Guidelines for Assessment of Cognition in Relation to Congenital Deafblindness

Nordic Centre for Welfare and Social Issues

Inspiration booklet

Nordic Centre for
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Guidelines for Assessment of Cognition
in Relation to Congenital Deafblindness

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Introduction

In 2007, the Network on Cognition in Relation to Deafblindness was established. From the beginning, it was a Nordic project. The network is connected to the Nordic Centre for Welfare and Social Issues (NVC), but also has participants from other European countries, such as the Netherlands and Switzerland. All members are professionals within the deafblind-field working practically in different disciplines or with research. Our purpose is – as the name of the group indicates – to develop assessment of cognition in relation to deafblindness.

The subtitle of our project has been "from sensation to dialogue", suggesting that cognition, referring to learning and knowing, should be addressed in a broad sense, involving the fields of physiology, neuroscience, cognitive, and developmental psychology, as well as social psychology, pedagogy, and semiotics.

The point of view has been practical, about sharing experiences and developing competence. Assessment of cognitive abilities in persons with deafblindness is no doubt connected to difficulties. Expressions are not easy to interpret, especially in the group of people with congenital or early deafblindness. Our project is mainly focusing on this group, but deafblindness as such is also addressed, and acquired deafblindness is an important reference for our work.

Psychometric instruments, analytical models and norms are lacking to a high degree. Our project aims to increase the competency among professionals to understand, observe, describe, and assess cognitive abilities in persons with deafblindness. Increased knowledge about deafblind-specific aspects of cognition is a prerequisite: In other words, knowledge about bodily-tactile cognition. We are primarily focusing on cognition in interaction, preferably in optimal settings where potential for development becomes observable.

Cognitive ability is manifested in moments of shared attention. Expressions reveal capacity, but also give us possibilities to estimate schematic ability and comprehension of reality. The developmental profile, a psychosocial cognitive scale, addresses communicative complexity, but could also be used when cognitive potential is focused. Profile cues have been paraphrased into clear questions, to adapt and refine the profile for use for baseline assessments of cognitive abilities in relation to congenital deafblindness. Everyday knowledge about the person in focus, emanating from shared experiences (CDB), is vital. Hence, staff must take part in the evaluation. A dynamic assessment, also including the social network, is the best guarantee for valid and reliable results.

Working memory is a core cognitive function. A scale has been developed to encode tactile information in interaction, plotting a profile and interpreting ability to encode, maintain and manipulate tactile information. Another scale is specifically addressing the ability to execute a plan and, when necessary, adapt it to a new situation that can be observed in daily life.

There are some standardized instruments which are possible to develop and test out. A qualitative use could be recommended when there is residual hearing and vision beyond a critical level, but that requires a competent observer. In other words, someone with knowledge about cognition and cogni-

tive development and, at the same time, experience from working with the group of people with CDB.

The long-term goal of our network is to present developmental scales concerning different cognitive abilities, but a necessary first step is to describe proper ways to describe and analyse cognition in deafblind interaction. These guidelines are written for professionals involved in the assessment of persons with congenital early deafblindness and cover deafblind-specific aspects. The general guidelines include a model of cognition/development and assessment, addressing the issue of why and what to measure. We have included examples from our different sub-projects, which include specific target descriptions, procedural descriptions, and/or stepwise prescriptions. Hopefully, these guidelines will be helpful in every-day assessments of cognition in relation to deafblindness with the focus on potential and possible fulfilment of potential. At the very least, we hope that this booklet will serve as a starting point for discussions and developmental work on the practice and theory of assessment of cognition in relation to CDB.

The Guidelines are structured in three parts. Part I gives an introduction to the theoretical foundation of the work of the network and of the guidelines in the present booklet. Part II is an analysis of textbooks and introductions to assessment in general, that aim at teasing out general guidelines that need specific CDB focus. This part ends up in a set of recommendations for assessment of cognition in relation to CDB. Part III is a series of examples from our own work that present different attempts at applying the presented guidelines and theoretical foundation, in combination with more specific assessment targets and procedures.

Hans Erik Frölander

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PART I: Theoretical Foundation

Congenital Deafblindness, Cognition and Assessment

These guidelines are written for professionals involved in the assessment of persons with deafblindness. The professional background of these professionals can vary a lot, as can the experience they have with assessment in general and, more specifically, with assessment of persons with deafblindness (DB).

Flemming Ask Larsen & Saskia Damen

One example of professionals conducting assessment in relation to deafblindness is psychologists working in settings for people with disabilities. They may have a lot of experience with psychological assessment, but they rarely see people with deafblindness. Another example is a pedagogue highly experienced in the education of people with deafblindness, but without formal training in assessment. Both types of professionals may be asked to give a professional opinion on the cognitive abilities and needs of people with congenital deafblindness, based on information they have gathered. We aim these guidelines at both groups and others with similar professional obligations for cognitive assessment in relation to people with congenital deafblindness.

DEFINITIONS

The group of people with congenital deafblindness is not a homogeneous group. Deafblindness is an internationally accepted term for people with a combination of visual and auditory disabilities. However, how to define and operationalize the term differs across countries and across the literature on deafblindness.

The worldwide organization for people with deafblindness, *DeafBlind International* (DBI), and those who are involved with them, defines the term as follows:

The term deafblindness describes a condition that combines in varying degrees both hearing and visual impairment. Two sensory impairments multiply and intensify the impact of each other creating a severe disability which is different and unique. All deafblind people experience problems with communication, access to information and mobility. However, their specific needs vary enormously according to age, onset and type of deafblindness (www.deafblindinternational.org).

One discrepancy in the literature on deafblindness, regarding definitions of deafblindness, is between those based on the sensory impairments and those based on the level of functioning that results from the combination of sensory impairments and the demands from the environment. The former correspond roughly to the legal definitions of deafness and blindness in the USA, and the latter to the Nordic definition of deafblindness, often labelled *functional* (Rönnberg, Samuelsson, & Borg, 2002; Danermark & Möller, 2008). The American definition takes the medical/functional degree of the two separate sensory impairments as the defining factors, adhering to international standards of diagnoses (e.g. ICD-10). The Nordic definition stresses the total outcome of DB on ability and functioning in relation to communication, access to information, and mobility (Dammeyer, 2012).

Also, there is a discrepancy in the literature regarding the use of the term *functional*. Some authors use the term in its medical sense, which is comparable to the definition of impairment as damage to structure or function of body parts in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). Others use the term in the Nordic sense, in line with the ICF definitions of Functioning and Disability, referring to the outcome of the interplay between body functions and structure on the one hand, and activity limitations and participation restrictions on the other hand. In order to overcome this difference in how the term is used, we may label the former group of definitions as *medical/functional* definitions and the latter group as definitions based on *ability/functioning* (Ask Larsen & Damen, submitted).

How congenital deafblindness (CDB) is distinguished from acquired deafblindness (ADB) is yet another discrepancy in the literature. It is generally understood that CDB is DB with early onset. Some authors define CDB as DB with onset before a certain chronological age, e.g. 'from birth' (Dammeyer, 2009; Möller, 2003; Prain, McVilly & Ramcharan, 2012) or 'before 2 years of age' (Dalby et al., 2009a; Guthrie et al., 2011). Others define CDB as DB with onset relative to communication development and/or before language acquisition (Dammeyer, 2011; Rødbroe & Janssen, 2006). In the latter

case, CDB is sometimes labelled "pre-lingual deafblindness" (Dammeyer, 2011). More fine-grained categories are sometimes used in scientific writing – especially concerning CDB (Cf. Dammeyer, 2012; Hart, 2010:26).

We do not wish to exclude any of these different definitions. The problem of assessing cognition in relation to deafblindness is not, as we see it, dependent on how you define congenital deafblindness. We hope that the present booklet will be equally relevant for professionals adhering to any of the definitions mentioned here.

To sum up the different definitions:

- **Deafblindness (DB)**
  - *Medical/function*
    Based on sensory impairment
    (E.g. legal blindness and deafness in the USA)
  - *Ability/functioning*
    Based on resulting functioning in relation to the dual sensory loss (E.g. functioning of mobility, access to information, and communication. Cf. the Nordic "functional" definition)
- **Congenital deafblindness (CDB)**
  - Chronological definitions
    "from birth", "before year 2", or "before year 3"
  - Developmental definitions
    "pre-linguistically acquired DB", "before fundamental communication abilities", etc.
- **Acquired deafblindness (ADB)**
  - Post-linguistically acquired DB

Cognition

One of the major challenges we face when dealing with cognition in general is that cognition is only accessible via interpretation from behaviour. When we seek to assess cognitive ability of people who express almost no linguistic behaviour, as for instance people with congenital deafblindness, this challenge is even greater. Whether it concerns neurological, neuropsychological, psychological, sociological, educational, or developmental issues, we need to map a theoretical model of cognition onto some observable behaviour in order to get access to cognition.

This leaves us with three very intriguing challenges. Firstly, we need to have a good theory about cognition. Secondly, it is crucial to our results how we understand behaviour. Thirdly, it is important that we 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, 2009).

The Oxford Dictionary defines cognition in the following manner:

> *The mental action or process of acquiring knowledge and understanding through thought, experience, and the senses (Oxford Dictionary, online access 2013).*

Cognition is thus a mental process. According to Piaget, cognition is the active creation and application of mental schemata in order to relate appropriately to the world. He describes this process as an assimilation of the experienced world to already entrenched schemata, and when something new and unexpected happens, you have to accommodate these schemas to the new knowledge. In this way, the mind develops by reconfiguring the schemas in order to obtain a more and more complex understanding of the world (Piaget, 1950, 1954).

In addition to these purely cognitive processes, Gibson suggests that how we understand the world is dependent on two things: (1) The intentions and goals of the individual and (2) the structure of the environment that will *afford* certain patterns of possible interactions in relation to the intentions of the individual. This reciprocal relation between the intentions of the individual and the affordances of the environment is the basis of his ecological approach to cognition (Gibson, 1986).

Another way of addressing this reciprocal relation between the individual and the environment is offered by Sameroff. He includes the biological aspects in his transactional model of development, and states that cognition and behaviour must be analysed in a wider dynamic system including the transactions over time between biological, behavioural as well as the environmental systems (Sameroff, 1975; 2000).

In order to complete the dynamic structure of cognition, we must recognize the notion of Vygotsky which states that cognition is only understandable as part of an individual's interaction with the socio-cultural structures that surround him. According to Vygotsky, the individual internalises cultural tools, procedures and norms via active participation in interactions with other people (Vygotsky, 1978; Stetsenko & Vianna, 2009). At the same time, the individual externalizes his own understandings and intentions in the interaction

(Vygotsky, 1978). If we take all of these theories of cognition and cognitive development into consideration, we get the following definition of cognition:

- Cognition is a mental process of making sense of/in the world
- Cognition is observable in motivated action
- Cognition is situated and interactive
- Cognition is an imbedded dynamic system
- Culture and social relationships are part of that dynamic system

Access to the cognition of others

Because cognition is a mental process, cognition of other people is accessible only through inference from their actions in interaction with the world, especially in interaction with the social world of other people. This inference, or interpretation, is a semiotic process where we try to map behavioural form onto some mental content. In order to access the cognition of others, we apply our own cognitive (phenomenological, theoretical, and intuitive) schemata as a measure for comparison and recognition. This means that we *recognize* cognitions on the basis of our own experiences as cognizing humans. In this way, the mapping is always between our own understanding and the behaviour of the other, which make understanding their cognition prone to semiotic analysis – i.e. we always have to ask ourselves what we base our interpretations on. Based on these considerations, we get the following definition of access to the cognitions of others:

- Access to cognition is interpretation
- Access to cognition is based on the meaningful inter-acts of the other
- Access to cognition is recognition of cognitive activity
- Access to cognition is realizing the meaningfulness of the actions of the other

ASSESSMENT

Assessment is giving some kind of evaluation of the cognitions that you interpret from the actions of another person. In that process some kind of value or measurement is applied to the interpretations. The Oxford Dictionary gives the following definition:

> *Assessment is the action of evaluating or estimating the nature, ability, or quality of someone or something (Oxford Dictionary, online access 2013).*

In the literature on psychological assessment, several definitions of assessment can be found. Linden & Hewitt provide the following distinctions between testing and assessment in their recent book on Clinical Psychology:

> *Psychological testing is thought of as the process of administering, scoring, and interpreting psychological tests (Maloney & Ward, 1976). Test scores provide the information that the clinical conclusions, decisions, and recommendations are based upon (Cohen et al. 1996). Psychological assessment, on the other hand, goes beyond test scores and uses many sources of data (including tests) to arrive at conclusions regarding psychological problems that an individual(s) is seeking help for. Moreover, according to Maloney & Ward (1976), whereas psychological testing measures the issues, problems, concerns, strengths, and limitations a person has, psychological assessment extends to include how and why the person developed the problems and how the problems are maintained. (Linden & Hewitt, 2012, p. 102 f.)*

Another example of how to define assessment is found in a standard textbook, used at the department for Psychology at the University of Copenhagen when giving courses on psychological assessment:

> *Assessment may be defined as systematic information gathering in clinical work for the guidance of psychologists and psychiatrists in their decision making regarding treatment. These decisions are related to screening, treatment planning, and monitoring of treatment. (Elsass, et al., 2006, p. 15. Our translation)*

The essence of these quotes seems to be that assessment of cognition is the goal-directed, purposeful, and evaluating judgements that we make in our practice in order to make decisions regarding the people we work with. We will come back to practical implications of this later. For now we will sum up these definitions in the following points:

- Assessment of cognition is based on our access to cognition
- Assessment of cognition is recognition of cognitive ability
- Assessment of cognition is evaluating the meaningfulness and the success of the actions of the other
- Assessment of cognition always has a purpose in a given context

Inter-relational definitions

The concepts of cognition, access to cognition, and assessment of cognition, as we have defined them above, may be understood as related to each other as different layers in a transactional model. When we add reporting of the findings, we get the model, presented in figure 1.

