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# Cognition in Interaction: Challenges in Assessing Persons with Sensory and Multiple disabilities

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## Abstract

This article reports a qualitative study of cognitive assessments of three teenagers with sensory and multiple disabilities, including moderate to profound developmental disability. The aim was to evaluate the possibilities for adapting standardized tests and the implementation of interactional partnership in assessment. Cognitive assessments were made with an individually-adapted psychological assessment tool, the Bayley Scales of Infant and Toddler Development. The assessment situations were video-recorded and analyzed based on sociocultural theories of early interaction, dynamic assessment, and the bodily-tactile modality of cognition. The results showed that the requirements for assessment are complex and highly individualized, extending beyond universal guidelines on test adaptations. The assessments were built on developmental steps within the standardized test, but required a special emphasis on individuality and interaction. We conclude that the study provides novel insights into an under-researched area of cognitive assessment, confirming earlier findings that cognitive skills become observable in unique moments of intensive interaction. The assessor must follow the principles of dynamic assessment, applying competent partner strategies such as providing safety, supporting attention, activity, and alertness, and scaffolding the target skills in the zone of proximal development. Conducted thus, the cognitive assessment process can enable the assessor to recognize, support and authenticate the agency of persons with complex disabilities.

## Keywords

sensory and multiple disabilities, congenital deafblindness, cognitive assessment, dynamic assessment, competent interactional partnership, agency

## Introduction

The groups of people with complex developmental and communicational needs are small and diverse. The concept used in this study is ‘sensory and multiple disabilities’, referring to moderate, severe or profound developmental disability, losses in vision and/or hearing and associative motor and/or medical problems. The concept is close to ‘congenital deafblindness’ and ‘profound and multiple disabilities’. The cognitive functions of people with complex disabilities are not easily observed or assessed in a structured and manualized manner. Structured cognitive assessment methods are mostly unsuitable for assessing early developmental stages or atypical cognitive progress (Bagnato et al., 2014; Soorya et al., 2017; Visser et al., 2012). In practice, this has often led to questioning whether such assessments should be conducted at all. However, without gathering knowledge on the cognitive capabilities of these individuals, there is a risk that expectations for their development remain modest and their skills underestimated (Bagnato et al., 2014; Damen et al., 2020; Einarsson et al., 2020).

Individuals with congenital deafblindness can display surprising cognitive skills in proficient interaction with a competent communication partner, and these skills can further develop when interaction is improved (Ask Larsen & Damen, 2014b; Nafstad & Rødbroe, 2013; Rødbroe & Nafstad, 1999). Finding ways to adapt standardized tests and devising an optimal interactional and dynamic assessment process may help to make the hidden cognitive potential of these people visible and available for the setting of educational and rehabilitation goals.

For the developmental psychologist, assessing cognition to predict and support development and to locate developmental deviations is a routine task. Standardized tests are rarely designed to assess or the standardization data does not include people with sensory disabilities or with severe to profound developmental disabilities (Bayley, 2009; Wechsler, 2002; 2003). Nevertheless, they are commonly used to diagnose developmental disabilities or to assess the general intelligence of a person with sensory deficits.

Visser et al. (2012) have reviewed standardized assessment instruments designed to assess small children (0-4yrs of calendar age), and their applicability for testing children with special (motor, visual or linguistic) needs. The overall result of the review of 18 tests show low reliability in testing children with special needs, because of norm problems (test floor effect) and excessive impact of the motor-, visual-, or linguistic problems on task performance, even when tasks do not directly measure motor-, visual-, or linguistic functions (Visser et al., 2012). As Soorya et al. (2017) state, no child should be judged as untestable due to the lack of suitable tests. They emphasize the growing need for reliable and valid methods for the developmental and neuropsychological evaluation of persons with profound intellectual and multiple disabilities (PIMD), for both clinical and research purposes. Dammeyer (2011) defends the cognitive testing of persons with congenital deafblindness, despite the shortcomings: multidisciplinary assessments combining structured tests and observations are especially important in clarifying comorbidities and hierarchies in diagnostics and in planning the best support.

The argument for standardized cognitive assessment rests on the idea that individuals' cognitive skills can be objectively measured, independent of the assessor. However, several studies have shown that standardized assessment conducted by the manual is also an interactional phenomenon, very much related to the behaviour and interpretations of the assessor (see, e.g., Marlaire & Maynard, 1990; Maynard & Marlaire, 1992; Muskett et al., 2012). Authentic assessment, meaning systematic, long-term observations of development in natural settings, is described in Bagnato et al. (2014) as more sensitive, practical, understandable and socially valid than conventional standardized testing (e.g., Bayley Scales).

