative skills from the wider surroundings.

Vignette 6: Case study from Tactile Communication (2018, p. 158)[9]

Santeri was offered a language system very early, tactile sign language and haptic exploration of the outside world. His deafblindness was never seen as an obstacle for him to learn a language. Concepts were built up and explained by haptic exploration to find common meanings for objects and elements. Santeri made his first sign before he was one year old and at the age of two, he could sign more than 200 characters. His ability to learn concepts and causal relationships between different elements was good. Thus, Santeri developed tactile sign language and written language with Braille.

ANALYSIS

The support network believed from the very beginning that Santeri had cognitive potential and abilities that it was difficult for him to show. Based on this belief, significant others tried to give Santeri expressive opportunities. His CDB was not accepted as an obstacle for linguistic, intellectual or social development.

The matching of cultural language between the test person and the administrator is a prerequisite for establishing a relationship based on trust and equality. Vignette number 7 gives an illustration of the importance of matched communication.

Vignette 7: Maria is a ten-year-old girl with severely affected vision and hearing

Maria's parents wished to switch from tactile sign language to "normal" voice communication. They wanted to implement a new behavioural program for children with brain injuries. In this program, the teacher had to use voice and gestures. Maria had difficulties benefiting from the teacher's instructions. She used her authentic language, touch and smell, in problem solving.

ANALYSIS

Maria's authentic language is built on using her tactile and olfactory senses. There is thus a mismatch between Maria's understanding of the world and that of the teacher. Further, Maria's linguistic capacity and the teacher's instructions are not matched, resulting in parallel communication. The teacher needs to bridge the communicative gap between them. To do so she must gain access to Maria's authentic modes of expressions and use these as a foundation.

9.3 Further excerpts from the discussion in the fuller article

CDB is a multifaceted condition with both environmental as well as genetic causes, which make a holistic multidisciplinary perspective necessary. Psychological assessment is a process of testing that uses a combination of techniques to develop hypotheses about a person and their behaviour, personality, capacities and challenges. With reference to individuals with CDB, a recurrent argument is that they are untestable. This is contrary to our experience and a worrying attitude, which ultimately can promote discrimination and exclusion.

9 We recommend the book Tactile Communication (2018), it describes tactile language development from multiple perspectives. It contains a description by Emmi Tuomi and Rita Lahtinen of Santeri, a 16-year-old boy with deafblindness.

"To improve developmental conditions for the child, it is paramount to support families in such a way that they feel secure as caregivers, economically, practically, emotionally and psychologically."

In line with human rights, increased independent living and social engagement are major goals to examine when doing assessment. Many individuals with CDB need support with communication, access to information, and mobility (for example, Bodsworth, et al., 2011). This dependency on others increases the risk that others act as gatekeepers, even with best intentions, thus reducing the control people with CDB have over their own lives. Persons with severe or profound developmental and communication challenges can easily be marginalized in any discussion about agency, since they do not express their opinions using traditional formal language or perhaps have no independent voice, at all, relying instead on another person to co-create agency with them (Komulainen, 2007; Mietola et al., 2017).

In the case of people with CDB and co-existing conditions, ESSENCE makes perfect sense (Gilberg, 2018). In short, ESSENCE, Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examination, regards clusters of challenges as co-existing conditions usually overlap each other or exist in parallel. Thus, they rarely exist in isolation. This concept emphasises the need for early identification of different difficulties, so that the child can receive proper support and intervention as early as possible.

Inspired by Gilberg's concept, we believe that an integrated coordinated health service with a holistic and multidisciplinary medical approach that addresses all aspects of a child's development is necessary. To improve developmental conditions for the child, it is paramount to support families in such a way that they feel secure as caregivers, economically, practically, emotionally and psychologically.

You are welcome to read more on these subjects in our report Psychological assessment of individuals with deafblindness, available at the Nordic Welfare Centre's website.

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Dr. Saskia Damen works as an assistant professor at the Department of Inclusive and Special Needs Education at the University of Groningen in the Netherlands. She is also the curriculum coordinator of the International Master in Deafblindness at the university. She also works as a senior researcher at Royal Dutch Kentalis. Saskia is an advisor for the Dutch National Resource Center on Deafblindness and associate editor of the Journal of Deafblind Studies in Communication. In 2015 she finished her doctoral study on the effects of training for parents, caregivers and teachers on the quality of communication of children and adults with congenital deafblindness. She has over 20 years of work experience in the field of sensory disabilities and deafblindness and has published several articles and books. Her current research focuses on both congenital and early acquired deafblindness.