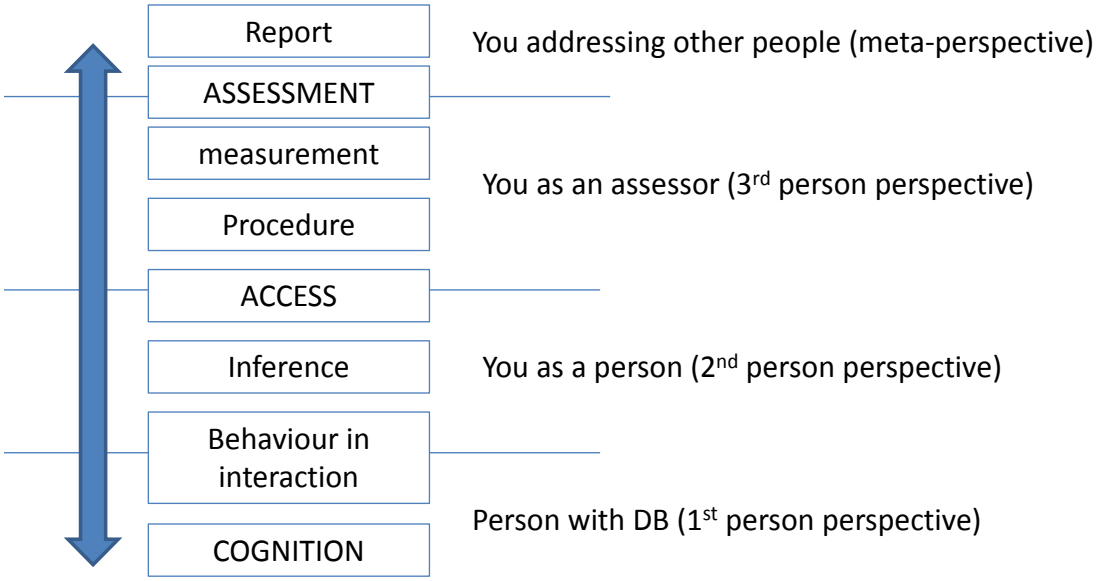

Figure 1
Transactional model of cognitive assessment

Assessment of deafblind cognition

Congenital deafblindness (CDB) is a specific disability that poses some significant risk factors for the development of the inflicted people. CDB influences both physical and social interaction with the environment, and may lead to deprivation at all levels of psycho-social development (Ask Larsen & Damen, in preparation).

These risk factors can be explained in terms of restrictions on the bodily-tactile access to the world. Some properties of this modality are fundamentally different from those of the audio-visual modality, and these differences result in added strain on working memory and cognition in general.

Firstly, bodily-tactile perceptual processing is sequential and fragmented, whereas audio-visual perception is simultaneous and holistic.

Secondly, there is a lack of distal perception and thereby restricted access to contextual cues and peripheral information, which makes it difficult to obtain and maintain an overview of the surroundings.

Thirdly, the haptic and tactile nature of bodily-tactile perception leads to longer input time.

If these risk factors are not accommodated by adaptations in the physical environment, it may lead to a decrease of explorative interaction with the environment, insecurity caused by lack of overview, and lack of referential input, which may result in motor-cognitive deprivation.

Likewise, the social environment must accommodate to the bodily-tactile modality. If not, lack of access to emotional

expressions of the other, lack of peripheral access to social interaction, lack of active participation in social interaction, and lack of experiences with joint attention, may lead to socio-emotional deprivation, resulting in behaviours that are easily mistaken for autistic behaviours.

Also, access to the cultural environment is at risk. Disabled peripheral access to activities of others, disabled active participation in activities, and disabled participation in negotiations about activity motives, goals, and division of labour, may lead to culture deprivation; understood here as lack of access to cultural practices.

As no linguistic culture that provides a natural tactile language exists, reliance on the bodily-tactile modality commonly leads to lack of exposure to language, lack of contingency and meaningfulness in language use, disabled access to pragmatic context and relevance, and the end-result will, most likely, be language deprivation and impeded communication development (Ask Larsen, 2013).

We may, thus, list a set of risk factors pertaining to reliance on bodily-tactile perception for development (Ask Larsen, in press). The risks arise from the combination of; on the one hand, strain on bodily-tactile perception and cognition and, on the other hand, insufficient accommodation of the physical, social and cultural environment to the bodily-tactile modality. The results may be motor-cognitive, socio-emotional, cultural, and/or linguistic deprivation.

In summary, this may lead to what we may term a *content problem* for our assessment. Cognition itself may be organized in an atypical manner and thus be difficult to recognize as meaningful.

Atypical actions

In order for us to come to an understanding of cognition from observing behaviour, we must first of all understand how the specific behaviour makes sense for the one who performs the actions. When we cannot simply ask the person in question, we must analyse this conceptualisation from the actions themselves. This kind of analyses is semiotic interpretation. By making these interpretations as motivated as possible, we can set up good hypotheses about the cognitive abilities and potentials of the person we are trying to assess. All other kinds of assessment of cognition are likewise based on interpretation of actions. We, in the field of deafblindness, just need more analysis than what is normally needed, because we need to analyse many of the parameters that are normally accounted for by linguistic instruction of, or report from, the participants.

CDB-specific influences on psycho-social development often causes the actions of people with CDB to appear to be very different from typical behaviour. In other words, the cognitions of people with deafblindness may be expressed in atypical ways. This makes interpretation from behaviour to psychological processes difficult. This needs to be taken into consideration when performing psychological assessment of people with CDB. In summary, this leads to an *interpretation/form problem* in the access to cognition.

Two additional problems may be identified as CDB-specific. The first is a *procedure problem*, mainly concerning how to organize our observations in a valid way, or, in other words, how to accommodate procedures and tools. The second problem is a *report problem*. How do we communicate our findings when they are based on interpretations from atypical behaviour? In the communication of our findings, it is important to consider all the layers in the transactional model of assessment, in order to make sure that the interpretations we make are well founded in theory and good observational cues. This is to ensure that others can follow and understand our interpretations.

We may sum up the specific challenges with assessment of cognition in relation to congenital deafblindness in the following four points:

- Content problem: Deafblind cognition may be organized in an atypical manner. Deafblindness potentially influences cognition and cognitive development in specific ways.
- Interpretation/form problem: Deafblind cognition may be expressed in atypical ways.
- Procedure problem: How to accommodate procedures and tools?
- Report problem: How to communicate our findings? All steps must be considered.

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PART II: Guidelines

Guidelines for assessment of cognition in relation to congenital deafblindness

Figure 2 shows a schematic overview of the topics of this part (II). This part of the present booklet addresses three different questions.

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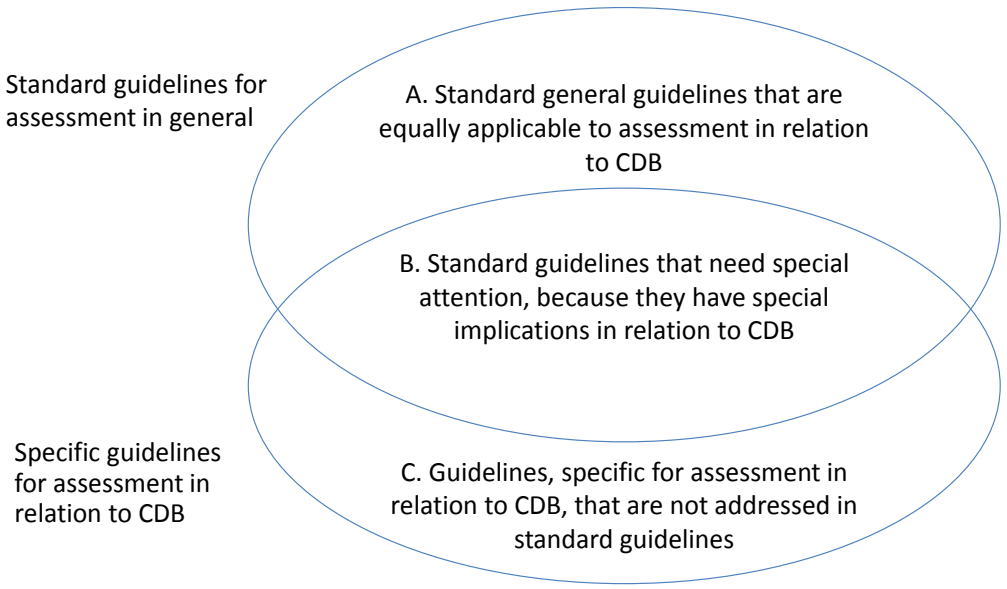
The first purpose of Part II is to introduce guidelines for psychological assessment in general, as it may be found in standard textbooks on assessment (The top circle in Figure 2). We do this for two reasons. Firstly, in order to make sure that assessment of cognition in relation to CDB is done in as professional a manner as possible. Secondly, we will try to specify these guidelines for the assessment in relation to CDB.

The second question is whether some of these general guidelines need special focus, because they have special consequences in relation to CDB (B in Figure 2). We analyse the standard guidelines in more depth, in order to tease out deafblind specific aspects that may not be fully covered by standard guidelines for assessment, and thus may not be part of the training of assessors in general.

Figure 2
Guidelines for assessment



In addition to general guidelines that need special attention, we furthermore suggest and discuss some aspects of assessment that are not included in standard guidelines for assessment, but that have proven themselves to be very important for assessment of cognition in relation to congenital deafblindness (C in figure 2).

TOPICS FROM STANDARD GUIDELINES

In the literature on assessment, we find some considerations that are addressed by more or less all the handbooks and textbooks on cognition. These are:

- Ethics
- Quality of the assessment
- Reasons for assessment
- Targets for assessment
- Assessment procedure guidelines
- The use of tools
- Accommodation of tools
- Nonverbal assessment
- Risks when assessing – the mistakes you want to avoid

In the following, we will address these questions briefly one by one.

Ethics

In case of any psychological assessment, the assessor must give sufficient information to the person to be assessed about the assessment procedure and the possible consequences of the outcome of such a procedure. The assessment can only start if informed consent is given for it.

Ethics are especially important for people who cannot decide for themselves if they want to be part of an assessment or are not able to oversee the consequences of it, such as in the case of some children and people with certain disabilities, and, of course, also in relation to people with CDB. Legal representatives, such as parents or guardians, will then have to give permission for the assessment on behalf of the person to be assessed.

Assessors should know the ethical rules for assessment formulated by the national society of psychologists of their country. Rules of national ethical boards will often be based on rules established by overarching societies for professionals, such as the European Federation of Psychologists' Associations or the American Psychiatric Association (APA) (www.apa.org, 2014). For example, the Danish ethical guidelines are based on the Nordic ethical principles for assessment, and

published on the webpage of the Danish Psychologists' Organization (www.dp.dk, 2014). The ethical code from international organizations therefore can be relevant to consider in addition to the national guidelines, especially if one is working in an international context or wants to publish about outcomes of assessments. The APA ethical code is widely used and can be found on the webpage of APA (www.apa.org, 2014).

Quality of the assessment

The terms 'validity' and 'reliability' are important when judging the quality of the assessment.

Reliability has two meanings. One is the quantitative measure of the consistency of your measurement tool, or the degree to which an instrument measures the same way each time it is used under the same conditions with the same subjects. In short, it is the repeatability of your measurement. A measure is considered (quantitatively) reliable if a person's score on the same test given twice is similar or if two independent assessors have the same outcome.

The other meaning is in relation to qualitative interpretation. In this case, reliability is evaluated on the grounds of the systematicity and transparency of the deductive process. In other words, the better another person is able to follow your interpretative process, the better the reliability can be evaluated. In this case, the logical deduction from precise observation cues to the final interpretation is what you need to present, in order for others to use this description and decide whether they agree or disagree.

Validity is the strength of our conclusions. Cook and Campbell (1979) defined it as "the best available approximation to the truth of a given inference, proposition or conclusion." More formally, we may say that ensuring validity is to make sure that you measure the constructs you say you measure.

In order to take care of sufficient validity and reliability, authors have formulated some general guidelines for the assessment procedure, the use of tools, the assessor, the report and the interpretation of results (see for example Krishnamurthy, R., VandeCreek, L., Kaslow, N. J., Tazeau, Y. N., Miville, M. L., Kerns, R. et al., 2004).

Reasons for assessment

Damen and Worm (2013) state that the aim of any psychological assessment procedure should be to support an individual as best as possible in his daily life (Damen & Worm, p. 31, 2013 referring to Pameijer, 2002): "we call these assess-

ments action-oriented. They produce concrete proposals for parenting, support and/or education."

Linden & Hewitt (2012 p 106 f) list the following goals of psychological assessment (p 107 ff):

- Problem explication
- Formulation (e.g. case formulation)
- Prognosis
- Treatment issues and recommendations
- Provision of therapeutic context
- Communication of findings (e.g. to referral source and parents)

Brun & Knudsen (2006, p.18) have a longer list of reasons for performing psychological assessment, including research, military related, work related and administration related assessment (e.g. for referral or evaluation). The authors also use the term 'diagnostic assessment' and subdivide this form of assessment into cognitive/neuropsychological assessment and personality-psychological assessment. Child-psychological examinations are listed as a separate category beside these two types of diagnostic assessment.

The motivation for assessment of people with congenital deafblindness seems to be closely connected to their lifelong support needs. Damen and Worm (2013) state that congenital deafblindness has a major impact on development. In literature (see for example Van Dijk & Janssen, 1993), a lack of sensory information, also called 'deprivation' is described in these people and it is reported that they often show serious delays in all developmental areas (McInnes, 1999). Problems in social interaction are regularly observed between children and adults with deafblindness and their social partners (Janssen, 2003; Rodbroe & Souriau, 1999; Goode, 1990).

Supporting children and adults with deafblindness is highly specialized work. Specific deafblind services are often needed, since the support for people with blindness or deafness is in general not sufficient for them. Assessment prior to intake/referral to deafblind services is given by Jones (1988) as an important motivation for assessment. The fact that the target group of people with congenital deafblindness is heterogeneous makes it impossible to offer them a standard intervention. It is the combination of the complexity of the disabilities and the uniqueness of every individual with deafblindness that demands that a diagnostic intervention cycle is (repeatedly) followed in order to offer an individualized education and support program.

With regard to individuals with deafblindness, the types of assessment purposes that are clinically most prevalent are diagnostic and rehabilitative assessments focusing on intervention planning and monitoring of development. Diagnostic assessment is very difficult in relation to congenital deafblindness because of the problems with differentiating between diagnoses (cf. Dammeyer, 2010; Jones, 1988, p. 4). Assessment with regard to research is also highly relevant, but guidelines for assessment in relation to CDB are needed (Ask Larsen & Damen, in preparation).

Targets for assessment

According to Van Hemel and Snow (2008), assessing infants and preschool children with disabilities requires a functional rather than a domain specific approach to assessment. Assessment of young children usually concerns the following areas:

- General cognitive skills
- Language
- Motor development
- Socio-emotional development

In addition to these general targets, assessment in relation to CDB requires some additional focus points. Carroll J. Jones (Jones, 1988) sets up the following dimensions of psychological assessment in relation to CDB development and intervention (or programming, as she puts it):

- Vision (perception and functioning)
- Hearing (perception and functioning)
- Secondary senses (tactile, olfactory, vestibular, etc.)
- Sensory-motor development
- Cognitive development
- Language development
- Social/emotional development

Cognitive assessment cannot be performed in relation to people with CDB without knowledge of and focus upon the dimensions added by Jones. For example, we need to know if the person has some functional hearing or vision, if he learned symbolic communication and if he uses a specific communication system.

Assessment procedure guidelines

Van Hemel and Snow (2008) point to the importance of two aspects: purposefulness and a systematic approach. With respect to purposefulness, the assessor should decide before-

hand what purpose the assessment has. Different purposes acquire different types of assessment (Van Hemel & Snow, 2008). Considering the systematic approach, assessment should not be considered as an activity that stands on its own. Rather, it should be conducted within 'a coherent system of medical and educational and family support services'. The more consequence assessment outcomes will have in terms of decision making, the more certain and convincing the evidence should be (Van Hemel & Snow, 2008).