However, by applying a standardized test in a dynamic and qualitative way, the assessment processes in this study largely meet the definition of authentic assessment. The study is based on socio-cultural theories that underline the importance of other people and interaction in cognitive development, functioning and assessment. As Ask Larsen & Damen (2014a) have stated, to *assess* the cognition, you first need to *access* it: Access needs interpretation of *what is* cognition, and recognition that there *is* cognitive activity. It also requires meaningful interaction and realization that the actions of the partner are *meaningful* (Ask Larsen & Damen, 2014a). This principle of accessing as a prerequisite for assessing has guided the planning and the analysis of this study. In the *Guidelines for Assessment of Cognition in Relation to Congenital Deafblindness* (Ask Larsen & Damen, 2014b) the specific elements of assessment include for example the use of video analysis, dynamic assessment, emphasizing the bodily-tactile modality, and optimizing the interaction in the assessment situation. The interactional theories supporting these principles are presented next.

Sameroff (1975) suggests a dynamic combination of observing transactions between biological, behavioral and environmental systems. Taken further, Vygotski (1978) thinks that cognition is only understandable in interaction. Dynamic assessment (DA) has a long history in the assessment of normal learning as well as specific aspects of learning (Feuerstein et al., 1994; Haywood & Lidz, 2007; Tzuriel, 2001). Whereas traditional psychological assessment with standardized tests tries to find out what the child knows and has learned compared to others, in DA the procedure is individualized: The goal is to find out potential in optimized settings and to reduce the obstacles of learning; to find out what the person is capable to learn and how (Haywood & Lidz, 2007). In DA, the assessor is an active partner, who scaffolds the learner across the gap between observable and potential skills and whose role and skills are an important part of the assessment (Haywood & Lidz, 2007). Vygotski (1978) describes this gap as the 'zone of proximal development'. DA gives information about individual development and is recommendable when standardized tests either cannot be applied or they give unreliable (usually too low) results of the individual's abilities (Haywood & Lidz, 2007).

The importance of interaction in cognitive assessment becomes understandable also when considering the relevance of interaction in cognitive development and functioning. According to Trevarthen and Aitken (2001), theories and studies of intersubjectivity describe how human beings have innate awareness of and receptiveness to subjective states of other people, and how this natural sociability serves to motivate companionship and cooperative awareness, leading eventually to

development of language. Early intersubjectivity, also achievable in the earliest developmental stages, is based on motivational and emotional elements of interaction with rhythmic, musical, repeated, slowly changing, cyclic narratives of emotion, where expressions are exaggerated, clarifying feelings and intentions, while minimizing the importance of words (Trevarthen & Aitken, 2001). In the dialogical view, communication develops through successful connection achieved by mutual striving for reciprocity, common perspectives, and a shared social world (Markova, 2017; Seikkula et al., 2018). Individuals' affective arousal is mutually regulated in interaction, which comprises a constant stream of multiple communicational modalities, even in primarily language-based couple therapy situations (Seikkula et al., 2018). If a person has even mild visual and auditory losses, the tactile sense is more in use in all information gathering and in social and physical relations (Nicholas, 2010; 2013; Nordic Centre for Welfare and Social Issues, 2011). Bodily-tactile contact is natural for people with sensory and multiple disabilities, and therefore crucial in assessing their cognitive processes. For a person communicating in bodily-tactile way, close contact to another person is extremely important, and communicative expressions are not easy to separate from other actions (Linell, 2017; Nicholas, 2010). To connect to others requires 'listening other' that recognizes the other as an interesting individual having meaningful thoughts and actions, having cognitive skills even though they would not be easily readable and accessible (Nafstad, 2015). Non-verbal, bodily-tactile communication is easily misunderstood or disregarded, leaving persons who are reliant on it at a constant risk of feeling that they are not being listened to, not being noticed, and not being (Markova, 2017; Nafstad, 2015). Communication between a person with congenital deafblindness or other multiple disabilities and his communicative partner is always asymmetric, as much in sensory-perceptual and cognitive as in cultural ways (Linell, 2017). The person's special kind of attunement (related to oversensitive or minimal reactions and lack of feedback) needs to be noticed by the communicative partner and supported by bodily-tactile modality (Janssen & Rødbroe, 2007). Elements like concentrating, waiting and pausing, being responsive, alert and emotional, and adapting one's own communication, promote a competent interactional partnership (see e.g., Forster, 2008; Janssen & Rødbroe, 2007; Nind & Hewett, 2011). Agency can be defined as a person's experience of being and growing as a self in a dialogical space (Nafstad, 2015). By communicative agency, Nafstad refers to a person's ability to endure the tension between striving towards the self and towards the other. Trusting that one is being listened to gives a person the necessary sense of co-presence, a feeling of respect from the listening other (Nafstad, 2015). The tension between one's own understanding and mutual understanding must be on the right level: if too low or too high, the motivation to communicate diminishes (Nafstad & Rødbroe, 2013). Hostyn et al. (2010) state that it is meaningful and rewarding to strive for shared understanding, even if this is not achieved. For it to occur, the more capable partner must believe there is potential for communication (Linell, 2017; Nafstad, 2015).