Vuokko Einarsson, Resource center deafblind within the National Agency for special Needs Eduction and Schools, Sweden

Vuokko Einarsson is a clinical Psychologist and Psychotherapist working at Resource centre deafblind within the National Agency for special Needs Education and Schools, in Sweden. During her career she has worked with psychological assessment and treatment with children, adolescents and families.

Eline Falch Melhuus, Statped, Norway

Eline Falch Melhuus works as a teacher at Statped, Skådalen School for children who are congenitally deafblind. She has nine years of experience from the field, and is a special needs educator with further education in autism spectre disorders and in atypical communication.

Joe Gibson, Statped, Norway

Joe Gibson currently works as a teacher at Statped, Skådalen school for children who are congenitally deafblind. He is responsible for outdoor and physical activities at the school, and previously worked for Sense Scotland as the Outdoor Activities coordinator. He has a PhD focused on the experiences of two adults with congenital deafblindness participating in outdoor activities.

Torill Gullvik, Statped, Norway

Torill Gullvik has been a teacher at Statped, Skådalen school for children who are congenitally deafblind for over 15 years. Her interest and experience in the field began in 1982 with the birth of her son Thomas who was born with deafblindness. She now combines both a professional and personal interest in the field. She is a special needs educator and has further education in AAC and atypical communication.

Paul Hart, Sense Scotland

Paul Hart has worked in the field of deafblindness for more than 30 years. He holds the post of Head of Research and Practice at Sense Scotland, an organisation that works alongside people with a wide variety of communication support needs. He has been a member of various Deafblind International Networks and currently also lectures on Communication and Deafblindness at the University of Groningen. In 2010 he completed his PhD at Dundee University, entitled. Moving Beyond the Common Touchpoint – discovering language with congenitally deafblind people.

Elena Hauge, University Hospital of North Norway, Regional Center for Deafblind people

Elena Hauge is a specialist in clinical psychology at the University Hospital of North Norway, Regional Center for Deafblind people. She has a broad clinical experience in working with and providing care to people with both congenital and acquired conditions. She has demonstrated a special interest and her work was mainly focused on interdisciplinary approach in the habilitation process.

Annika Maria Johannessen, Statped Norway

Annika Maria Johannessen has a Master of Science in Communication and Congenital Deafblindness. She works as a Senior Adviser at National unit for combined visual and hearing loss and deafblindness, Statped, Bergen, Norway, with about 20 years of clinical experience within the field of special education, and about twelve of those with people with congenital deafblindness. She has been a member of expert network Cognition in relation to congenital deafblindness coordinated by the Nordic Welfare Centre, since it's start in 2008.

Olai Johnsgård, Statped, Norway

Olai Johnsgård is a teacher at Statped, Skådalen school for children who are congenitally deafblind. He is responsible for physical and group activities at the school. Complementing his teacher education, he has a lifelong experience of deafblindness having an older brother who is deafblind.

Odd Erik Madsen, Statped, Norway

Odd-Erik Madsen is an adviser at Statpeds nationwide professional Unit for Dual Visual and Hearing Loss and Deafblindness. He previously worked at Statped, Skådalen school for children who are congenitally deafblind.

Tanja Møller Chistiansen, Centre for Communication and Sensory loss, Denmark

Tanja Møller Chistiansen is a Pedagogue at Centre for Communication and Sensory loss (former known as Center for Deafblind and Hearing loss) in Aalborg, Denmark. She is working at a group home, with both youth and adults with deafblindness since 2014, and has recently completed the course called National education, for employees working with people with congenital deafblindness. She is currently part of a project about technology designed to help people with congenital deafblindness in all aspects of improving their quality of life - which has been one of her interests since she started working at Centre for Communication and Sensory loss.

Anne Nafstad, Statped, Norway

Anne Nafstad (Master of Science in Psychology) is a licensed Psychologist. She has worked in the field since 1982, most of the time developing and spreading knowledge and competence concerning congenital deafblindness and communication development. She currently holds a position as Psychologist specialized in deafblindness at the National unit for combined visual and hearing loss and deafblindness, Statped, Oslo, Norway.