The use of tools

Psychological assessment tools are used by clinicians to gather a more objective image of characteristics of an individual (Van Yperen & Veerman, 1998) and are often referred to as 'instruments'. Instruments that have norm data enable the comparison of individuals with each other. Some instruments can be used to draw inferences about future development and behavior. Clinicians with an educational background will, however, not only use instruments to gather information about the individual, but will also study characteristics of the social and/or educational system.

With regard to the instruments chosen, the assessor must be aware of three aspects: (a) domains that are the focus of the assessment, (b) psychometric properties of the instrument and (c) evidence supporting the appropriateness of the instrument in relation to the characteristics of the individual that is to be assessed, such as age, language, ethnicity, or disability.

With regard to the assessment of behavior and functioning of children and adults with disabilities Damen and Worm (2013) distinguished three types of assessment instruments:

a) Questionnaires for the primary caregivers about activities and developmental milestones

b) Observation instruments that explore specific areas, such as social life skills

c) Standardized tests or ordinal scales that measure someone's functioning in comparison with a norm group, resulting in for example a developmental age.

An example of a questionnaire on development milestones is the KID-N, developed for infants by Schneider, Loots & Reuter, 1990. The Vineland Adaptive Behavior Scales (see Oakland & Houchins, 1985), is a commonly used instrument to observe

functional skills in people with intellectual disabilities.

Concerning standardized tests, the Wechsler Intelligence Scale for Children (Wechsler, 1949) is widely used to measure the intelligence of children between 6 and 16 years of age resulting in a so called `intelligence quotient' (IQ score). Several authors emphasized that test tasks are given verbally and in many tasks a verbal answer is expected (Damen & Worm, 2013; Van Hemel & Snow, 2008). This is a disadvantage for children with language or communication difficulties or children for whom the language used by the assessor is a second language. Damen and Worm (2013) stated that the Wechsler scales that measure cognitive abilities, including those developed for toddlers and adults (so called WPPSI and WAIS), also demand a lot of visual capacity.

It is also known that standardized tests can be culturally loaded. This means that children who do not have the mainstream cultural background of a country can have difficulties with specific test items (Reynolds, 1999).

In the case of deafblindness, standardized instruments are seldom usable, since they measure cognition using visual and auditory senses (Damen & Worm, 2013; Mar, 2010).

Although standardized tests are seldom usable, some kind of rating seems desirable. The question is therefore; which successful methods are available in the field of deafblindness in order to evaluate cognition. We will emphasize adaptation of standard tools and the development of specific tools in the following.

Accommodation of tools

Instruments that are used in the assessment should be the best ones available for the domain or function to be assessed and for the individual to be assessed (Van Yperen & Veerman, 2008). In identifying the best assessment instrument, the assessors are normally advised to first look at a widely used instrument. If needed, adaptations can be made of existing instruments, or a new instrument can be developed.

Instruments that are developed for seeing-hearing people are generally not suitable for people with deafblindness. They either need to be adapted, or are not at all usable.

Members of the Network on Cognition in Relation to Deafblindness have made some preliminary attempts at adapting the following instruments: PEP-R (Schopler, Reichler, Bachford, Lansing & Marcus, 1990) and the Bayley Scales of Infant Development (Bayley, 2008). Other members have developed new instruments or used instruments especially developed for people with deafblindness, such as: memory in reality test, tactile form recognition tests, tactile working memory scale,

developmental profile (Nafstad & Rodbroe, 1999), child guided strategies (Nelson et al. 2009), executive functioning scale, checklist on deployment and regulation of attention during tactual tasks. Some of these attempts will be presented in Part III.

NONVERBAL ASSESSMENT

According to Hall, Bernieri, and Carney (2008), there are many definitions of and methods to measure perceptible nonverbal behavior, such as facial expressions. The authors refer to these behaviors as 'cues'. The accuracy of judging the meaning of nonverbal behaviors, as well as the accuracy of noticing and recalling these behaviors, is defined as 'personal sensitivity' by the abovementioned authors. They emphasize that in daily life, human beings are constantly processing and evaluating cues that are conveyed by others.

Hall, Bernieri & Carney (2008, p. 239) recognize several processes that influence the processing and evaluation of nonverbal behavior:

- The depth of cue processing (attentional versus inferential),
- The degree of awareness of cue processing (not conscious versus conscious),
- The dynamics of the stimulus (static, such as facial features; semi-static, such as clothing style; or dynamic, such as hand gestures)
- Spontaneity of encoding (posed/provoked versus spontaneous)
- Construct domain (such as states versus traits)
- What specific construct is being measured

Regarding the measuring of the constructs, the abovementioned authors state that the measurement of affect states is most common. Other states that are commonly evaluated are thoughts, intentions and needs. The evaluation of intelligence and specific competencies belong to the domain of the 'traits'.

Hall, Bernieri & Carney (2008) emphasize that in many cases, the person who performs an evaluation of nonverbal behaviors is not sure if he or she made an accurate judgment of that behavior. We suggest that the accuracy of the measurement of the nonverbal problem is a topic that should always be addressed in formal assessment of people with congenital deafblindness.

Hall, Bernieri & Carney (2008) suggest how the evaluator can be more certain about the accuracy of his evaluations. First of all, he or she must be aware that evaluating rather

concrete aspects of behavior is likely to be more accurate than drawing high-order inferences about the behavior that is observed.

There are also solutions to improve the likelihood of being accurate in evaluating nonverbal behavior (Hall, Bernieri & Garney, 2008). Using a coding system that is performed by trained coders independently is a way out. The inter-observer agreement can then be calculated and can give an idea of the amount to which the two evaluators agree. However, agreement does not necessarily say that they are right. Reaching consensus between observers can also be a solution to improve the accuracy of the evaluation, but again, the observers could be biased. Consensus is found to work better when the construct is socially defined (such as when measuring of expressed friendliness) than when what is evaluated is something residing in the person being assessed (such as pain). Another solution is to involve expert judgments (although they also can be biased or can miss relevant behavior) or to deliberately provoke behaviors to test if judgment of these behaviors is accurate.

Different kinds of methods for observing and assessing nonverbal behavior may be very relevant for professionals concerned with assessment of cognition in relation to CDB, as verbal and linguistic communication is often weak or lacking.

We would like to point to three reasons for being cautious when applying nonverbal assessment methods. Firstly, verbal communication is often placed as the top performance when doing nonverbal assessment instruments, e.g. the Bayley Scales (Van der Meulen et al., 2002) or the Rowland Communication Matrix (Rowland & Fried-Oken, 2010). Secondly, such procedures are often developed to measure very early stages of development (e.g. Reynell & Zinkin, 1979), which is not relevant for people with CDB at a more advanced stage of development. Thirdly, assessment of nonverbal behavior is based on behavioral cues, which in the case of CDB may be very different from typical behavior and, therefore, difficult to observe and interpret.

Risks when assessing – the mistakes you want to avoid

Van Hemel & Snow (2008) described several mistakes an assessor must try to avoid, when interpreting results:

1. *Variability of development and learning and experiences*: the developmental abilities of children of similar age can show substantial differences as a result of inter-personal differences in development and as a result of differences in experiences and learning. Two children who appear to

have variations in development can both function within the normal developmental range.

2. *Wrong labelling*: specific delays in development or behavioral symptoms can have different etiologies and the same etiology can result in different kind of delays or symptoms. In young children, deviation from what is regarded as the expected functioning or behavior can also be temporary or subject to change. This implicates that the assessor is at risk of giving wrong labels. It can be difficult to change a label when it is given, since it will influence how the child is addressed, and professionals easily adopt information in formal reports without evaluation.
3. *Unfair judgment:* evaluations are made within a certain moment in time and can be subject to accidental influences. An example of aspects that can influence the performance of a person is lack of motivation, limited awareness and understanding of the test situation or physical barriers such as fatigue or hunger.
4. *Blaming the person that is assessed*: development outcomes of a person cannot be regarded as the result of individual characteristics alone. Children develop in a social environment and when the social environment is not able to meet the child's developmental needs, this will affect developmental outcomes. Regarding developmental outcomes as the characteristics of a person, does not acknowledge the influence of the educational environment/history, and therefore can easily become a way of 'blaming the individual'.
5. *Child outcome is not the same as the effectiveness of a program:* the opposite of blaming the child is to describe development as the direct result of the educational environment. When evaluating a program, it is important to make sure that the educational program is performed in the supposed manner, and that the program is addressing the individual's learning style and learning needs. Each case can be seen as a single case study and it is important to get a sufficient idea of the situation before the start of the educational program, to monitor the learning progress and evaluate in between, in order to adjust to program to the individuals learning needs.

The mistakes an assessor can make when assessing (preverbal or young) children seem to apply even more in the case of CDB. Furthermore, they not only apply to children, but also to adults with CDB.

Individual variations

Since the term deafblindness is used for people with a variety of sensory abilities and disabilities, different etiologies and accompanying medical and psychological problems, it is difficult to set up any standard norms for the target group. Also, the setting the person with deafblindness is raised or educated in can differ a great deal as well as their learning experiences. Children with CDB can for example be educated in schools for the blind, schools for the deaf, day care centers for people with multiple disabilities, at home or in a large institution for people with intellectual disability. Their educators can lack special training or experience with deafblindness or, at the opposite, can have years of special training and experience. Often, the communication systems used reflect the type of environment the child is raised in rather than the sensory abilities and preferences of the child.

Wrong labeling

Test performance of people with deafblindness can, even more than in the case of very young children, be influenced by familiarity with the examiner, familiarity with the activity, responsiveness of the examiner, shyness etc. People with deafblindness can be considered even more vulnerable than typical children, since they often have idiosyncratic communication systems and limited knowledge of the world.

The influence of arousal state and attention, when assessing children below 2 years old, on their performance, can also be seen in children and adults with congenital deafblindness.

Attention must be given to these aspects, as well as aspects such as motivation, task awareness, emotional security and communication. The interaction between the assessor and the child with deafblindness or the intervener must be evaluated in order to see if the prerequisites are there for an optimal performance of the child with deafblindness: mutual understanding, motivation etc. When the circumstances are not optimal, the assessment situation has to be optimized prior to or as part of the assessment procedure.

Blaming the person with deafblindness

As we stated earlier regarding developmental outcomes as characteristics of a person does not account for the influence of the educational environment/history, and therefore can easily become a way of blaming the individual. Children with congenital deafblindness are at risk of developing cognitive impairments. It is important to be aware that what a child is

displaying at a given moment, is something else than his/her cognitive level. Most children with CDB are not able to realize their full cognitive potential. The more optimal the educational situation is, the better are the chances that the child is able to display more of his/her potential. According to several authors, an optimal environment for the child with CDB is an inspiring and narrative interplay with a competent partner.

THREE UNDERLYING QUESTIONS

The above introduction to general guidelines may be condensed into three questions that anyone doing psychological assessment needs to pose:

- Why to assess? (Reasons for assessing)
- What to assess? (Areas of psychology/cognition to assess)
- How to assess? (Procedures and ethics of assessment)

What do we need to add?

Two relevant questions for us to ask with regard to setting up guidelines for assessment of cognition in relation to CDB are, firstly, if any of the above mentioned guidelines need a closer examination with a special CDB focus, and, secondly, if anything is missing in these guidelines that we need to add. The first question we have tried to address along the way above, but the second question needs a closer look. In other words, can we identify the following?

- Specific reasons for assessing in relation to deafblindness (why?)
- Specific areas of cognition to assess in relation to deafblindness (what?)
- Specific procedures of assessment in relation to deafblindness (how?)

The assessor should also be aware of the specific way of being in the world of people with deafblindness, and the influence this has on cognitive development. Damen and Worm (2013) express this as follows, referring to Dammeyer (2011):

> *A person with sensory disabilities has limited access to the surrounding world and can develop unclear impressions of that world. Limited sensory information hinders cognitive development, as this process takes place when children use their senses to come into contact with the world. Many people with deafblindness have developed a relatively limited number of concepts and links between concepts due to their limited sensory information. Impaired cognitive development on the other hand, makes coping with sensory disabilities much more difficult. (Damen and Worm, 2013, p. 11)*

We will address the three questions separately in the following.

SPECIFIC REASONS FOR ASSESSING IN RELATION TO DEAFBLINDNESS

As we see it, it is hard to identify any specific reasons for assessing cognition in relation to CDB, compared with what is done in other areas. Therefore, we refer to the previous chapters for reasons for assessing. In Part III, the practice examples will follow up on this, and give the motivation for the different assessments.

SPECIFIC AREAS OF COGNITION TO ASSESS IN RELATION TO DEAFBLINDNESS

With regard to targets for assessment, we have identified some targets that are not addressed by the standard guidelines, and thus may not be part of standard training for psychological assessment. These are:

- Skewed developmental profiles/splinter skills
- Tactile cognition

We will address these separately in the following.

Skewed developmental profile/splinter skills

It is known that people with congenital deafblindness can have a skewed developmental profile. This means that some areas of functioning can be better developed than others. An individual can for example be relatively skilled in self-help activities, being able to dress him or herself or to make coffee. However, the person might have serious difficulty in engaging in sustained social interaction with other people, which suggests that his social-emotional development is more limited. This means that information of a person's skills in one target area is not sufficient as the only source for intervention planning.

Tactile perception, cognition and interaction/ dialogue

An important topic for assessment, and a specific focus also for cognitive assessment, is to see how a person with deafblindness comes into contact with the world, using his tactile sense. The next step is to see how (when the person is able to make full use of his tactile modality) the person deals with and understands the situation. Is he for example able to learn a social routine tactually, or can we see anticipatory behavior, and how does the person deal with novelty? This type of

approach involves both a focus on the tactile interaction/dialogue between the person with congenital deafblindness and his (social) environment and a focus on a so-called "tactile cognition" (Nicholas, 2010).

Tactile cognition refers to the higher order processing and integration of tactile information through active touch. This processing includes the mental processes of attention and memory and working memory (Nicholas, 2013). Working memory is widely thought to be one of the most important mental resources and critical for cognitive abilities, such as planning, problem solving, reasoning, and language acquisition.

While visual and auditory working memory are well researched and better understood, relatively little is known about the working memory in the tactile modality. Until recently, few studies had attempted to investigate the effects of tactile working memory. Recent research in neuroimaging and neuropsychology, however, has made us learn far more about the nature and mechanisms underlying tactile working memory than ever before. Recent neuroimaging studies (Nicoletta et. al., 2012; Savini et. al., 2007; Ricciardi et. al., 2006) and neuropsychological studies (Cohen et. al., 2010; Bliss & Hamalainen, 2005) have highlighted the presence of working memory in the tactile modality. Specifically, tactile working memory has been found to be altered through experience indicating that tactual experience plays a crucial role in shaping working memory (Bliss & Hamalainen, 2005; Cohen et. al., 2011).