## **Aims of the study**

The scientific research on the cognitive assessment of persons with sensory and multiple disabilities is scarce. This study aimed to contribute to this rather limited literature by addressing the utility of standardized tests and the use of DA in cognitive assessment of these individuals.

The research questions were: 1) How can standardized tests be adapted to assess persons with sensory and multiple disabilities? 2) What effects do elements of DA have on the assessment? 3) How does cognition manifest in interaction?

This study holds back from offering recommendations or guidelines on adaptations of standardized tests or drawing conclusions about effective versus non-effective interactional elements in the assessment situation. Neither does it seek to define general types of bodily-tactile cognitive manifestations. If it was hoped to find general elements of these kinds in this study, any such aim was eclipsed by the main finding of extreme individuality.

The agency and self-determination of persons with severe or profound developmental disabilities require both acknowledging the existence of their cognitive potential and respecting the complexity and diversity of interaction and cognitive manifestations, including also the non-verbal and bodily-tactile modalities of them. This study aimed to approach and discuss the roles and implementations of interaction in understanding and assessing cognitive functions, and to evaluate the role of cognitive assessment process in recognizing cognitive potential and agency.

## **Method**

### **Ethics**

The Ethical Committee of the Hospital District of Helsinki and Uusimaa (Finland) and the authority responsible for the rehabilitation of the participants (Rinne Foundation) approved the research.

Informed consents were given by the under-aged participants' parents as their legal representatives. Because the participants lacked the intellectual and communicative abilities to give their views on participation, the assessment procedure was planned and implemented to respect individual needs and optimize environmental and interactional conditions. The procedure was discussed with the parents in detail, including the possibility to withdraw from the study at any time without explanation. Parents had a possibility to take part on planning the assessments and also to see the video data afterwards. The anonymization procedure as well as the safe processing and storing of the data was explained in detail.

## **Instrument**

The Bayley Scales of Infant and Toddler Development (Third edition) (Bayley, 2009) is a standardized and well-established psychological assessment tool designed to evaluate early developmental stages and possible dysfunctions in young children (age 0-43 months). The Bayley Scales have been rigorously developed and draw on cognitive and developmental (e.g. Piagetian and Vygotskian) theories (Bayley, 2009; Albers & Grieve, 2007). The instrument is also flexible not only in accomplishing separate tasks but in detecting developmental phenomena.

The Cognitive Scale of Bayley III (Bayley, 2009) assesses the following cognitive functions: attention and anticipatory performance, habituation, exploration and manipulation of the environment, self-awareness, object retention and permanence, causation (items 1-39: reference age 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), and numeracy, multischeme combination play, grouping, sorting, classification, discrimination, and spatial memory (items 70-91: 39-42 months). The Bayley Scales were originally designed to assess children without severe disabilities (Bayley, 2009). In clinical work, psychologists in the developmental disability field also use the tool to assess persons whose complexity of problems or developmental stage does not allow the use of other standardized assessment tools (e.g. Wechsler tests; Wechsler, 2002; 2003). The test materials and assessment practices of the Bayley (toys, everyday objects, functionality, play-based tasks) have been found to motivate those using tactile modality to compensate for visual and auditory deficits (see e.g. Tuomi, 2014).

## **Procedure of data collection**

The data consisted of video-recorded cognitive assessment situations of three participants with sensory and multiple disabilities. The assessments were conducted with individually accommodated tasks based on the Bayley's Cognitive Scale (Bayley, 2009).

