Psychological assessment of individuals with deafblindness

Nordic Welfare Centre

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Foreword

People with congenital deafblindness often have hidden cognitive potential that those around them fail to detect. This report is intended to help professionals assessing cognition – and thus be able to elaborate adapted strategies so that people with congenital deafblindness can develop their full potential. Furthermore, the aim of the report is to help professionals who are involved in making examinations and assessments of cognition in cases of congenital deafblindness in both children and adults.
The Nordic Welfare Centre, an institution belonging to Nordic Council of Ministers, facilitates knowledge-development, networks, expert groups, research and education in many different areas. One is disability issues, including the specific disability deafblindness.

As part of this, the Nordic Welfare Centre has published books on topics such as cognition in relation to congenital deafblindness, communication and language development and tactile working memory.
One of the Nordic Welfare Centre's network has focus on cognition in relation to congenital deafblindness. The participants are experts in the field, including psychologists and special educators with assignments in research and clinical and educational work. The main aim of the network is to promote professional competency in understanding cognitive development and identifying cognitions and their relation to learning and everyday functioning of individuals with congenital deafblindness.
The five authors of this report are all psychologists and members of the Nordic network, mentioned above. They are fully responsible for the content of the report.
The authors have also contributed with a chapter in the book Revealing hidden potentials, published in August 2020 by Nordic Welfare Centre, where the issue of assessing cognition in individuals with deafblindness is addressed from a wide range of perspectives.
The purpose of this report is to make a difference for people with congenital deafblindness, and the Nordic Welfare Centre would like to thank all the authors for their work and their contribution to that.

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Prologue

Starting out this writing process, we soon realized that we would need a whole series of books to cover all relevant topics thoroughly. Since the topic Psychological Assessment of Individuals with Deafblindness is complex and huge, we had to undertake some "painful" prioritizing. In the sections that follow, you will find highlighting of some topics while briefly mentioning or neglecting others.

We hope you will find this publication valuable by giving insights to the complexity of the psychological assessment process in the field of deafblindness. Furthermore, we hope the following sections can be useful in reference to your own practice giving you confidence to expand the clinical use of psychological assessment.

Special thanks to Pia Solholt, psychologist at ISHD - Institut for Syn, Hørelse og Døvblindhed in Denmark, for examples of modification in test situations.

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Introduction: The "Who", "Why", "How" and "What" in psychological assessment

As psychologists in the professional field of deafblindness in Sweden, Norway, Finland, and Denmark, we all register shortcomings in the systematic assessment of individuals with deafblindness. In our everyday practice both the individual with deafblindness, the parents and professionals raise many questions and concerns that psychological assessment can help enlighten. Some of these addresses the individual's developmental level and potential, choice of intervention to promote functional progress in different arenas, comorbidity issues and prognosis and diagnostic aspects. This paper is a start on answering these questions.

As a starting premise, we regard psychological assessment a tool for promoting learning, health, and development. During the assessment process, psychologists detect and describe the child's developmental level, possibilities as well as difficulties. The findings give information about what kind of interventions can optimize development.

Parents and significant others often have a long history of encounters with professionals within educational and health care systems. Parents often struggle to get a holistic evaluation of their child's functional profile and specific challenges. We want to highlight the necessity of parents and significant others as active participants in the assessment process.

In our practice in the deafblind field, we experience a resistance to acknowledge comorbidity issues, i.e. coexistence of other conditions in combination with deafblindness. At the same time, professionals and families are raising questions only possible to answer by recognizing such coexistence. Handling comorbidity questions are an important part of psychological assessment. We will address these issues with the aim to expand the understanding of individuals with deafblindness.

Parents, health care and health law systems require diagnostics from medical doctors and psychologists. We want to highlight that diagnostics are an intrinsic part of the psychological practice.

Furthermore, there is a need to underline that diagnostics function as a safeguard to human rights ensuring the individual with deafblindness the aids needed.

In the booklet Guidelines for Assessment of Cognition in Relation to Congenital Deafblindness cognition was conceptualized as; a mental process of making sense of the world; observable in motivated action; situated and interactive, and imbedded in a cultural and social dynamic system (Larsen & Damen, 2014, p. 11). However, in respect to psychological assessment we want to broaden the cognition concept further by including a neurobiological perspective.