Specific procedures for assessment in relation to deafblindness

As with the targets, we have also identified some specific procedures necessary for a good assessment of cognition in relation to CDB that are not mentioned in standard guidelines on psychological assessment. These are:

- Video analysis as a prerequisite for assessment
- The bodily-tactile modality is the main (but not the only) modality on which to perform assessment of cognition in relation to deafblindness
- Optimisation of the interaction/dialogue
- Dynamic Assessment

Video analysis is a prerequisite for assessment

To overcome the difficulties in accessing the cognitions of the person with CDB mentioned in Part I, video analysis is believed to be a necessary tool in the process of interpretation of CDB behaviors. According to Anne Varran Nafstad and

Inger Rødbroe (2013), video analysis provides an excellent tool for looking for, and looking at, the bodily emotions relating to anticipation that are displayed by people with deafblindness. The authors also suggest that video analysis can be used for staff training, as it can be a means to develop their observation skills. They argue that observation skills are needed for professionals involved in the support of people with deafblindness, enabling them to listen to these people and to be attentive to their reactions.

Video analysis can also be used to do evaluations of people with deafblindness together, involving different professionals as well as parents. Group video analysis enables sharing different perspectives and making use of the expertise of more people.

Video analysis also enables the performance of micro-analysis. The signals that people with deafblindness express can be so small that they are easily overlooked when performing a live observation. Especially when they interact with another person, it can be worthwhile to perform repeated observations of small video fragments to see how both persons take turns and respond to each other. This kind of video-analysis is called 'video based interaction analysis'. According to Nafstad and Rødbroe (2013), such analysis can reveal important aspects of behavior and learning of the person with deafblindness.

The bodily-tactile modality

The bodily-tactile modality is the main (but not the only) modality on which to perform assessment of cognition in relation to deafblindness. When we consider the performance of a person with deafblindness as the object of an evaluation of cognitive ability, we must know something about how deafblindness affects performance and what to expect of the performance of a person with deafblindness. 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 deafblindness.

Optimisation of the interaction/dialogue

Psychological assessment of people with congenital deafblindness can have the same focus areas as assessment of seeing-hearing people. However, evaluating the abilities of an individual with deafblindness is not possible without evaluating to which extent the educational environment addresses the specific needs of the individual, with specific attention to the stimulation of interaction and communication – at the

moment and in the past. When the social and educational environment does not meet the needs of the individual with deafblindness this environment must be optimized before any evaluation can be made regarding the (cognitive) abilities of that individual.

It is important to be aware that the quality of the interaction/dialogue has influence on the outcome of the cognitive assessment. Hence, it is absolutely essential to focus on the competences of the communication partners, such as parents, teachers and professional caregivers, when assessing the potentials of people with CDB (Boers, Janssen, Minnaert & Ruijssenaars, 2013). Sufficient competence of the social partners who daily interact with the individual is crucial to enable the individual to develop and show his full potential.

It is known that communication with people with CDB is often challenging even for familiar communication partners (Janssen & Rødbroe, 2006). People with congenital deafblindness often use their own unique bodily-tactile communication signals or patterns, such as movements, natural gestures, body positions or muscle tension, which may be missed or misunderstood by parents or caregivers. In such case, video feedback training can support social partners to become better attuned to the communication needs of the individual with CDB (Damen, Janssen, Huisman, Rijssenaars & Schuengel, in press; Janssen et al., 2003).

The partner who is interacting with the person with CDB during the assessment situation or during the observation that is used to assess the individual's potentials should also be a competent partner. This means that he or she is able to understand the patterns and conventions of social interaction of the individual and is able to interact in a bodily-tactile way. The hand-under-hand method is an example of bodily-tactile interaction (Miles, McLetchie & National consortium on deafblindness, 2008): an adult follows the child's exploration of an object by lightly putting his hand on top of the child's hand or invites the child to follow what he is doing by putting his hand under the hands of the child. If the child accepts, joint attention can develop between the adult and child. The following partner competences are also believed to be important in order to develop high quality communication in people with deafblindness: perceiving, open interpreting, negotiating, elaborating and creating a narrative context (Damen, et al., submitted). Furthermore, the regulation of attention and emotions are found to be important tasks of the communication partners during the interaction.

The context in which an individual which CDB shows his abilities is not only formed by the persons he/she interacts with. The activity the individual is involved in must be added

as a component in evaluations of the context (Ask Larsen, in preparation).

Moreover, other aspects can influence the assessment situation in a negative way, such as unfamiliarity with the test situation and arousal. Since people with deafblindness are often difficult to understand for somebody who is unfamiliar with them, it is important to use familiar caretakers to check for the presence of disturbing factors. What the assessor needs to know is if he has seen the individual in the most optimal conditions. If not, it is important to optimize the assessment conditions to be able to make a proper evaluation.

Dynamic Assessment

It is very common to assess people with deafblindness in order to determine their needs and develop interventions. This can become an ongoing process in which assessment and intervention planning go hand in hand. The start of the assessment procedure can be determining the actual functioning of the child with CDB in his educational environment, with a special focus on interaction and communication. The next step is to formulate intervention targets to improve the educational situation and possible gains on the level of the functioning of the child. After optimizing the environmental situation, the quality of the environment and the interaction between child and environment can be evaluated again and new targets can be formulated. We call this a dynamic assessment procedure (Boers, Janssen, Minneart & Ruijssenaars, 2013; see also part III, page 41 of these guidelines)

Dynamic assessment is an assessment model that does take the asset or potential of a person into account. Although different models of dynamic assessment have been posited over the last several decades, they all highlight the general principle that guided learning can make a valuable contribution to the assessment process (Jitendra & Kameenui, 1993). In contrast to traditional standardized assessment approaches, dynamic assessment focuses on the support that an individual requires to successfully perform a task rather than on the level of difficulty at which performance breaks down. The theoretical background of dynamic assessment is to be found in the theory of Vygotsky (Vygotsky, 1978) and Feuerstein's Mediated Learning Experience (MLE) theory (Feuerstein, Rand & Hoffman, 1979; Feuerstein, Rand, Hoffman & Miller, 1980). Feuerstein's decidedly humanistic view of assessment is certainly in line with Vygotsky and both theories emphasize the concept of mediation. For instance, the concept of MLE in Feuerstein's theory is defined as a process

in which adults interpose themselves between a set of stimuli and the child and modify the stimuli for the child. The MLEs often include components of mediation, such as the mediation of intentionality, meaning, transcendence or competence. In other words, a dynamic assessment procedure involves determining the sources of difficulty individuals experience and the forms of mediation to which they are most responsive.

Multidisciplinary team

The assessor should be a trained professional with experience in both the assessment group as well as the type of assessment and instruments he is using. In several countries, professionals can only perform psychological assessments if they have had a specific training in assessment, including a substantial amount of supervision. General assessment training is usually at a post-master level and leads to an official registration that the professional cannot maintain unless he keeps his knowledge and skills up-to-date. For the administration of specific tests, a specific course can be required.

The assessor should be someone who is considered an expert in deafblindness and is a competent communication partner. The assessor should be aware of basic assessment guidelines and specific guidelines in relation to the assessment of people with deafblindness.

Assessment of people with deafblindness must be performed in an interdisciplinary way, since the dual sensory impairments affect so many functional areas that, in their turn, affect each other as well. Many people with deafblindness have specific syndromes, such as CHARGE syndrome (Horsch & Scheele, 2011) and Congenital Rubella Syndrome (Nicholas, 2000) and other etiologies that influence cognitive functions, such as information processing, inhibition etc.

SUMMARY

CDB-specific focus-points:

- Optimise social interaction and environment
- Multidisciplinary team
- Dynamic assessment procedure
- Video based interaction analysis
- Tactile modality of cognition, action, and assessment
- Skewed developmental profile/splinter skills

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Part III: Practice examples

Photo: Remke Spijkers

The following is a series of examples from our own work that present different attempts at applying the presented guidelines and theoretical foundation. The projects have been directed towards different specific assessment targets and procedures. These practice examples should be read as a "work in progress", and not as already fully developed assessment tools or procedures. We hope they will serve as inspirational input to the work with assessment of cognition in relation to people with congenital deafblindness.

ASSESSING POTENTIAL AND OPTIMIZING CONTEXT FOR LEARNING DURING INTERACTION: THE GREAT BENEFITS OF DYNAMIC ASSESSMENT

Erika Boers

Assessment is at the heart of the development of a child who is deafblind. Previously, the assessment procedures have focused on the use of standardized static tests. The term 'static' refers to a test where the examiner presents items to the child, and records his or her response without any attempt to intervene in order to change, guide, or improve the child's performance.

Often the tests do describe the child in general terms; mostly in relation to their relative position in their peer group. These tests do give us an idea of what the child has learned so far, and may describe the cognitive limitations of a child. However, they are inadequate in revealing the child's cognitive potential.

When assessment is based on utilizing only standardized static tests, there is a high risk of not recognizing the potential of the child with deafblindness. Many children with deafblindness fail on static tests because of lack of opportunity for learning experiences. But that does not say that they don't have the potential to learn. To provide accurate information about the child's learning ability, change processes, and mediational strategies that are responsible for cognitive modifiability, the assessment should be dynamic.

THE DYNAMIC ASSESSMENT MODEL

By performing an assessment in a dynamic way, the examiner gets the possibility to get insights in the child's potential to learn new skills, their learning processes and advancing teaching strategies. This information can only be collected by the inclusion of the child as well as communication partners in the assessment, giving them opportunities for learning experiences.

Generally defined, dynamic assessment is "an interactive test – intervene – retest model of psychological and psychoeducational assessment" (Haywood & Lidz, 2007, p. ix). In contrast to traditional static assessment, the dynamic assessment model includes: a) two test periods instead of testing the person only one time (the so-called pretest and retest), and b) a teaching phase where the person is supported to learn new skills (see figure 1). During the teaching phase, the person is offered assistance to master a task, in interaction with a more capable communication partner.

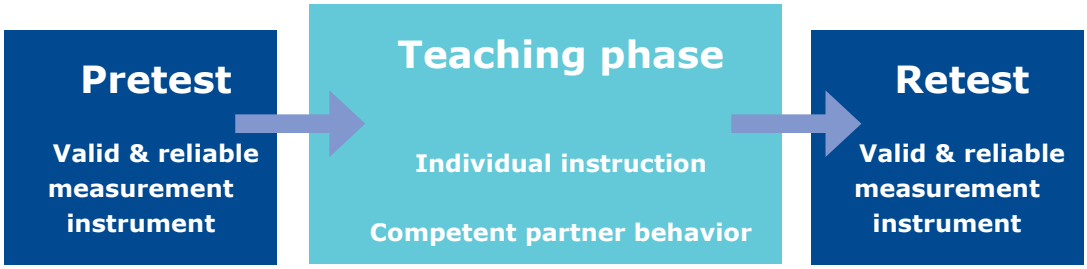

Figure 1:
General dynamic assessment model

The main differences between normative, static assessment and dynamic assessment can be found in Table 1 (adapted from Haywood & Lidz, 2007).

	Normative assessment	**Dynamic Assessment**
What is compared?	Self with others	Self with self
The process is:	Standardized; the same for everybody	Individualized; responsive to person's learning obstacles
The major question is:	How much has this person already learned? What can he/she do or not do? How does this person's current level of performance compare with others of similar demographics?	How does this person learn in new situations? How, and how much, can learning and performance be improved? What are the obstacles to a more optimal level of competence?
Outcome:	Global estimates of ability, for example IQ or developmental age Current level of independent functioning	Learning potential: What is possible with reduced obstacles to learning? How can such obstacles be reduced? How does the individual function with a more experienced interventionist?

Table 1
Comparison of normative and dynamic assessment approaches

In the literature on dynamic assessment, different perspectives are discernible: a) determining the amount of change demonstrated by a person on a given task in response to intervention, b) determining the amount of mediation needed to bring the person to some specified level of competence, c) determining the extent to which the person benefits from assistance, and d) the identification of inhibiting factors in learning and processes or means that enable the individual to learn a new task and determination of promising interventions.

PERFORMING DYNAMIC ASSESSMENT WITH PERSONS WHO ARE DEAFBLIND

The red thread of dynamic assessment is that children might perform above the limits of their initial capabilities when assisted by a more experienced adult in harmonious interactions (Vygotsky, 1978). However, it is known that communication with persons who are deafblind, especially those who function at a prelinguistic level – by gestures, vocalizations, eye-gaze etc. – is challenging, even for familiar communication partners (Downing, 1993; Holte et al., 2006; Janssen & Rødbroe, 2007). In this case, the question arises whether the competence of the person with deafblindness is constrained by his or her capacity to use the help and support provided by the communication partner or whether it is constrained by the partners' abilities to provide adequate assistance to the person during the assessment. To overcome this problem, it is important that dynamic assessment procedures for persons who are deafblind include: the identification of partner behaviors that support the person's competence, and teaching supporting behavior to the adult that interacts with the person during the assessment (Boers, Janssen, Minnaert & Ruijssenaars, 2013). The focus of a dynamic assessment procedure for persons who are congenitally deafblind should therefore be threefold:

1. Identification of partner behaviors that support the person's competence.
2. Positively change the behaviors of the communication partner.
3. Assessing the response to the positively changed partner behaviors.

CONCLUSION

The dynamic assessment model is a general model that can be applied for all kind of abilities. The information, dynamic assessment can offer us, is essential for the following reasons: it supplies the familiar communication partners with guidelines on how to interact with the child with deafblindness to ensure development; it provides us with information about what the child is capable of; and, it offers the child with deafblindness the opportunity to show what they are capable of. For children with deafblindness, dynamic assessment is the way to assess their abilities to learn; and, most importantly, to let them develop, by learning through interaction.

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TACTILE WORKING MEMORY SCALE (TWMS)

Jude Nicholas &
Annika Johannessen

AIM OF THE ASSESSMENT

The Tactile Working Memory Scale (TWMS) is an observer-based behavioral rating scale. It has been developed for professionals to facilitate identification of tactile working memory in persons with congenital deafblindness (CDB), in their everyday environment or during their social interaction with a communication partner.

WORKING MEMORY IN THE TACTILE MODALITY

Tactile working memory is the ability to actively maintain somatosensory or tactile information and remain focused "on task", especially under conditions of distraction or interference. Without active working memory, initial tactual precepts may decay quickly. Furthermore, tactile working memory may possess a number of properties which can help explain the emergence and maintenance of a tactile language (Nicholas, 2013).

Working memory is widely thought to be one of the most important mental resources critical for cognitive abilities, such as planning, problem solving, reasoning, and language acquisition.

Although working memory is an outstanding mental resource, the capacity for mentally holding and manipulating information in working memory is limited. Nevertheless, there are several strategies for overcoming the limitations of working memory, such as memory elaborative strategies that enhance the accessibility of long term episodic-autobiographical memory, mental rehearsal strategies (i.e. cumulative rehearsal strategy) or cognitive load reducing strategies (i.e. errorless learning strategy).

Thus, identification or assessment of tactile working memory processes in persons with CDB is clearly desirable given the links between working memory and important cognitive abilities, particularly emerging language abilities. Moreover, the assessment can play a valuable role in teaching or supervising communication partners to provide adequate support to regulate tactile working memory in persons with CDB.