Parental interviews, medical records and videos and observational notes on daily situations served as baseline data (Tzuriel, 2001; Haywood & Lidz, 2007) considered essential in DA and in assessing persons communicating on a prelinguistic level (Boers et al., 2013), with congenital deafblindness (Ask Larsen & Damen (eds.), 2014b) or with PIMD (Soorya et al., 2017; Simmons & Watson, 2014).

Based on this data, individual assessment procedures were planned. The interactional and other environmental elements (lighting, temperature, auditory impact, safety) of the situation were optimized. The test materials were accommodated to best support the sensory modalities and interests of each participant (see e.g., Tuomi, 2014; Visser et al., 2013; 2014): The visual stimuli of the Bayley tasks were replaced partly or entirely by tactile or olfactory stimuli, while following the idea of the original task. Alternative objects based on individual interests (like slimy worm instead of a miniature car, a comfortably familiar toy, or a toy with vibration, sound and light) were used to motivate and to support the multisensory modality in tasks measuring problem solving, following instructions, matching and

play (Bayley, 2009). Participants were offered time and encouraged to gain acquaintance with the tasks and to explore the objects tactually.

DA methods (Haywood & Lidz, 2007), especially the unique methods used with young children listed by Tzuriel (2001, p.64), were applied in the planning and implementation of the assessment: Bayley Scales III was chosen as the assessment tool partly because of its *attractive and manipulative test materials*. The materials were *accommodated individually*. The tasks were presented gradually in order of difficulty and were linked to each other (slightly different versions of the same task). This allowed *bridging* from concrete operations to abstract levels of functioning, towards more difficult tasks (Tzuriel, 2001). *Communicational aspects* ranged from wholly gesture-based (Anna) to shifting visual-bodily-tactile (Lisa) and to verbally fluent but bodily-tactically supported communication (Onni). *Assessments of non-intellective factors* (e.g., accessibility to mediation, frustration tolerance, alertness, defensiveness, confidence) were an integral part of the procedures (Tzuriel, 2001).

The assessments were divided in several meetings to build up the interaction and to allow comparisons between situations. Assessments were video recorded with one camera, with the bodies of both the participant and the psychologist on view as much as possible.

## Participants

The three participants were Anna, Lisa and Onni (fictive names), ages between 13 and 16 years. The participants were chosen not only as representative of the target group of persons with sensory and multiple disabilities, but also because they differed in the level and type of their disabilities, thereby representing the diversity and richness considered important for qualitative research data (see e.g., Markova, 2017; Cresswell & Miller, 2000). Owing to the lack of suitable assessment methods, participants' cognitive and developmental stages and the precise status of their hearing and vision were not always specified in their medical records.

The first author carried out the cognitive assessments. As a psychologist in the disability service system that all three participants were using, she was already familiar with them. In the case descriptions, the first author is referred to as the psychologist, to separate her multiple roles in this study as the researcher, the author of this article, and the practitioner conducting the assessments.

Anna was a 15-year-old girl with profound developmental and severe motor disability. From birth, she was thought to have no sight at all, but later she had been tested to see at close range (80cm). Her hearing was assumed to be normal but hypersensitive to sudden sounds. Anna's particular challenge concerned her habit of putting her hands in her mouth, ears, and eyes, easily hurting herself. For this reason, she used loosely fitting gloves whenever unaccompanied. This compounded her motor disability, as it prevented effective tactile exploration with her fingers or hands. Thus this safety precaution (gloves) had probably made things worse complicating her learning. Anna communicated by vocal, facial, and bodily means. Her facial expressions and vocal prosody were informative, but she was not active in expressing herself. Anna spent most of her time with other people but without being



in contact with them. She usually reacted when someone made bodily-tactile or very close visual and spoken contact with her. She especially liked clear, even “rough”, physical contact, such as having her arms shaken or cold fingers carefully touching her face: Anna’s body tensed, her respiration intensified and she tried to make visual contact. Lisa was a 16-year-old girl with severe/profound developmental disability, including features of an autism spectrum. Although according to her medical records she was diagnosed as blind, in parental interviews and observational notes she was described to see when under optimal psychological and environmental conditions. This difference was probably connected to challenges in assessments of vision that do not evaluate functional vision adequately. There was no diagnosed hearing loss, but Lisa became easily disturbed by any sounds, causing her to withdraw from contact. She had a habit of tapping her ear with her fingers, assumedly both to avoid external voices and to cause sensory stimuli to herself. Headphones helped her to tolerate ambient sounds but also easily led her to “go into her own world”. Lisa communicated by vocal, facial, and bodily means and through some object and picture symbols. According to her parents and teachers, Lisa’s observable cognitive abilities depended heavily on the communication skills of her partner. Onni was a 13-year-old boy with a diagnosis of moderate developmental disability. Onni was born blind, without any use of vision. His hearing was evaluated as normal but sensitive. Onni used tactile means to explore his environment. He knew how to use a white stick but preferred personal assistance outside his own living room or classroom. Onni communicated in two spoken languages (native language and language used at school) almost equally fluently, but his thinking was concrete and his interactional discussion abilities were not as good as his technical language skills. For example, Onni could remember details from long-ago experiences but found it difficult to describe what he did at school yesterday. He also found it especially difficult to express his emotions, opinions and thoughts.