Jude Nicholas, Statped, Norway

Dr Jude Nicholas is a certified clinical Neuropsychologist and a researcher employed at National unit for combined visual and hearing loss and deafblindness, Statped, Bergen, Norway and at Haukeland University Hospital in Bergen, Norway. Dr. Nicholas has some 25 years of clinical and research experience working with children and adults with different sensory loss. He has a longstanding interest in genetic syndromes and neurological conditions involving sensory impairments and cognitive functions. He is the author of several articles and book chapters on these topics. His current research investigates the neuropsychological functions of tactile cognition, particularly in people with deafblindness. He has been a member of the expert network Cognition in relation to congenital deafblindness, coordinated by the Nordic Welfare Centre, since it started in 2008.

Jonathan Reid, Health and Social Alliance Scotland

Jonathan Reid has worked in the field of deafblindness and complex communication for over 20 years, primarily with Sense Scotland. He holds a Master in Communication with Deafblindness from the University of Groningen in the Netherlands and is also a graduate of the UK-wide diploma in Deafblind Studies, a course which he has taught and assessed during the last ten years. Reid has lectured nationally and internationally on the use of creative approaches towards communication within the field, and currently works for the Health and Social Care Alliance and the Scottish Government, coordinating the national See Hear strategy for people with sensory loss across Scotland.

Lone Rømer Jensen, Centre for Communication and Sensory loss, Denmark

Pedagogue at Centre for Communication and Sensory loss (former known as Center for Deafblind and Hearing loss in Aalborg, Denmark). Lone Römer Jensen is working at a group home, with both youth and adults with deafblindness as a Pedagogue since 2003. In 2017 she completed a Diploma Program in Psychology at University College. Lone has a special interest in applying neuropsychology knowledge and theories into the practice-oriented field of deafblindness. Her daily practice comprise day-to-day pedagogic work in combination with coordination-, facilitation- and communication activities across staff groups.

Lynn Skei, Signo, Norway

Lynn Skei is a clinical neuropsychologist currently working at Signo Resource Centre in Vestfold, Norway. She has devoted almost all her career to children and adolescents with congenital and acquired neurological conditions. Before starting at Signo, she was working as a clinical psychologist within the specialized healthcare services in Norway, such as Ullevål, Sunnaas and Vestfold hospital.

Jacky Smith, Sense Scotland

Jacky Smith works as a Communication Development Practitioner for Sense Scotland's Partners in Communication Project, based in Glasgow and working across Scotland. She has more than 20 years of experience supporting people with congenital deafblindness or complex communication support needs. She has a master in Communication and Congenital Deafblindness from the University of Groningen, in The Netherlands. She has focused on human rights, inclusive communication and supporting choice and control for people who have complex communication support needs.

Camilla Tostrup Lyngar, Statped, Norway

Camilla Tostrup Lyngar has been a teacher at Statped, Skådalen school for children who are congenitally deafblind since 2013. While Tostrup Lyngars educational background is within humanities, everyday life with a deafblind daughter (born in 1991) has inspired a special interest in facilitation of cognitive development and atypical communication.

Gro-Anita Tunes Nummedal, Statped, Norway

Gro-Anita Tunes Nummedal has a Master's in special education and a Master's in communication and deafblindness. She has long experience working in the deafblind field and is a member of the expert network Cognition in relation to congenital deafblindness.

Emmi Tuomi, The Finnish Deafblind Association, Finland

Emmi Tuomi is a Psychologist; Licentiate of Arts (Psychology), Senior Advisor (congenital deafblindness) at The Finnish Deafblind Association and PhD Student, University of Jyväskylä, Finland. She has worked in the field of serious and combined disabilities and congenital deafblindness for ten years. She is a member of Nordic Welfare Centre's expert network Cognition in relation to congenital deafblindness. Emmi is completing her doctoral thesis at Jyväskylä University in cognition and communication with people with multifunctional disabilities and congenital deafblindness.

People with congenital deafblindness often have hidden cognitive potential that those around them fail to detect. This can lead to missing out on communication, or not even having the opportunity to develop a tactile language. A professional assessment of the cognition may reveal latent abilities and with suitable strategies the person with congenital deafblindness can develop their full potential. This book presents varying assessment purposes, procedures and analytic approaches for professionals who are involved in making examinations and assessments of cognition in cases of congenital deafblindness in both children and adults.

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