ASSESSMENT OF WORKING MEMORY IN THE TACTILE MODALITY

Generally, assessments of working memory encompass a range of direct measures (standardized ability tests such as the Backward Digit Span Test, n-Back tasks) to indirect measures (behavior rating scales such as Behavior Rating

Inventory of Executive Function, Gioia, Isquith, Guy, & Kenworthy, 2000, *Working Memory Rating Scale, Alloway & Kirkwood, 2008).* However, to the best of our knowledge, there is no tool available that captures tactile working memory in everyday environment or during social interactions.

Although persons with CDB may use residual vision and/or hearing for communication, deafblind persons use primarily active touch and body movements. They use these in ways which no one else does to explore objects and the environment, to perceive feelings, to interact, and to communicate. Persons with deafblindness are strongly dependent on the tactile sense to establish interpersonal relationships and experience the world (Janssen & Rødbroe, 2006; Nicholas. 2012). Based on the assumption that the person with CDB may be better equipped at perceiving the world from a tactile-bodily perspective, the TWMS is developed to capture the working memory processes of the person with CDB in the tactile modality. The TWMS will increase the chances of detection and subsequently provide effective support to regulate tactile working memory in persons with CDB.

We believe the CDB person's everyday environment or their social interaction with a communication partner serve as important venues for observing and assessing the essence of working memory in the tactile modality.

THE TWMS WITHIN A DYNAMIC ASSESSMENT OF COGNITION PROCEDURE

Dynamic assessment of cognition is a diagnostic approach in which specific interventions are integrated into assessment procedures to estimate cognitive modifiability (Wiedl, Schöttke & Dolores Calero, 2001). The dynamic assessment of cognition has been applied to different clinical and educational groups, such as elderly with and without dementia (Wiedl et. al., 2001) and children with learning difficulties (i.e., Waber et. al., 1994; Kirkwood et.al, 2001). However, little is known about the dynamic assessment of cognition for persons who are congenital deafblind.

The focus of the dynamic assessment procedure of the TWMS is that a person with CDB might perform above the limits of their initial tactile working memory capabilities when assisted by a more experienced communication partner in shared and harmonious interactions. The development of tactile working memory in those with CDB is a phenomenon that occurs synchronously in relation to the social environment, and tends to occur in situations with considerable contextual support. In other words, the tactile working memory of the deafblind person is not exclusively intrinsic or

personal, but it is built up along with the non-deafblind communication partner as they co-construct their relationship.

To improve the identification of tactile working memory processes in persons with CDB, it is important that dynamic assessment includes two important intervention procedures. Firstly, we need to optimize the physical and social environment of the person with CDB within a bodily-tactile modality. In other words, one should establish high-quality bodily-tactile communication between the person with CDB and their non-deafblind communication partner. Partner abilities or competencies are important for the communicative and language development of people with CDB. These partner abilities or competencies include: whether the partner is able to attune his/her own acts to the unique bodily-tactile communication signals of the deafblind person and use these communication signals for interaction, whether the partner allows adequate response time during the interaction, whether the partner is able to take initiatives to recognize, confirm, respond and interpret the bodily-tactile signals, whether the partner recognizes bodily-tactile signals as declarative expressions, whether the partner uses symbols fluently in their communicative exchange or whether the partner is able to negotiate the meaning of the bodily-tactile signals. Negotiation of meaning is the process the person with CDB and the communication partner go through to reach a clear understanding of each other. It is thus vital that a partner can negotiate with a deafblind person to unravel uncertainties and ensure the shared meaning of an expression (Souriau, Rødbroe & Janssen, 2009).

Secondly, we need to provide the opportunity to teach or supervise the communication partner to mediate effective cognitive strategies during the assessment. In other words, the communication partner should be able to initiate working memory strategies during the dyadic interaction. The communication partner is the one who creates the experiences and scaffolds in the working memory in such a way that the deafblind person feels secure. If the context is well established or if the signals are recognizable to the partner, the partner can introduce working memory strategies without disrupting the flow of interaction. The deafblind person needs an interaction partner who clearly regulates working memory in a smooth manner. For example this includes whether the partner is able to provide an interactional bodily-spatial rehearsal strategy to the person with CDB during the interaction. An interactional bodily-spatial rehearsal is the process of mentally refreshing stored bodily-tactile locations in the working memory of the person with CDB to keep them highly accessible (Nicholas, 2013).

Thus, the dynamic assessment procedure of the TWMS attempts to link a step-wise assessment with intervention, enabling examiners to assess present levels of tactile working memory potentials or assets.

THE TACTILE WORKING MEMORY SCALE (TWMS)

To promote construct validity, the domains of working memory were identified based on theory, clinical practice and research literature. The literature on working memory was reviewed with special emphasis on the link between working memory and attention (i.e., Baddeley, 1993; Miyake & Shah, 1999; Awh & Jonides, 2001). Research suggests a close link between the working memory capacities of a person and their ability to control the information from the environment that they can selectively enhance or ignore (Fukuda & Vogel, 2009). Particular emphasis was given to the term of working memory used by Daryl Fougnie: *working memory, the ability to retain information in an accessible state includes the processes of encoding, maintainence and manipulatation of information* (Fougnie, 2008).The scales of the tactile working memory were identified and defined based on this research literature on working memory and on the literature on tactile information processing (i.e., Song & Francis, 2013; Gallace & Spence, 2009). This process yielded three scales of tactile working memory that are included in the TWMS.

The form of the TWMS contains 12 items within three theoretically derived scales that measure different processes of tactile working memory; to encode tactile information in the everyday environment and during interaction (ENCODE), to maintain tactile information during interaction (MAINTAIN) and to manipulate tactile information during interaction (MANIPULATE). Additionally, the ENCODE scale is split into three subscales; fundamental tactualization; spatial tactualization and social-communicative tactualization. The behavioral descriptions of the TWM scales are displayed in Table 1.

The TWMS materials consist of the TWMS form and the Scoring summary/profile form. The cover page of the TWMS form includes instructions for completing the form and the second page contains an area for recording general information about the person and information about the person's sensory functions. The remaining three pages of the form are followed by the 12 TWMS items with examples and response choices (i.e., *Present, Emerge; partially present, Absent, N/A; not applicable*).

The Scoring summary/profile form provides information for hand-scoring the TWMS, as well as a graph for plotting raw

scores to visually portray the individual's raw scores.

The rating of items on the TWMS could be done by direct observation or through video analysis. However, it is highly recommended to use video to capture the behavioral events in the person's everyday environment or during his/her interactions with a communication partner. That is to say, filming and storing the event or embedding activity before, during, and after the activity. On the basis of video analyses, it will be possible for the observer to analyze the material in a very minute way. It can be assumed that those subtle behavioral cues would have been missed when direct observation methods are used.

TWM scales	No. of items	Behavioral description
To encode tactile information in the everyday environment and during interaction (ENCODE)	6	Tactile object oriented (*fundamental tactualization)*; tactual-spatial oriented (*spatial tactualization)*; tactile object, but not person oriented; tactile object and person oriented; person oriented during interaction; exploration of person during interaction (*social-communicative tactualization)*
To temporarily maintain tactile information during interaction (MAINTAIN)	3	Maintaining attention to unfamiliar or novel features during interaction; maintaining attention with mental breaks during interaction; maintaining attention after mental breaks during interaction
To actively maintain and on-line manipulate tactile information during interaction (MANIPULATE).	3	Mentally extracting contents and meaning from existing knowledge in long term memory during interaction; exercising attentional control in the face of distractions or in the midst of interruptions during interaction; improving working memory efficiency by strategies during interaction

Table 1
Description of the scales on the TWMS

Video analysis is an effective way to interpret the behavioral cues of tactile working memory in persons with CDB. Video analysis should be considered a prerequisite for the assessment procedure and it is the best and most reliable way to rate the items on the TWMS.

ASSESSING WORKING MEMORY BY UTILIZING THE TWMS – CASE ILLUSTRATION

Thomas is a young adult with residual sight and hearing, and he has been identified as a person with CDB. Since kindergarten he has been introduced to visual sign language. It has been reported that he has knowledge of about approx. 300 signs. However, he has not been able to use these signs in a communicative manner. He rarely or never used visual sign

language in communication. He communicated mainly by hand-leading, vocalization or through emotional bodily expressions. He has been described by his staff as a person with poor language development and poor language acquisition skills. He has also been described as a person with severe attention and concentration problems.

The TWMS was utilized as part of the assessment process. It was rated by a consultant working with persons with CDB. The rating of items on the TWMS was done partly by direct observation, but mainly through video analysis. The venue for the behavioral observation was Thomas' everyday environment and during his interaction with an experienced and competent non-deafblind communication partner. The assessment was done in a step-wise manner.

Results on the ENCODE scale of the TWMS revealed the presence of abilities related to fundamental tactualization and spatial tactualization, but revealed only emerging, or absence of, abilities related to social-communicative tactualization. At this point, the items on the MAINTAIN and MANIPULATE scales were rated as *not applicable (N/A*).

According to the dynamic assessment procedure, it was necessary to optimize the physical and social environment of Thomas within a bodily-tactile modality. The experienced and competent non-deafblind communication partner attuned her own acts to the unique bodily-tactile communication signals of Thomas, and used these communication signals for further interaction. She also took initiatives to recognize, confirm, respond to and interpret the bodily-tactile expressions of Thomas.

Later in the assessment process, focus was given to the rating of items in the MAINTAIN scale. Data was collected on the behaviors relating to how Thomas maintained his attention for a brief period while displaying several observable mental breaks, or to how he maintained his attention for a relatively longer period of time after an observable mental break. Emphasis was also given on how Thomas maintained his attention when an unfamiliar or novel feature was introduced.

Initial results on the MAINTAIN scale showed the emergence (partial presence) of tactile attention abilities. This led to a refocus on intervention strategies emphasizing more on Thomas' interaction and dialogue patterns within the bodily-tactile modality. The communication partners used symbols fluently in their communicative exchange and took further initiatives to give Thomas access to negotiation of meaning in the bodily-tactile modality. Through a tactile-bodily meaning negotiation process, they often reached a clear understanding of each other. The video analysis revealed that Thomas was

actively involved in the negotiation process, and was displaying many communicative initiatives. Analysis also showed that Thomas recognized the gestures and the bodily-tactile signs of his communication partner. During this intervention process, Thomas had also managed to transfer many of the visual signs that he knew to bodily-tactile signs. He was using these signs in a communicative manner, in different situations, and during different activities.

Prior to rating the MANIPULATE scale, the communication partner was introduced to specific working memory strategies and was supervised by the consultant and a neuropsychologist to mediate effective partner-supported bodily-tactile working memory strategies during the assessment. For example, the communication partner was supervised to enhance the accessibility of Thomas' autobiographical memory by providing him with a memory elaboration strategy, she was supervised to improve Thomas' working memory efficiency by providing him with an interactional bodily-spatial rehearsal strategy, or she was supervised to reduce Thomas' working memory overload by providing him with an errorless learning strategy.

During the assessment, the communication partner was able to provide Thomas with an errorless learning strategy and simultaneously initiate an interactional bodily-spatial rehearsal strategy within the dyadic interaction. For example, when Thomas used the tactile sign for *bathing* (hands on the body-downwards), the partner detected this as a "sign error" in relation to the context, and provided Thomas with the "right sign" *happy* (hands on the body- upwards), without disrupting the flow of the interaction. This illustrates how the communication partner supported Thomas' working memory by providing him with an errorless learning strategy without disrupting the interactional flow.

The communication partner also guided Thomas with an interactional bodily-spatial rehearsal strategy. For instance, rehearsing together several times the "right sign", *happy*, first on Thomas' own body and then on her own body in a turn-taking manner. This illustrates how the communication partner guided Thomas' working memory, by providing him with an interactional bodily-spatial rehearsal strategy.

During the video analysis, we also observed Thomas assuming a position of "thinking", such as looking away and delaying the tempo of his activity. Eventually, when the communication partner asked Thomas what he was thinking about, he replied by using the sign *happy*. The interpretation here could be that during the dyadic interaction, the tactile-bodily experiences formed in Thomas' tactile working memory were transferred to long term autobiographical memory and

were then retrieved when needed.

After the intervention process, the results on the MANIPULATE scale showed the presence and emergence of the different flexible working memory abilities. Thomas was now able to connect an earlier experience with the current activity by commenting it through gestures, signs, body movements, or tactile signs. He also displayed "staying on activity" behavior in spite of interruptions during dyadic and triadic interactions.

Whereas the initial raw scores of the TWMS scales showed a skewed distribution pattern, post-intervention scores on all scales showed an even pattern. In other words, the TWMS profile portrayed the presence or emergence of the different processes of tactile working memory, suggesting the likelihood of appropriate tactile working memory potentials or assets. The TWMS profile displayed the tactile working memory processes that actively shaped the communicative and language development of Thomas.

Interventions designed to assist the development of Thomas' communicative and language skills, including working memory abilities, were implemented in his environment. Supervision was given to Thomas' staff on a regular basis. He now communicates with others in tactile sign language and he is also able to describe and relate to several themes or topics fluently in tactile sign language. His concept and expression of emotions have been extended and nuanced, and he uses tactile sign language to talk about his emotions. He is now considered by his staff as a person with adequate attention and concentration abilities and good language development.

FUTURE RESEARCH

When utilized within a dynamic assessment procedure, the Tactile Working Memory Scale (TWMS) enables professionals to assess tactile working memory potentials in persons with CDB. Clearly, further research is needed to understand the psychometric properties of the instrument.

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THE QUALITATIVE USE OF A STANDARDIZED TEST – A PRACTICAL APPLICATION OF BAYLEY SCALES III

Emmi Tuomi

TARGET OF ASSESSMENT AND WHY TO USE A STANDARDIZED TEST

Congenitally deafblind persons usually function at a very early developmental stage, described as the result of a severe or profound cognitive disability (or PMLD = profound and multiple learning difficulties). Targets of evaluation are interaction behaviors observable in very early developmental and prelinguistic phases, like reciprocity, imitation, turn taking, anticipation, waiting, expressing needs and will, attention, object permanency, causation, early classification etc. (Sandberg, 2013). There are not many assessment methods that evaluate early developmental stages, and the assessment of these phenomena require individual applications and modification of the methods.

It is of course possible to observe and evaluate these phenomena in everyday situations. On the other hand, using structured assessment methods has its benefits: the examiner is usually someone who is formally trained to administrate and interpret standardized assessment tools and knows psychometrics (usually a psychologist). Such an examiner is also familiar with the principles and operational models of assessment and able to understand child development, cognition and neuropsychological functions. While knowing well the method, the nature of the tasks and the target of the evaluation, she can concentrate on observing the individual features and skills of the person; and on modifying the tasks in a way the person assessed and the situation requires.