## Data analysis

The videos were watched several times by the psychologist and with two of the three mothers of the subjects (separately). Mothers made comments on whether they thought their child was acting as usual or if they saw something unusual or especially interesting.

Following the principles of observing unique characteristics in optimal circumstances (Nafstad & Rødbroe, 2013), two or three videos of each assessment process were chosen for closer analysis. The videos were between 9-31 minutes in duration. Written descriptions were made based on what happens in these video clips, not by making turn-by-turn analysis but in less detailed coding by categories that were created for this study. The categories were named *contact*, *pause*, *dyadic-triadic*, *initiation*, *answer*, *other reaction*, *Bayley*, *DA*, *cognition*, *bodily-tactile modality*, helping in answering to the research questions (DA elements, Bayley Scales tasks and the manifestations of cognitive elements) and drawing attention to rich moments of interaction and expressions not easily detected, like pausing contact, initiating interaction, or shifting attention from the dyad to a third party, based on the characteristic interactional phenomena of the target group (presented in the introduction) (Forster,

2008; Janssen & Rødbroe, 2007; Nind & Hewett, 2011). Some of the categories were planned to refer more to the participant's activity (*contact, pause, initiation, answer, other reaction, cognition*), some more to the actions of the psychologist (*Bayley, DA*) and some more clearly to reciprocal functions (*dyadic-triadic, bodily-tactile*).

**Table 1**

*The Categories Used in the Analysis*

Category	Description
<i>Contact</i>	Contact established between partners via vision, voice, or touch
<i>Pause</i>	Contact ceased by the participant (by turning gaze, head, or body away, closing eyes, disengaging from tactile contact)
<i>Initiation</i>	Participant attempts to shift the activity or discussion in another direction
<i>Answer</i>	Participant seems to respond to the psychologist's initiative.
<i>Dyadic-Triadic</i>	Attention shifts from between the two partners to a third person or an object
<i>Other Reaction</i>	"Commentary field" for remarks on interesting expressions or interactional elements
<i>Bayley</i>	Clear adaptations of Bayley Scales tasks
<i>Da</i>	Psychologist using methods of DA
<i>Cognition</i>	Observations of more advanced cognitive skills (language, memory, problem solving)
<i>Bodily-Tactile</i>	Unique use of the bodily-tactile modality (exploring the environment or being in contact)

The category matrices served as a frame to foreground the most interesting moments. These moments, evaluated as having either something commonly found in theory or something uncommonly and surprisingly rich (Markova, 2017), were described as the participant's stories and exemplified with transcribed video clips. Examples of the stories are presented in the results.

## Results

The three assessment processes gave unique and multifaceted answers to the research questions on adapting standardized tests, using DA and observing manifestations of cognition in interaction.

Ten to fifteen adapted Bayley Scales III (Bayley, 2009) tasks were successfully implemented with each participant. Anna, the participant with profound developmental disability,

scored some of the first-section tasks (reference age 0-16 months) and Lisa and Onni also several of the more advanced ones. The most difficult tasks, (reference age 39-42 months) were too challenging even for Onni, whose developmental age was evaluated as clearly exceeding 42 months.

The analysis of selected video clips showed that participants benefitted from the adaptations in various ways: Lisa clearly benefitted when the task equipment was unfamiliar and therefore of special interest to her, whereas Anna's cognitive skills were better observed when she used her own familiar toys. Replacing the visual stimuli by tactile or olfactory stimuli both compensated for and balanced the participants' sensory functions. The effect was not only related to better functioning of the senses but also to the optimized contact between the participant and the psychologist. The equipment supporting the bodily-tactile modality seemed to improve the participants' attention and something that could be interpreted as motivation, thereby reinforcing the interaction and on occasion leading to surprising observations with respect to cognition.