This paper mainly discusses psychological assessment of children and adolescents with congenital deafblindness. The choice of focus is derived from two assumptions: (i) due to natural biological maturation, separating and understanding contributing factors is somewhat easier in adulthood than earlier in life, (ii) if the clinician successfully assess and understand the symptomatology expressed in early childhood and during adolescence, assessment of adults will be less challenging.

Psychological assessment cannot be separated from theory. Thus, some theoretical paradigms we find especially valuable in our work within the field of deafblindness are presented. Through small vignettes, test procedures and individual adjustments are illustrated. Individuals in the vignettes are anonymized, thus their presentation are superficial and short. Some of them will appear in several vignettes, such as Lisa and Gunnar, but their conditions will only be described the first time they appear in the text.

This paper takes a health perspective to understand development in general and in reference to congenital deafblindness. We emphasize the importance of separating different professions, roles and duties. Through such clarification, the contribution of experiential knowledge from each discipline is much easier to compile and be used as a basis for expanding scientific knowledge in the deafblind field.

Theoretical framework

Psychological assessment is always theory based and theory driven. In this section some of the theoretical perspectives we experience especially useful are presented. However, before reviewing this theoretical framework there is a need to address the concept cognition from a neurobiological point of view.

The Concept of Cognition

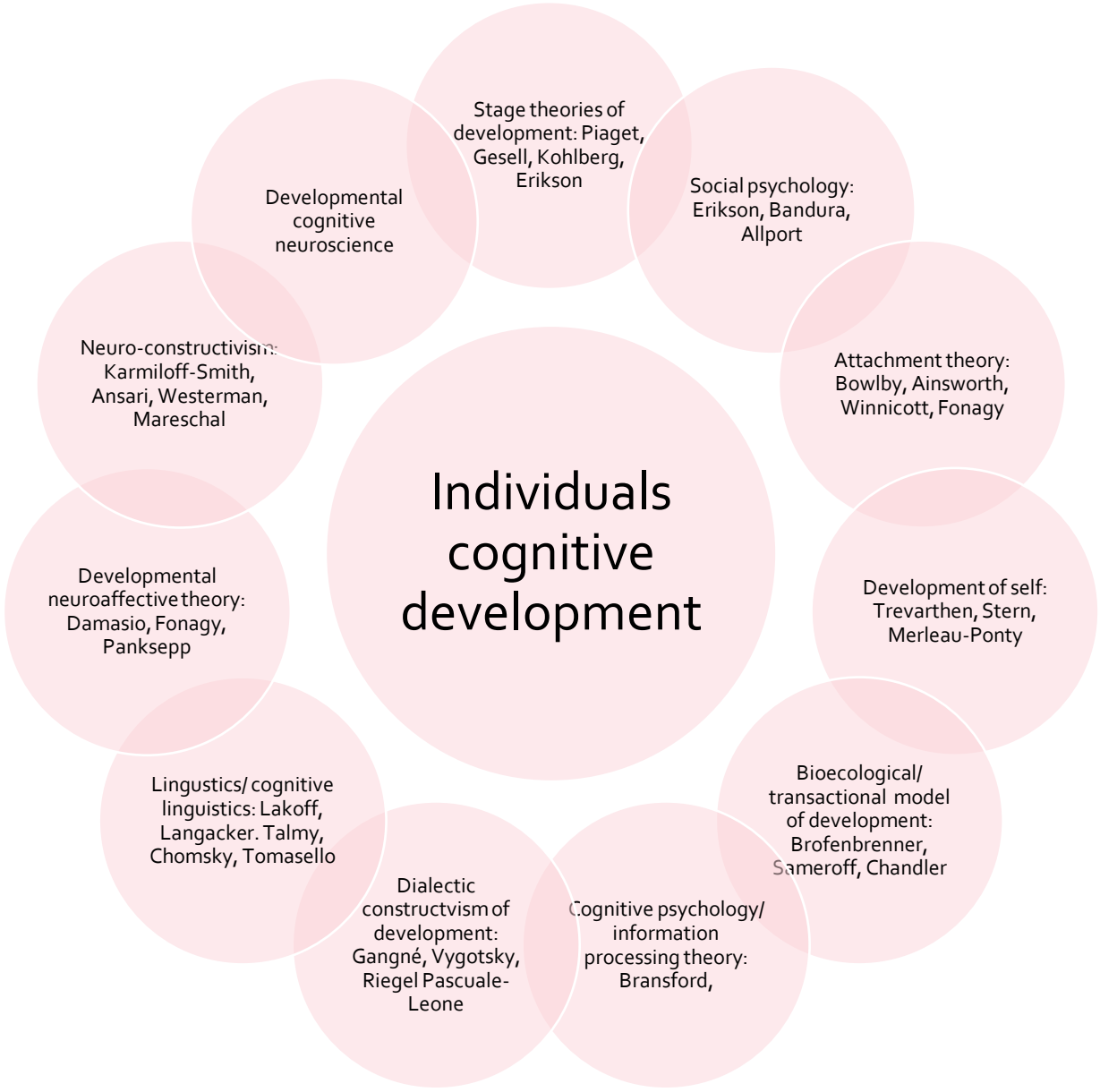
The human brain is a complex adaptive system in which a vast array of behaviours arises from coordinated neural activity across diverse spatial and temporal scales. Through sensory, perceptual and motoric systems, the human influences the environment and vice versa. Linking activity within this large-scale neural architecture to cognitive function remains an important goal for neuroscience. In this framework, cognition is considered as a result of neurobiological processes organized in major interconnected networks. These networks are conceptualized as modules associated with major cognitive functions. Distributed interactions between these networks are considered to facilitate mental functions and behaviour. Emotion and cognition have historically been recognized as separate mental systems, but neuroscientific studies have highlighted their mutual bidirectional interconnectedness. Thus, the display of different behaviours can be indicative of cognition in action (Lezak, 2012).