THE PRINCIPLES OF THE ASSESSMENT

The instrument

Bayley Scales of Infant and Toddler Development (Third edition) is a method designed to evaluate early developmental stages and possible dysfunctions of small children (age 0-43 months). The flexibility of Bayley-III is based on finding out and describing developmental milestones, not only the accomplishment of tasks. Because of that, the unique application as well as the normal use of Bayley-III requires strong knowledge of developmental phenomena and understanding of what is being measured at each task (Munck, 2013). The tasks evaluate many of the developmental phenomena

ITEM number	Instruction/ Idea Of The Task	Modification	Target Of Assessment
9. Reacts to the face disappearing	How does the child react when a familiar face (mom, nurse) is presented to him/her (eye contact) and then quickly disappears	How does the child react when a **familiar voice, touch or smell** disappears or stops, after having very intensive contact	Reactions and interest to the environment, early object permanence (things are there though not seen)
28., 29., 59. Pursuing an object	Pulling a cloth (28) or a string (29) to get an interesting object (first having a possibility to explore it). Using a pencil to get an object placed on the other side of the table (after having first modeled it to the child)	An object with a **bright light, strong voice or smell – possibility to observe it from farther away**. A **vibrator that can be felt through** the table or floor. Sufficient time to explore, **motivate and wake up the interest**; then observing any attempt (**reaching out hand, grasping, body directiveness, goal-directed voice etc.**) to reach for it when taken further away. Pressing **a switch or a push-button** is also an expression of understanding causation.	Causation (my actions cause something), modeling.
11. Visual preference 12. Habituation to an object 13. Visually selecting a new object 14. Habituation to a picture 15. Visually selecting a new picture	Assessing if the child habituates to an object/picture (loses interest) and then reacts when a new one comes to sight	Habituation and selection by other than visual sense: **Soft/harsh surfaces, light/strong vibration, two different smells or tastes etc.**; **observing any changes** (tension, facial expression) as a sign of making difference between the two different targets	Habituation, understanding concept of difference
43., 52. Transparent box	An interesting object (car, duck) is hidden in a transparent box with one open side. The child should try to get it out of the box without lifting the box.	Can be accomplished if some vision left. The object must be **interesting and clear enough** (e.g. an object with a light/sound). Tactually: **replacing the box with a fabric bag** (also included in the Bayley accessories): the item can be explored through the fabric (compare: seeing the object through the transparent box) and then trying to find the opening of the bag and get the object out.	Problem solving

Table 1
Examples of Bayley Scales application

described above: attention and anticipatory performance, habituation, exploration and manipulation of environment, self awareness, object retention and permanence, causation (items 1-39: age reference 0-16 months); simple problem solving, imitation, relational play, following instructions (items 40-55: 17-25 months); problem solving, attention, object assembly, matching, representational and imaginary play, concept formation (items 56-69: 26-38 months); numeracy, multischeme combination play, grouping, sorting, classification, discrimination, spatial memory (items 70-91: 39-42 months). (Bayley, 2008)

Bayley Scales is originally designed to test children without severe physical or sensory disabilities (Bayley, 2008). Despite that, in my practical work as a psychologist, I've used the method to evaluate persons whose developmental capacity doesn't reach the stage where Wechsler Scales and other standardized assessment tools are applicable. In my experience, the Bayley-III is also applicable to assess people with congenital deafblindness. In this article, I describe some practical examples of the use. Other standardized tests have been used to assess people with congenital deafblindness too, for example PEP (Psychoeducational Profile) and WPPSI-III (Wechsler preschool and primary scale of intelligence, third ed.).

THE USE OF THE INSTRUMENT – PRACTICAL EXAMPLES

The test materials and assessment practices (toys, everyday objects, functionality, play-based tasks) of Bayley-III are motivating and interesting, also for those who use tactile modality for compensating visual and auditory senses. Additionally, in my experience, the tasks can be "accomplished" not only by vision or hearing, but also tactually or by using the sense of smell or taste. In the boxes (see table 1), there are some examples of applications of the Bayley Scales III tasks.

Test situation

Using Bayley-III is not bound to a specific place or presentation mode. Assessment is best carried out in a familiar and safe place, and I often make the assessment on the floor. If needed, I modify the surface of the table or floor with clear contrasts and activating materials. The lighting, temperature and sound environment should be as pleasant as possible, to support the attention and activity of the person evaluated.

Test administration

Complementing speech and modeling with signs, tactual signs and overall tactile-bodily interaction is always helpful when interacting with persons having sensory deficits. Slow, clear speech and numerous repetitions clarify the situation. I try changing the tone, height and volume of my voice to find out the best way to interact and keeping the attention. One young blind man I met only got in contact with me and received the instructions when I was *singing* them to him. Normal speech didn't reach him, regardless his alleged normal hearing. Knowledge of individual prerequisites for the test situation can be obtained in advance, but also by daring to try out. The elements of *dynamic assessment* and *intensive interaction* (see Nind & Hewett, 2001) help me to concentrate on the interaction. Making a video of the assessment situation and watching and analyzing it together, is interesting, helpful and often necessary to find out small things and to demonstrate them to others.

Test materials: tactile modality and the use of vision

Many of the test materials, especially in the first, easier tasks of Bayley-III, are three-dimensional. There are everyday objects (spoons, cups, comb); toys (doll, teddy bear, ball, toy car) and other objects which are explorable also tactually (form boards, peg board, cubes, and cloths). They are safe and washable, making it possible to explore them by the mouth. If necessary, I also modify the objects (different textures or contrasts) or replace them by something more interesting (person's own motivating toys, for example) and easier to handle (bigger, clearer forms etc.) materials.

In later tasks (expected developmental age over 35 months), two-dimensional pictures are used. These pictures are rather clear and usable if the person has some residual sight. The pictures can also be zoomed in, brightened or given more contrast. The pictures can be separated and removed or placed in visual frameworks. Answering to the questions happens mostly by pointing (I use also YES/NO-cards) or by single words or signs. The most difficult tasks require more high-level linguistic skills.

CONCLUSION

It is clear that after applying and adapting the tasks in a highly individual way, I can't score or interpret the results using a developmental age. Not all tasks can be modified, not

all the results are reliable (do not express the actual skill of the person), and the goal cannot be to carry out the whole scale. The targets of the assessment are developmental and cognitive phenomena, and my goal of the evaluation is *maybe* to discover and observe some very individual and delicate cognitive skills, which, without the assessment situation, may not come up. After discovering something, it is possible to concentrate more on that through other assessment methods.

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OPTIMIZING INTERACTION: A PRECONDITION FOR ASSESSING COGNITION

Anne Varran Nafstad

ON WHAT TO OBSERVE

Making sense of one's relation to the world here-and-now is a fundamental continuous and shared human activity (cf. e.g. Nelson, 1996). It is therefore essential to observe and understand how a person with congenital deafblindness (CDB) is doing that. Cognitive assessment is, accordingly, understood here as an activity that professionals are engaged in, in order to get to know and understand how a particular person with congenital deafblindness engages in organizing and making sense of his/her situated interactional experience. This type of knowledge has direct practical clinical relevance to the care-taking environment that needs to continuously adapt to the activity of the individual person with CDB. Such observations of on-going and situated sense-making activities can only be made in episodes when the person with CDB is engaged in reciprocal interaction with the environment, or on the background of such episodes. Accordingly, this type of cognitive assessment requires a basic level intervention. Basic level intervention is geared at optimizing interaction so that the person with CDB can be active in reciprocal interaction with the environment. That participating inter-activity will in turn enable him/her to engage in making sense of his/her interactional experience.

Empowering participation in ongoing reciprocal exchanges with the environment is, in other words, a prerequisite for observing cognitive activity in the form of creative acts of pattern-making, sense-making, and meaning-making. The next challenge for professionals is how to recognize the manner in which a person with congenital deafblindness engages in such activities. This means to consider not only tactile cognition, but also embodied cognition. A person with CDB may for example engage in recycling patterned motion and positioning in physical space to create an embodied cognitive image that helps him/her make sense of the world and his/her situated relation to it. In sum, this paper addresses the interactional contexts that are required in order to be able to observe how a person with CDB engages in making sense of and understanding the world while he/she is in the process of interacting with it.

About relevance

The relevance of optimizing interaction is derived from developmental theory and the focus on transactional developmental

effects (e.g. Sameroff & Emde, 1998; Sameroff & Fiese, 1990). What is meant by transactional effects can be clarified in contrast to other concepts of developmental effects. If a child with congenital deafblindness does not develop in accordance with the cultural expectancy, there are four different explanatory assumptions possible:

1. The failure resides mainly in the child. In developmental theoretical terms, this assumption refers to the idea of a main effect of biological constraints on developmental outcome.
2. The failure resides mainly in the inability of the significant persons in the caretaking environment to adapt to the child. In developmental theoretical terms, this assumption refers to the idea of a main effect of environmental factors on developmental outcome.
3. The failure is the result of a negative bidirectional influence between characteristics of the child and characteristics of the caretaking environment, which corresponds with the idea of an interactional effect of biological and environmental factors on developmental outcome.
4. A negative interactional effect of organism and environment may escalate over time and over different significant relationships. Escalations of interactional effects in a positive or negative direction are in accord with the idea of transactional effects on developmental outcome.

This paper proposes, as mentioned, to understand cognition and congenital deafblindness in terms of the fourth type of explanation – transactional developmental effects. There is a high risk of negative transactional developmental effects of congenital deafblindness. To access cognition by focusing products of learning may not be valid, although reliability may be high. In other words, it may be that professionals easily agree on skills and contents that are lacking from a mainstream point of view, but this does not mean that they have assessed the person's actual and active use of cognition. It may rather be that it is more difficult to recognize how the person with CDB actually engages in making sense, than it is to recognize a lack of culturally expected forms.

About instruments

In accord with the relevance mentioned above, we need instruments that help us observe the circumstances, and the manner, in which the person actualizes cognitive potential during the process of interacting with the environment.

Nafstad and Rødbroe (1999; 2013) developed a model that builds on the mentioned principles adapted from developmental theory. The model is also based on exemplary case studies from the clinical practical field of congenital deafblindness. The model, referred to as 'the developmental profile', presents guidelines to basic level intervention that is geared at empowering the processes that are basic to the development of symbolic communicative relations. The model also presents observational cues that help identify the manner in which a person with CDB, without language, makes use of embodied cognition during and on the basis of interacting with the world, within playful, affectionate and explorative relations. The model proposes to look for observational cues to creative and co-creative engagement in acts of sense-making, meaning-making and language-making during, or on the basis of, the interactional experience that is built up in these relations. The instrument requires that the episodes of interest are videotaped. The instrument guides what type of episodes to tape, the formal qualities of such episodes, how to analyse the videotapes and presents guidelines for analysis-based interventions.

The context for assessment

The instrument referred to as 'the developmental profile' proposes that the basic context for psychological development is bio-ecological and captured in the context of face-to-face interaction. The face-to-face context is in turn divided into four sub-contexts, called environmental relations. The three basic relations are built up as dyadic interaction patterns and they are referred to as 'social-interactive play', 'social-affectionate play', and 'exploration-from-base'. The fourth relation is triadic and referred to as 'conversational symbolic interaction'. The model describes how the triadic relation (i.e. conversational symbolic interaction) is an implied possibility of the mentioned dyadic relations. A central reference in terms of developmental theory is the bio-ecological model of development described by Bronfenbrenner and Ceci (1994). According to this model, potential can only be known from what is actualized. It is possible, however, to enhance proximal exchange processes in order to increase the actualized potential for effective psychological functioning.

When proximal exchange processes are strong, exchanges take on an increasingly more complex dynamic structure, which in turn enables more genetic potential to be actualized. When they are weak, progressively more complex dynamic

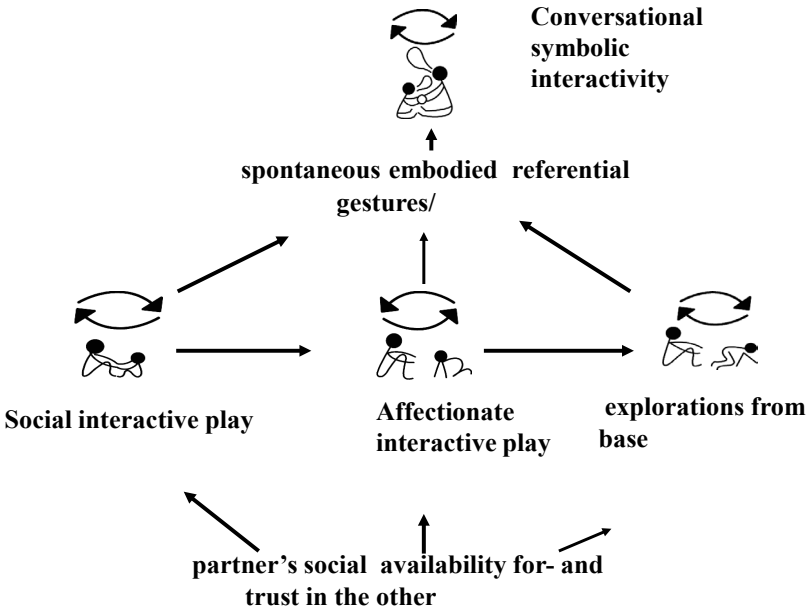
structure regulating exchanges are impaired and relatively less potential is actualized. Accordingly, the focus during analysis of cognition is on strong proximal exchange processes. Strong proximal exchange processes in the domain of face-to-face interaction will then characterize a core context for psychological assessment as it will lead to the development of different basic dimensions of agency. There are a number of different observational cues to different dimensions of agency given in 'the developmental profile'. The characteristics of strong proximal processes are:

1. The person with CDB is active throughout the sequence.
2. Exchange sequences have high levels of reciprocity.
3. Sequences with high levels of reciprocity are maintained.
4. Increasing complexity of micro exchanges inside the sequence.
5. Sequences of increasing complexity are stable over time and across central arenas in daily life.
6. Interaction patterns that regulate uptake from the environment take on increasingly complex dynamic structure.

Basic intervention is accordingly geared at empowering these proximal exchange processes, on the basis of which one may observe the manner in which the person with CDB engages in making sense of interactional experience. The model 'the developmental profile' is illustrated below (Figure 1). The illustration reads from bottom up and from left to right. The basic requirement is that the partner is socially available for the person with CDB and trusts in his/her basic interest to engage in face-to-face interaction. The bidirectional arrows illustrate a relation established through reciprocal exchanges. The unidirectional arrows illustrate the commonly observed main direction of positive transactional processes. This means, in other words, that reciprocal engagement in the relation called 'social interactive play' will empower the person with CDB to move closer to the playmate and eventually engage in more affectionate interactivity. The person with CDB may on the basis of such interactional experience construct the partner in the role of a secure base, from which he may venture to explore some aspect of the world. Not necessarily physically distal aspects, but aspects that are capturing his attention and leading him to engage in processes of making sense or categorizing interactional experience. Such engagement expresses cognitive agency and may for example be indicated by the person's spontaneous creation of an embodied gesture, often an idiosyncratic one. Other cues to

cognitive agency in the process of interaction come from observing the dynamic structure that characterizes the manner in which the person with CDB directs attention within the different frames, and in particular within the conversational frame. Conversational agency will be a complex variation of cognitive agency.