#### Example 1 (Anna)

*Different adapted test objects are offered to Anna. A familiar toy seems to make her less tense, helping her use her hands and target her gaze better, thereby improving contact. Objects that only have visual elements do not seem to interest her. She gets easily irritated by smells. A firm or rough touch and musical, familiar sounds maintain Anna's attention best.*

#### Example 2 (Lisa)

*Of several objects with different sensory qualities, the one that really seems to interest Lisa is a slimy, pink worm with small fringes attached to its sides. She seems to remember the worm from her previous assessment session four months ago. In the transparent box task, the psychologist uses the worm to motivate her to take the object out of the box through an open wall. The miniature car or bracelet (from the manual) do not interest Lisa and she seems even not to see the box. But, when the psychologist puts the slimy pink worm in the box, Lisa lifts her head, smiles and quickly performs the task.*

DA methods were (as expected) diverse and necessary in the assessments. Methods from the minimal scaffolding (focusing concentration, clarifying instructions, minimal feedback) to medium-sized (more clarification and feedback, guiding questions, supporting self-regulation), and, finally, to the clearest (teaching) (Haywood & Lidz, 2007) were used. The unique characteristics of DA for use with young children (Tzuriel, 2001) were observable.

#### Example 3 (Lisa):

*The Bayley III Cognitive Scale task Ring with a string attracts Lisa's interest. She looks at the ring, lifts it, and stops tapping her ear with her fingers. She holds the ring for a while and gives it back. When the psychologist then gives it again to Lisa, she holds it a while longer. Together, they explore the string attached to the ring (partial score for task 23: Playing with the string) while the psychologist carefully guides her hand off her ear to maintain better contact. She shows Lisa how to get the ring off the table by*

*pulling the string (task 29) and how to hold the ring by the string and swing it (task 41: Dangle the ring from the string).*

Example 4 (Lisa):

*The psychologist puts the peg board on the table loudly (wagging it against the table) and the noise draws Lisa's attention. She looks at the board and lets the psychologist take her hand to explore it (partial score for task 38: Exploring the holes in the board). After a minute, the psychologist puts pegs on the board and guides Lisa's hand to explore them, which she does (still tapping her ear with the other hand and frowning). Suddenly, Lisa takes her hand off her ear, looks at the psychologist and smiles. Then she leans into the psychologist, looks into her eyes and takes one of the pegs out of the board. The psychologist reacts very enthusiastically, looking genuinely surprised and happy for her score.*

In the categorization, the *contact, pauses, initiations, answers* and the *dyadic-triadic* included examples of very intensive interaction. They were often moments where the participant was alert or seemingly trying to express something, and that guided the psychologist to monitor the participant more intensively. In the video clips, these moments appeared to have less talk or movement on the part of the psychologist, and both participants showed higher tension in their bodies and facial expressions, and changes in their use of prosody. The moments lasted 1-2 minutes and were followed by a pause and withdrawal from contact by the participant. The psychologist modified her own expressions, seemingly both intentionally as well as unintentionally, adapting herself to the pace and expressive means used by the participant. The psychologist's expressions conveyed uncertainty over the correct interpretation of the participant's' expressions as well as enthusiasm and surprise.

Example 5 (Anna):

*Anna looks intently at the teddy bear. The psychologist smiles and says "You like looking at this one, don't you!? Now you have calmed down to look at straight at it, haven't you? Yes, you have!" The psychologist pets Anna's cheek, Anna lifts her hand and pushes the button to make the teddy bear talk or sing. The psychologist smiles: "Did you push it yourself? Yes, do that, push it!" Anna lifts her hand and pushes the button, repeating the action when the song stops, but not succeeding in eliciting a sound. After few attempts, psychologist helps Anna so that the teddy bear sings when Anna pushes it. Anna takes small breaks (looking away) and then pushes the bear again, making a rasping sound (unclear if the sound is communicative or not). Then Anna presses the button in the middle of a song. The psychologist scaffolds so that the song stops and is replaced by another song. At that moment, Anna looks at the teddy bear, then at the psychologist, and starts smiling and laughing.*

### Example 6 (Onni):

*Onni and the psychologist have long interaction-building conversations unrelated to the assessment tasks. The first session begins with long conversation about the video camera and what video recording means. Onni confuses the video camera with his scary memory of a hospital X-ray camera. Next, they talk about the plastic bag holding the assessment equipment: The bag makes a rustling noise that frightens and annoys Onni. He wants to know the size of the bag and if it has text printed on it. The conversation shifts between 'bags' (in Finnish: 'pussi') and 'buses' (in Finnish: 'bussi', one of Onni's special interests). They then have a long, intensive moment of brushing each other's hands with a stiff brush, gently and intensively, on both sides of their hands and lower arms.*

All the videos featured times where “nothing” seemed to happen: nothing was done with the assessment equipment or there was no visible contact between partners. This could indicate a prolonged time needed for stimulus processing or just a need for a break from interactional contact. Sometimes, after this pause, the participant did something surprising and exceptional, exhibiting cognitive deduction that was not observable at other times.