Within the neurobiological approach, processes like neural plasticity and epigenetics becomes relevant in the explanation and understanding of developmental potential and obstacles. In short, neural plasticity refer to the neurons and synapses ability to heal themselves after some kind of trauma. Epigenetics is a scientific area that explain how environmental influences actually affect the expression and genes, thus bridging the gap between the nature-nurture dichotomy.

Figure 1. illustrates some of the perspectives that goes hand in hand in psychological assessment. When describing and evaluating human development, cognition is one of several domains that must be considered as well as how they interact and influence each other. To fully understand an individual's developmental trajectory, it is necessary to use different schools of thought. These perspectives

play central roles when assessing an individual's cognitive level and potential. When psychologists are doing observations, either naturalistic, semi-structured or controlled the hypotheses, analysis and conclusions are always theory driven.

Figure 1.



In reference to individuals with deafblindness, we want to highlight three perspectives that can give important guidance in the cognitive assessment process: (A) *Piaget stage theory*, (B) *Bowlby-Ainsworth attachment theory* and (C) *Developmental Cognitive Neuroscience and Neuroconstructivism*. First, Piaget's stage theory, with a focus on sensori-motoric functioning, can contribute in the evaluation of the developmental level in children with atypical trajectories. It gives an

opportunity to classification were this can be challenging. Secondly, attachment theory is useful in reference to individuals with congenital deafblindness since many have a rough start with several hospital stays and severe medical conditions, which often can affect the attachment relation. Attachment theories can contribute to pinpoint factors that are missing and must be stimulated in a relationship to further growth and quality of life. Lastly, developmental cognitive neuroscience and neuroconstructivism can help us understand the mechanisms behind cognitive change. Gaining this knowledge, we can promote development both specifically and generally.

A. Piaget's theory on cognitive development

In reference to psychological assessment of individuals with deafblindness, Piaget's stage theory can give valuable guidance when evaluating competence level and priority in special education needs.

Piaget (1936-1980) was the first psychologist to make a systematic study of cognitive development. His theory focused on understanding intelligence, and how children acquire knowledge. Piaget's primary interest was directed toward the way fundamental concepts emerged in human thinking, such as causality, time, quantity and counting. Piaget's theory of cognitive development (1976) describes how children constructs mental models of the world. He regarded cognitive development as a dynamic process occurring between the individual's biological maturation and interaction with the environment.