Figure 1
The developmental model



An example

E is 10 years old. She is an athletic person; likes for example to jump on the big trampoline in the garden, likes balancing and climbing, and can do that on her own. E has CDB, and she has no language in the linguistic sense. She communicates mainly through bodily positioning, pushing-and-pulling gestures, and can also use such gestures in tactile conversational play. The purpose of the observation is to understand the manner in which E makes sense of interactional experience, i.e. how she uses embodied cognition (cf. e.g. Johnson, 1987). In order to observe that, we need a context that motivates her to engage in such activity. Two consultants specialized in deafblindness design the observation. They collaborate closely with her professional contact person, who is also E's major playmate, a person to whom she is positively attached, and also her major communication partner. The collaborating contact is accordingly a person who is likely to be very sensitive and responsive in relation to E's expressions.

The consultants guide the contact person during the observation and videotape the session. Afterwards, they analyze the tape in detail and inform about the result in a meeting with staff and parents. Implications for intervention are then discussed. The intervention is, basically speaking, about us all understanding the child better, in particular the child's use of embodied cognition. Thereby her sense-making activity may be met and expanded on, leading to improved developmental conditions.

We observe the following events, categorized according to the principles in 'the developmental profile':

The contact person is asked to position herself in the role of playmate on the trampoline, offering to jump together. She is advised to follow her jumping, give her the lead. After a while of jumping together face-to-face while in tactile contact, the child stops. We advise the contact person to stay in the same place on the trampoline and observe what E does.

When analyzing, we take this phase to be social interactive play, and that the experience has a positive transactional effect on the child in the sense that she can construct the contact person in the role of a secure base, from which she can explore the characteristics of the trampoline and her situated availability for her on it.

E starts to move away from the contact person, she moves away to the edge. Then she starts to move in a patterned manner around the edge of the big trampoline and across the trampoline from all four corners, swiping the contact person lightly with her hand as she passes. This pattern is recycled during an episode of several minutes. The contact person is told to remain in the same location.

During analysis, we take this to be an indication of E making a scanned mental image of the trampoline, and the location of the available secure base in the middle. E uses her whole body in the process; patterned, recycled motion, positions, and locations. We notice how much work it is for E to build up this image, and how long it takes from our sighted and hearing perspective.

On the basis of this fragment of the observation, we learn to understand why E can so easily be disturbed in her projects of making sense of interactional experience, and that the manner in which she uses her body is very patterned and maybe more cognitive-bodily than motoric in the usual sense.

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THE DEVELOPMENTAL PROFILE AS A BASELINE ASSESSMENT TOOL FOR DEAFBLIND ADULTS

Henriette Hunsperger-Ehrlich

AIM OF THE ASSESSMENT

The original purpose of the developmental profile (Nafstad & Rødbroe, 1999) was the use as a model for improvement of the quality of interaction between a deafblind child and its teacher. Besides that, it is possible to use it as a basic instrument for assessment of cognitive and communicative capacities in children, youngsters and adults with dual-sensory impairment and multiple cognitive and bodily disabilities. For this purpose, we have made a few amendments (Ehrlich, 2007). Pedagogic professionals with experience in the field of deafblindness and knowledge about the Co-Creating Communication Approach (Nafstad & Rødbroe, 1999) can accomplish it.

The developmental profile shows a couple of cognitive and communicative capacities which are needed for communication. This means that they are needed for social interaction too. They are categorised in four fields which are the crucial parts in communication development. Those are: the co-regulation of social interaction, proximity, exploration, and communicative expressions. If a deafblind person shows all of the described capacities, he or she is able to perform symbolic, referential, and deictic gestures; in other words, to communicate on a high level.

The aim of the assessment is to get more detailed information about the cognitive and communicative capacities of a deafblind person, in order to support his or her communication development as well as possible.

PRINCIPLES OF PROCEDURES

The deafblind person in focus is being observed and assessed in a usual daily life situation of social interaction with a competent interaction partner. It is necessary to record several different situations on video, in order to select 10 minutes where the deafblind person in focus shows his or her best.

The assessor needs to know the theoretical background of the developmental profile (Nafstad & Rødbroe, 1999). He or she needs also to consider individual details of the person in focus. Therefore, he or she analyses the video sequence together with a person who knows the deafblind person in focus and his or her life story very well. For the analysis, they use a questionnaire which includes 18 items with assessment questions concerning different cues. The items are organized in the five areas (A) Emotional Involvement in each other/ Bonding/Sociability, (B) Co-regulation of social interaction, (C) Co-regulation of proximity and distance, (D) Co-regulation of

exploration, and (E) Communicative expressions.

After answering the assessment questionnaire, the results can be transferred into the communication profile (see the example in Figure 1). Now, a baseline of the cognitive and communicative developmental stage of the deafblind person in focus is made observable. In the green field, we see already developed capacities and possible potential of improvement. In the red fields, we see the lack of development and where intervention has to take place.

The intervention for building up and improving cognitive and communicative capacities should be based on the Co-Creating Communication Approach also.

B Co-Regulation of social interaction

4. Reciprocity		5. Attention		6. Intentionality		7. understanding intention		8. Anticipation	
dialogical play		joint attention		yes		yes		yes	
small dialog. sequences		attention on one		yes, sometimes		in parts		in parts	
				no, rather seldom					
no interactive play		difficulties		no, never		no		no	
not observable		not observable		not observable		not observable		not observable	
other		other		other		other		other	

Figure 1
Co-Regulation of social interaction

USING THE DEVELOPMENTAL PROFILE AS AN ASSESSMENT: AN EXAMPLE

When Karl, a 50 year old man, moved from a psychiatric hospital to a residential group home in Tanne (the Swiss foundation for people with deafblindness), he was described as deafblind, severely mentally retarded, withdrawn, self-abusing, and not able to communicate. Because his new caregivers believed he had more capacities than he showed, they wanted to make those capacities observable, and they aimed to develop his communication abilities. Therefore, they tried to use the developmental profile in an assessment of cognition and communication.

The following steps were undertaken:

1. Finding situations where Karl can show his best.
2. Selecting a competent interaction partner; informing him or her about the criteria for achieving a good video sequence.
3. Taping videos of Karl in interaction with the competent partner.
4. Watching the video material and selecting the best sequences of 10 minutes.

5. Analysing the sequences with the assessment guideline; answering as many questions as possible.
6. Description, interpretation and presentation of the results; intervention planning together with the team.

The following recommendations have been considered while using the Developmental Profile as an assessment:

Setting for observation

- The person with deafblindness (DB) in focus is in a good shape, not tired, not ill.
- The DB in focus is in interaction with a competent partner. A competent partner behaves in a way which makes dialogical interaction possible (see Co-Creating Communication).
- The interaction partner feels comfortable with being taped on video and being analysed.
- The DB in focus is in a well-known situation with well-known people in a familiar room. But there is also a challenging, new component in the situation which provokes the DB to show his or her capacities.
- The attachment persons of the DB choose a daily life situation where the DB normally shows his or her best. In other words, a situation where he or she is often active and communicative. It can be a situation that the DB likes very much, and in which, he or she is highly interested and motivated.
- The interaction partner aims to create a reciprocal, dialogical interaction where both partners are active in taking turns, pay attention to each other and to an object, and communicate about something. They experience a mutually influenced event together.
- The interaction partner does not have any plans for what exactly should happen in the situation or how it has to end. He or she is open to any contribution from the DB in focus.
- The interaction partner creates an artificial moment within the natural situation: He or she leaves the room for a few seconds and then comes back. Some of the cognitive and communicative capacities are best seen in this situation.
- The situation has to be taped on video. The analysis is only accomplishable by watching a video sequence again and again, and sometimes in slow motion.
- Nobody intervenes in the interaction.
- If possible, the interaction is limited to 10 minutes.

Principles for taping the video:

- The assessor must get the permission to tape the DB in

focus on video and to use it for the assessment.

- The video has to be taped either by a third person (e. g. the assessor), or by a camera in a fixed position.
- The camera operator does not talk or intervene in the situation. He or she tries to stay in the background and out of the focus of the DB.
- Both partners have to be fully visible all the time. Avoid zooming in for close-up-shots during the film.
- The camera should be fixed on a camera tripod and only be moved when necessary, because the interaction partners move out of the picture.
- The film should start a minute before the interaction partner contacts the DB in focus, in order to see the DB alone with him- or herself, how interaction begins, and how the DB changes when he or she is in interaction.
- The film ends a minute after the interaction has ended, in order to see how the interaction ends, and to see if any gestures occur afterwards which refer to the interaction.
- If the video sequence is longer than 10 minutes, the assessor has to cut out moments of less interest.
- If the attachment person considers the taped situation as not being the 'DB's best', a second or more videos can be made. It is important to have the same interaction partner for different videos.

Principles for the video analysis:

- For the analysis, the best 10 minutes of all video material have to be chosen. The best sequences are those with a sustained *duration of repetition* of interaction patterns, the highest *complexity, flexibility* and *stability* (Bronfenbrenner & Ceci, 1994).
- The assessor analyses the video together with an attachment person of the DB. They use the assessment guideline and try to find a shared answer for each question. The assessor contributes with the theoretical background and gives clues where and how to identify the cognitive and communicative capacities. The attachment person contributes with the individual personality facts of the DB and his experiences in contact with the DB in different situations.
- The selection of the best 10 minutes of the video material can take different amounts of time depending on the amount of video material. For the analysis, you should have at least two hours available.
- In the assessment questionnaire, not necessarily every question has to be answered. All questions, which can be

answered, are answered. It is allowed to check two answers to one question, but not to put a check-mark in-between two answers.

- The purpose of the communication profile, which arises from the analysis, is goal-directed communication intervention on the basis of the Co-Creating Communication Approach. Therefore, the results have to be interpreted with the aim of finding the focus of intervention.
- In the interpretation of the assessment results, the age, the life story and the impairments of the DB in focus have to be considered.
- When interpreting the results, one has also to be aware of the influence of the non-disabled interaction partner on the situation. It is possible that a DB shows more capacities in another situation with another interaction partner.

Karl's communication profile showed that he is able to perform high-level cues, but in a very unstable way. Low-level cues could hardly be found. This result gave the advice that Karl's communication skills were built up in valuable social interaction in his childhood, but were massively reduced by deprivation, perhaps due to the long-lasting hospitalization in the psychiatric hospital. It also brought clues for starting an intervention, namely to create situations where lower cues can be developed. How to build these situations is described in the Co-Creating Communication Approach.

After five years, the team of caregivers had completely changed. Due to Karl's communication profile, everybody knew about his communication skills.

Six years later, the team did not continue to follow the way of intervention, even if Karl's development occurred very slowly. It helped undertake the assessment again and to see little steps of development. Now (2013), Karl's caregivers are motivated again to concentrate on certain cues and intervention strategies.

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ASSESSMENT OF THE REGULATION OF INTERACTION

Vivi Andersen

TARGET OF THE ASSESSMENT

The target of the assessment is to evaluate the child's regulation of interaction. One of the crucial factors for the infant's ability to engage in social interaction is its level of alertness and activity (state). This affects the infant's contact and communication profoundly.

In a child with deafblindness, it can be difficult to interpret the different phases in the contact cycles, and it may even be difficult to establish contact at all. Children with disabilities are more delicate towards stimuli than other children, and will therefore often react by withdrawing themselves and showing borderline/limit reactions.

BACKGROUND INFORMATION ABOUT THE INSTRUMENT:

Assessment of a child's regulation of interaction is performed using observation of his behavior in interaction. The observation cues that are looked for are derived from three theories: (1) theory on alertness and activity (Brazelton, 1984), (2) theory on mother-child dyadic interaction (Lier, 1981), and (3) theory on communicative interplay (Tronick et al., 1980).

Alertness and activity

Brazelton (Brazelton, 1984; Brazelton et al., 1990) distinguishes between six basic levels of alertness and activity:

1. Deep sleep – the child sleeps without being disturbed by the sounds around it.
2. Light sleep – the child twitches occasionally. REM sleep corresponds to dreaming sleep in adults. Breathing is faster than during deep sleep.
3. Drowsiness – the child is calm and relaxed, with half-open eyes, relaxed movements. The transition between sleep and awakeness.
4. Quiet alert attention – intense observation of the surroundings, calm movements, regular respiration. Quiet alert attention is part of the communicative exchange game. For example when parents make patterns of exclamations, the child watches the parent observantly. It moves only slightly, the eyes are wide open; the expression is that of attentive listening. Cf. Tronick's play dialogue (Tronick, 2007).
5. Active alert attention – movement wise the child is active,

experimenting with sounds and mimic. In this active alert state the child interacts. It moves, looks around and makes sounds. If stressed, the movements of the child escalate and facial expression changes.

6. Crying – strong motor activity, upstart of restlessness and crying.

Shifts between the different stages appear regularly from birth and are regulated by the biological rhythm. As the child gets older, its ability to control these conditions gets better – just as the differentiation between them becomes clearer and the transition between them less abrupt.

MOTHER-CHILD DYADIC INTERACTION

As a basis for understanding the importance of dialogue, I have found Lene Lier's (Lier et al., 2005) thorough research of the interaction between mother and child, and its impact on child development, very helpful. Lier has described the synchronization of interaction in a contact cycle that contains the basic elements of a dialogue/communication. With regard to the need for contact, the child typically has a pattern where it shifts between looking at – and looking away from – the parent holding it. In contrast, the parents look at the baby almost all the time. In this way, the parents become a framework for communicative options for the child's expressions.

Lier and colleagues (2005) came up with the following in the mother-child dyad:

1. *An impressive (receptive) phase* characterized by the child's attention towards the mother's soft voice and gestures. The child is relaxed with lips soft and loose, open eyes, actively listening and paying attention.
2. *An expressive phase* begins with the child lifting his arms towards to parent. It is now active both in body movements and facial expressions while experimenting with producing sounds. The mother is listening, watching and awaiting the different expressions of the child.
3. *A pause phase:* The child seems to be able to self-regulate how many impressions and how much activity it can handle. When the activity is over, the child yawns, closes its eyes and turns its head away to show that it is now filled with impressions and needs a break.
   It is crucial for the child's understanding of dialogue or interaction that parents/staff respect the child's way of reacting and only try to resume communication when the

child shows that it is ready again. When ready to resume communication, it will look carefully at the mother's face and keep the body at rest.

4. *Limit reaction:* If the mother ignores the child's signals and continues to appeal to the child's attention with speech and gesture, it can result in the child becoming restless, crying and needing to be comforted and soothed.

Phase 1 and 2 constitute the communicative interplay – my turn/your turn-activity. Intuitively, the mother creates a structure in these first conversations with the child by alternating between talking to and smiling at it and waiting for the "answer". Thus, a dialogue is developed between mother and child during the child's first months where the child alternates between listening to the mother and responding to her with smiles and babble. During a contact cycle, the mother-child pair illustrates a spectrum of mutual adjustment where the balance between challenge and reassurance play a role in the child development.

COMMUNICATIVE INTERPLAY

Tronick and colleagues (1980) gives a detailed description of how the adult is trying to achieve contact. Tronick considers the following five phases to be typical of the interaction between a mother and a three month old baby:

1. *Initiation phase:* where either the adult or the child initiates contact. The mother's face lights up – she looks at the child – talks "baby talk" to it. Or the child starts the communication by vocalizing and smiling to the mother.
2. *Phase of mutual orientation*: where the adult and the child are preoccupied with looking at each other or body-wise facing each other. They smile at each other, maybe including body movement.
3. *Greeting phase*: Is characterized by the partners looking at each other.
4. *Play dialogue:* This phase corresponds with the phases 1 and 2 of Lene Lier's description (Lier, 1981). The mother speaks in a break – break (burst) pattern and the child responds by vocalizing during the periods in which the mother pauses.
5. *A disengagement phase*: This phase corresponds with Lene Lier's stages 3 and 4. This phase occurs when one party looks away from the other, while the other is still oriented towards interaction.