### Example 7 (Lisa):

*[...] When the psychologist inserts another red peg, Lisa wonders a while and then leans closer, laughing and putting her feet against the psychologist's feet (extensive bodily contact, which Lisa seems to prefer when experiencing positive emotions). The psychologist tenses herself, staying close to her, not moving much, trying to maintain eye contact, and waiting before initiating action. Lisa stays close. After a while, the psychologist swaps one of the yellow pegs for a blue one – and the same thing happens: Lisa takes out the blue peg, smells it and touches her upper lip with it.*

The assessments were time-consuming, and the investment in situational elements other than task presentation was considerable. Gathering the relevant pre-information, planning the procedure and optimizing the environment took 5-10 hours, the assessments 2-3 hours (several meetings). Contact between the participant and the psychologist was built slowly. Administering a single task could require 10-15 minutes, including the preparation phase, while the task itself was accomplished in just a few seconds.

### Example 8 (Onni):

*The meeting has lasted about 25 minutes. During that time, two tasks have been completed. Although both tasks were cognitively easy for him, they take time, with all the conversation and exploration time included. By now, Onni is tired and refuses to continue. The psychologist guides the conversation back to the safe topics of bus routes and ends the session with the brushing of hands, which again pleases Onni.*

In all three assessments, the intensity of the interaction was very high. Also, the fatigue set in quite suddenly and, in case of Onni, resulted in some dissonance between the assumed cognitive capacity and actual performance.

## Discussion

This study addressed the utility of adapting standardized tests, the use of DA, and the manifestation of cognition in interaction, especially in the bodily-tactile modality. These are phenomena that are well known to people living or working with persons with PIMD or congenital deafblindness (see e.g. Ask Larsen & Damen, 2014b; Damen et al., 2020; Janssen & Rödbroe, 2007; Nind & Hewett, 2011), and that have clinical relevance but have not been scientifically researched much.

Earlier notions and assumptions based on practical experience of adapting standardized tests to assess persons with sensory and multiple disabilities (e.g. Tuomi, 2014) were in part confirmed; however, the scientific approach applied here yielded new nuances on the topic: The most important finding, supporting the theory of cognition as co-constructed somewhere *in between* persons, was the assessments' extreme uniqueness. The situation-specific elements turned out to be various and changing, including between two sessions with the same participant or even within a single session.

The results emphasize the need for a competent interactional partnership and recognition of the highly individual needs of the person being assessed. Individuals with sensory and multiple disabilities need another person not only to scaffold them in demonstrating their skills but also to help them in constructing their thinking. Cognitive manifestations are more than the guesses and interpretations of others or the outcome of the help of others: they can be co-constructed between the partners (Nafstad & Rödbroe, 2013; Nafstad, 2015).

In several respects, the assessment procedure used in this study can be regarded as authentic assessment (Bagnato, 2014). Although the situations observed were interactive moments structured by the psychologist, the basic idea was to offer the participant possibilities to lead and change the direction of the interaction, to choose what to do or not to do, and to take her time with the tasks. Moreover, the data comprised several meetings with diverse interactional content.

Nevertheless, there is a practice of and need for using standardized tests for various diagnostic, pedagogic and rehabilitational reasons (Dammeyer, 2011; Einarsson et al, 2020; Soorya et al., 2017). In many countries, the use of standardized cognitive assessment tests is restricted to licensed psychologists who are knowledgeable about normal child development, cognition, neuropsychological functions, and operational models of assessment, all of which are crucial when assessing persons with developmental abnormalities (see, e.g., Einarsson et al., 2020). On the other hand, the education of psychologists often lacks training of dynamic and individualized assessment of persons with developmental or sensory disabilities, which is the concern this article points out to discuss and study further.