I find Tronick's descriptions important, because his three initial phases clearly illustrate some of the problems parents of children with deafblindness may have. Parents often find themselves in a situation where they do not feel that it is possible to achieve contact with their child. Thus, they find themselves stuck in the initiation phase constantly trying to make contact. For children who due to premature birth, and/or disabilities, are particularly vulnerable, these contact attempts may seem too overwhelming. The child looks away or shows limit/borderline action in the form of restlessness and crying.

In typical children and children with deafblindness, the following reasons for contact/communication breakdowns exist:

- Some children have very short phases of contact in both the receptive and the expressive phase, or need longer breaks to digest/process and provide response (be successful in their efforts).
- Some children have sharp/sudden changes in attention levels.
- Parents have difficulties in adapting to the mode of contact – to the child's condition and rhythm.

Through emotional interactions, the caregiver regulates the child's emotions during the various stages of childhood, with respect to their intensity as well as their complexity. Schore concludes that the essence of the self consists of affect regulation patterns that eventually manifest as permanent self-experiences (in Fonagy et al., 2006). Schore considers the concept of synchronization as important for attachment formation (Fonagy et al., 2006). Synchronization is defined as a match between caregiver and infant activities that support a positive atmosphere. The caregiver synchronizes with the child through structured interactions of play. Thus synchronization is also of the utmost importance for professionals involved with children with deafblindness.

THE INSTRUMENT

In order to help structure the observation, I developed a questionnaire. This questionnaire is a tool that can be used to observe the child and his/her social partner's ability to regulate the social interaction. The observation can both take place in a structured and unstructured situation.

When we look at the interaction of the selected situations, we can ask the following questions:

- What phases or contact cycles do the selected situations consist of?
- What does the start phase look like?
- What does the phase of mutual orientation look like?
- What does the greeting phase look like?

- How does the person with deafblindness show that he/she takes the world in (receptive stage)?
- How does the person with deafblindness show that he/she processes his/her impression?
- How does the person with deafblindness express himself (expressive phase)?
- How does the child express his/her interruption phase?
- How does the child express his/her borderline phase?

The abovementioned questions can be subdivided into the following phases:

1. Receptive phase:

- Can the parents or other adults elicit the child/adolescent or adult attention? If yes, how?
- Can focus be maintained over time? How long? Which factors maintained the awareness of the child, adolescent or adult?
- Does the child, adolescent or adult person follow things with the eyes? Is there a preference?
- How SMALL an impact is needed before the child/adolescent or adult reacts?

2. Expressive phase:

- How does the child/adolescent or adult express needs, desires, pleasure, discomfort, etc.
- Which signals and active movements does the child/adolescent or adult master? How does he use it?
- Does the child/adolescent or adult get sufficient time to answer?
- Do we respect the child's/adolescent's or adult's choice and activity (or do we interrupt it too fast or dominate with our proposal?)
- Does the child/adolescent or adult show initiative? How? Do we follow up on them? How?

3. Pause phase & 4. Border action:

- How does the child/youth or adult express that they need a break?

- Is the pause signal perceived and respected?
- Is the child/adolescent or adult easy or difficult to calm down after a border action? What does he/she/they do?

AN EXAMPLE OF A PRACTICAL APPROACH OF THE REGULATION OF AROUSAL

Peter is a 13-year-old boy with congenital deafblindness. He struggles with regulating his arousal levels and he is very sensitive to different types of stimuli. On one hand, he needs distinct stimuli to be "awake", on the other hand such stimuli can lead to overload. His teacher is concerned about his ability to stay focused in activities over time.

The aim of the assessment was to try to identify the phases of Peter's alertness and his activity levels, to support and facilitate his regulation of arousal in order for him to be able to participate longer during activities.

A dynamic assessment procedure was used, and it started with a video of an interaction between Peter and his teacher where they were singing and jumping on a trampoline. Thereafter, the assessor analysed the video together with the teacher, and intervened on how the teacher could recognise Peter's arousal levels and facilitate his regulation difficulties. The teacher invited Peter to a new interaction later on and tried to facilitate his regulation of arousal. They filmed it and again they analysed the new video.

In the beginning of the first activity, Peter acts very quiet and it is hard to spot any initiatives from him. This could be interpreted as the pause phase or the impressive phase. The teacher uses her body and voice to initiate the activity, and Peter turns towards the teacher. The teacher continues the jumping and singing and then she pauses, and asks Peter if he wants more. The teacher is not able to recognize Peter's different levels of alertness and activity, and this results in a breakdown of the interaction. They observe that Peter is turning his body away, getting restless, and then he starts screaming. This can be interpreted as Peter being in the disengagement phase.

The teacher and the assessor highlighted two targets for the intervention during the video analysis:

- The partner's (teacher's) tempo
- The partner's (teacher's) recognition of the responses of the child

The next activity was a dialogue between Peter and the teacher. During the video analysis, the assessor and the teacher observed that the teacher was aware of her and Peter's tempo. She managed to recognize his initiatives and responses that resulted in a sustained interaction.

The knowledge of the different phases in a dyadic interaction and the influence of arousal level helped the teacher to facilitate Peter's arousal regulation. This facilitation optimized the interaction and made Peter's cognitive potentials recognizable.

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ON PLANNING AND DEAFBLINDNESS

Henrik Okbøl

The ability to generate and execute a plan is a very important skill in all cultures, and an important prerequisite for independence. A person who cannot make or follow plans is severely disabled and totally dependent on others to take care of him and his needs.

Unfortunately, most people with deafblindness, especially those with congenital deafblindness, have problems in this area. It is therefore important for professionals to have at least a general knowledge of planning. The better the professional is able to describe and observe the different elements and parts in the process of making and executing a plan, the better he is able to aid and support the deafblind person. Enhancing a person's ability to make and execute plans will greatly increase his quality of life, by making it easier to obtain his goals and become more independent.

Planning can be described as "*The process of formulating an abstract sequence of operations intended for achieving some goal"* (Scholnick & Friedmann 1987). The representation of this sequence is called a plan. A plan can both have an external and an internal representation.

Plans range from short term and motoric (i.e. a sequence of key presses, taking a sip of tea) to the long term and cognitive (planning a trip to the cinema, a dinner or a holiday).

Within cognitive psychology, there are two views of planning:

1. *Successive refinement models* – a top-down, hierarchical process (much like a computer program) that controls the order in which a series of operations can be performed. Often, they include hierarchically organised sub-plans (cognitive and motor). At each level the planner executes a TOTE (test-operate-test-execute) unit, where the planner tests to see if a goal is achieved and then exits to the next goal. This model works well if there are no unforeseen changes or hindrances.
2. *Opportunistic models* – a data-driven process that can operate concurrently at several different levels of abstraction, with decisions at any level affecting subsequent decisions at both higher and lower levels. At each point in the process, a planner's current decision affects the opportunities available, and so decisions must be made on how to respond and change the subplans.

Examples of planning disorders:

1. **Representational degradation** – the person is unable to keep a representation of the goal in his mind, he forgets what it is.
2. **Disinhibition** – difficulty in inhibiting prepotent plans, resulting in the use of a wrong strategy.
3. **Deficits in thematic induction** – problems with recognizing the situation properly and seeing what kind of plan it calls for.
4. **Plan grammar deficits** – failure in following a sequential path when executing the plan.

When investigating a person's ability to make and execute plans, it is important to be clear about exactly what and how to investigate. The tool for this kind of investigation is always structured observations.

It is not possible to observe cognition directly. One can only observe it indirectly, by way of the actions. Therefore, it is very important to be as precise as possible when one makes the setting for the observations.

A good place to start is with the issues that make one wonder. Another question to ask before beginning is why it is important to investigate exactly this specific item? What are the practical consequences of the results? What is the applicability?

The next step is to choose a couple of situations that can elucidate the issue. In other words, one must find situations where the behavior, that is a result/consequence of what one wants to investigate, appears. One must be able to change the content in the situation, and it is important to be conscious of the things we change and the ones we keep constant.

At this point, one must observe the activity and record it on video.

After doing this, it is time to view the video several times and describe what one sees. It is important to stick to the description only and be as precise as possible.

Then, it is time to make interpretations. Here, it is important to distinguish between observations and interpretations. Make sure the interpretations are founded on the observations.

Now, based on the interpretations, one may make a hypothesis, and suggest things to try out in order to verify the interpretations, i.e. repeat the observations under different conditions.

Finally, it is also important to describe the connection between function and help in order to determine the optimal level of help needed for the best possible performance.

ABOUT THE EF-SCALE

In order to help structure the observation, one can use a scale. This scale, presented in Table 1, is a tool based on observations. The observations can both take place in structured and unstructured situations.

The first two items, under the heatdline "The ability to generate a plan" in Table 1, can take place in many different situations that require the making and executing of a plan, e.g. cooking, cleaning, sitting at the computer or shopping.

The third item requires that the observer takes initiative, and tries out different things to see which one, if any, does work.

The same holds true for the fourth item where the observer is going one step further, and presents a ready made plan for the DB person to see his reactions.

The rest of the schema is based on observations of the DBP (Deafblind Person) after a plan has been made, whether by the DBP himself or by others.

It is recommended to use video to enable the observer to look at the actions many times, as it can sometimes be difficult to decide the correct sequence of actions and their character.

When the video is ready, the relevant group of professionals gets together and makes the analysis according to the principles outlined above.

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Table 1
Screening test for planning abilities of deafblind persons

Items	Comments
The ability to generate a plan	
1. Does the DBP (Deafblind Person) show that he has a plan (an idea)? If yes, how does he show it? 2. Does the DBP take an initiative himself to initiate a plan? 3. If no, what kind of support or help is needed to get him to initiate a plan? 4. Does the student profit from a plan made by others? 5. What type of plans can the DBP make?	1. I.e. by grabbing an object or person, or by moving to a specific location (kitchen, car). 2. I.e. by grabbing or by making a move toward an object or a person, making a sign or in another way doing the initial things belonging to the first steps of a plan. 3. I.e. an object of reference, a tactile sign, a picture, a symbol, meeting a specific person or being taken to a specific location. 4. I.e. a schema for the day or an instruction about what to do. 5. Short/long – motor/cognitive.
Level of planning	
1. First level 2. Second level 3. Third level	1. Masters single sub-plans, but can't connect them into a flow. 2. Can connect known sub-plans into strings of action 3. Can create new plans, in accord with a new situation, where an old plan does not fit.
Planning (Only relevant for high-functioning DBP)	
1. Goal identification 2. Sequence 3. Time estimation 4. Strategy 5. Resources 6. Is the DBP able to collect the relevant information to execute the plan himself? 7. Is the DBP able to learn new plans and/or to add new components to an already existing plan?	1. Does the DBP execute the sub-plans in the right sequence? 2. Does the plan agree with the amount of time available? 3. Is the job done in a purposeful way? 4. Does the DBP have the necessary resources to execute the plan (i.e. helping hands)?
Execution	
1. Level of motivation? 2. Is the DBP easily sidetracked, so he loses track of the original activity? What distracts him (inner/outer distraction)? 3. Perseverance? 4. Flexibility 5. Shifting 6. Keeping the focus 7. Monitoring 8. Use feedback 9. Start – stop 10. The ability to collect relevant information, including the ability to judge between relevant and irrelevant information 11. How many part-elements can the DBP overlook in one plan?	1. What affects this? Are there big differences between different types of tasks? 2. IF the DBP is distracted and stops does he start again by himself without cuing? If no, what type of cuing is needed for him to get back to the task? 3. The ability to adjust the actions according to the situation (i.e. turning down the heat when cooking before the meat gets burned). 4. The ability to shift from one sub plan to another when necessary. 5. On-line evaluation of the progress of the plan. 6. Both from other persons and from the process itself. 7. Does the DBP need cues for every single sub-plan? If yes, which types of cues are best?

Conclusion and discussion

As part of compiling the present booklet, we have been looking for applicable assessment procedures for the assessment of cognition in relation to people with CDB. During that process, we have studied the general guidelines for psychological assessment commonly used, and we found these very helpful, but incomplete, when addressing CDB cognition and development. In order to formulate what, in our opinion, is needed in addition to such general guidelines, we have developed a few theoretical models to guide these additions.

Flemming Ask Larsen, Saskia Damen, and the Network on Cognition in Relation to Congenital Deafblindness

The dynamic/transactional model of assessment, presented in Part I, has been helpful in remembering the whole picture when devising assessment procedures and tools. We see the CDB-specific guidelines to assessment as part of assessment in general, in line with the model presented in Part II. We must never forget good standard practice and guidelines and think that CDB is so special that we cannot apply such guidelines. At the same time, we must remember the CDB-specific aspects of cognition, development, and assessment. We have tried to map out a few of these CDB-specific guidelines here, but we are aware that there is still a lot of work to be done in terms of correcting, refining, and expanding the guidelines presented here.

We have described, applied and started the development of tools and procedures from the different projects that the members of the network have been part of during the years. As an integrated part of that work, more specific theoretical models have been examined and adapted to the special case of CDB. They have served as the basis of the work undertaken to develop adequate tools and procedures for assessing specific aspects of cognition in relation to CDB. Specific

models have been developed to accommodate to the specific bodily-tactile conditions for cognition in CDB, such as the models on Tactile Working Memory and the Developmental Profile.

Our work is, as stated before, not done with the publication of this booklet. Further development of theories and procedures is needed in the future. There are still not many useful procedures and tools available for the assessment of cognition of people with CDB. To develop such tools and procedures in a sound and scientific manner is an important next step. It is our hope that the scientific society will take on this challenge in collaboration with CDB practice. The task of developing good procedures and tools can only be done in collaboration between professionals in different countries, and different areas of expertise. It is equally important that this work will integrate both theory and practice. For this to succeed, practice based research is of highest priority.

Multi-disciplinary approaches are important when developing procedures and tools for assessment of people with CDB, but they are equally important in the actual assessments in practice. For that reason, staff training on CDB-specific assessment and cognition is a future challenge.

This booklet is intended as a starting point for a thorough examination of the dynamic relations between CDB, cognition, and assessment. We hope that researchers, assessors, and interveners will find this booklet as inspiring as we have found the collaborative effort of developing and compiling its content. The final reflection will be on the title of the booklet: *Guidelines for Assessment of Cognition in Relation to Congenital Deafblindness*. We do not believe that we present ready-made guidelines for assessment of cognition in relation to deafblindness in this booklet. We do believe, however, that we present some guidelines for how to go about critically reflecting upon one's own practice and developmental work when assessing cognition in relation to congenital deafblindness.

Network on Assessment of Cognition in Relation to Deafblindness
from sensation to dialogue

Design: Johan Granli

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