The structure of the standardized test was beneficial in this study. The Bayley Scales III provided a framework with age-related references for specific cognitive skills. It also gave the psychologist a standardized framework to apply when looking for individual features - a "standardized freedom to individualize" - and can thus be recommended for use in assessing persons with disabilities

### Limitations and Practical Implications

The use of video recording and planning assessment procedures highly individual yet based on standardized tools and developmental theories can be recommended to clinical psychologists when assessing persons who are unsuited to standardized tests. The procedure takes time and the test results are not reliable to comparisons between individuals, but can yield unique findings that support individual service planning in crucial ways.

Questions of validity and reliability are highlighted when little previous research exists on the topic and the analysis is qualitatively based. Moreover, taking persons with profound communicational challenges as a target group raises ethical considerations: as Forsgren et al. (2018) and Markova (2017) note, the unique bodily-tactile expressions of such individuals often do not resemble known cultural languages and lack socially shared meanings, but instead are based on emotional and bodily experiences, shared between two person in a unique situation. This uniqueness presents a special challenge for the empirical study of these co-constructed dialogical relations (Markova, 2017). Interpretations of the data must be carefully described and argued for (Forsgren et al., 2018), as was aimed here by presenting detailed stories of the assessments.

The multiple roles of the first author as the planner of the research procedure, as the researcher conducting the study and as a participant in the data was also a complex matter. Her actions as part of the analysis have a special meaning for results that are based on co-constructed outputs. The results of the assessments are assessor-specific and the assessment situations cannot be replicated, even between the same two people. This is characteristic of a qualitative case study and can also be seen as a prerequisite for the uniqueness of the outcomes. Throughout the project, researcher reflexivity was accorded special emphasis. The author's supervisors and fellow researchers audited and peer-debriefed the findings (see e.g., Cresswell & Miller, 2000).

Cognitive assessment as described in this study takes time, more even than expected. Although constructing and maintaining good interactional contact was a long and intensive process, it rendered cognitive skills visible. Breaks and prolonged stimulus processing time were commonly needed, as compared to the time limits often recommended in standardized tests. By *accessing* cognition via successful interactional partnership (Ask Larsen & Damen, 2014a), some surprising skills came up when contact between the partners was at its most intense, often after a period of no visible activity. While these manifestations of cognition can arise in any situation with competent partners, they can also be easily overlooked in the hustle and bustle of everyday life. Individualized cognitive assessment is one possible way of making cognition visible.

## Conclusions

The need for interaction and co-constructing thoughts is universal, but with persons communicating on the early, pre-linguistic level, the question is more complicated. In a society that highlights individuality, independent agency and getting one's voice heard, those whose voices are not clear and accessible enough are at high risk for overinterpretation of their wishes. Because persons with

severe or profound developmental disabilities or congenital deafblindness often do not have an individual opinion or voice in the conventional sense, they need another person to construct their thoughts *with* them, not to translate or speak *for* them. Understanding and respecting the fundamental need for an interactional partnership and togetherness in cognitive functioning helps promote self-determination and agency also for individuals with the most unique ways of thinking and expressing. To acknowledge and trust that cognition, purposeful thinking, and intentions are also present in the minds of those who cannot express it in linguistic, culturally specific ways, is a way of giving them agency.

## Declarations

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**Conflicts of interest/Competing interests** No conflicts of interests or competing interests to disclose.

**Ethics approval.** The Ethical Committee of the University Hospital of Helsinki (Finland) has approved the research (21.5.2015/ §111).

**Consent to participate.** Informed consents for the study were signed by the parents of the participants, owing to the lack of sufficient intellectual and communicative abilities of the latter. The research procedure was discussed with the parents in detail, including the possibility to withdraw from the study at any time without explanation. The anonymization procedure as well as the safe processing and storing of the data was explained in detail.

**Consent for publication.** The parents signing the consents were aware that the data is gathered for the first authors PhD study and they understood and accepted that the results will be published in scientific seminars and journals.

**Availability of data and material** (data transparency). Due to the sensitivity of the data (video material revealing personal information about the subjects) the data is not openly available. Throughout the project, researcher reflexivity was accorded special emphasis. The first author's supervisors and fellow researchers audited and peer-debriefed the findings.

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psychologist in the field on developmental disabilities and congenital deafblindness. She is a member in international networks on congenital deafblindness and profound and multiple disabilities. Kykyri, Aro and Laitila are supervisors of Tuomi's PhD Studies and contributing writers in the article. They are affiliated in the Departments of Psychology in the universities of Jyväskylä and Tampere (Finland).

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