According to Piaget, children are born with a very basic genetically inherited and evolved mental structure on which all subsequent learning and knowledge are built upon. His theory of cognitive development includes four different stages of mental development which a child as an active participant in her own progress follow sequentially (c.f. table 1).

Table 1. Stages of cognitive development according to Piaget.

Piaget's stages of cognitive development:	Major Characteristics and Developmental Changes:
1. Sensorimotor stage: [birth to 2 years]	• The infant gets knowledge of the world through movements and sensations (sucking, grasping, looking, and listening) • Infants learn that things continue to exist even though they cannot be seen • Infants realize that their actions can cause things to happen in the world around them and experience that they are separate beings from their surroundings
2. Preoperational stage: [ages 2 to 7]	• Children begin to think symbolically representing object with words and pictures • Children tend to be egocentric and struggle to take the perspective of others • Children's thinking still tend to be concrete terms
3. Concrete operational stage: [ages 7 to 11]	• Children begin to thinking logically about concrete events • Children begin to understand the concept of conservation • Children's thinking becomes more logical and organized, but still very concrete • Children begin using inductive logic
4. Formal operational stage: [from age 12 and up]	• The adolescent or young adult begins to think abstractly and reason about hypothetical problems • Teens begin to think more about moral, philosophical, ethical, social, and political issues that require theoretical and abstract reasoning • Begin to use deductive logic

Piaget proposed that children take an active role in their own learning process, getting increased knowledge of the world and causalities by observing, acting, interacting and reacting. This

dynamic interplay gives the child continually confirming or new knowledge, which build upon their existing knowledge. Assimilation refer to the process of incorporating new information into already existing categories of knowledge. Adaption of previous knowledge to new inputs is the basic idea of accommodation. These processes is relatively subjective since individuals tend to modify experiences and information slightly to fit their pre-existing beliefs.

Lastly, Piaget believed that all children try to balance assimilation and accommodation through a mechanism called equilibration. Equilibration helps explain how children can move from one stage of thought to the next.

B. Bowlby-Ainsworth Attachment theory

Both in typical and atypical development the attachment between the child and her parents plays a central role. Due to their combined sensory impairment, children with deafblindness are particularly vulnerable in all stages of development and at risk for deviate development. This can put special strains on the attachment relations. Simultaneously, parenting and especially the attachment relation is one of the main points for facilitatory interventions. Attachment theory in psychology originates with the seminal work of John Bowlby (1907-1990). Drawing on concepts from ethology, cybernetics, information processing, developmental psychology, and psychoanalysts, the concept has been elaborated taking into account contemporary theory and empiricism.

By understanding attachment within an evolutionary context in that the caregiver provides safety and security for the infant, the theory is regarded as an evolutionary theory of attachment. In this perspective, children come into the world biologically pre-programmed to form attachments with others to enhance their survival Bowlby defined attachment as "lasting psychological connectedness between human being" (Bowlby, 1969, p. 194).

Bowlby highlighted the importance of the mother-child-relationship for the child's social, emotional and cognitive development, and that separation from the mother in infancy could lead to later maladjustment. Further, Bowlby emphasized the role of social networks and on economic as well as health factors in the development of well-functioning mother-child relationships:

"Just as children are absolutely dependent on their parents for sustenance, so in all hut the most primitive communities, are parents, especially their mothers, dependent on a greater society for economic provision. If a community values its children it must cherish their parents" (Bowlby, 1951, p. 84).

Psychologist Mary Ainsworth (1913-1999) provided the first empirical evidence of Bowlby's attachment theory. In order to investigate how attachments vary between children, Ainsworth invented an assessment procedure known as the Strange Situation Classification (1969). As a result of early interactions with the mother, Ainsworth (1970) identified three main attachment styles with separate characteristics, secure (type B), insecure avoidant (type A) and insecure ambivalent/resistant (type C). According to Ainsworth classification, securely attached children feel confident that the attachment figure will be available for them and use the attachment figure as a safe base to explore the environment. In comparison, insecure avoidant children are very independent of the attachment figure both physically and emotionally and do not orientate to their attachment figure while investigating the environment. Insecure ambivalent or insecure resistant children adopt an ambivalent behavioral style towards the attachment figure. These children will exhibit clingy and dependent behavior but reject the attachment figure when engaged in interaction.

In this context, evaluating the attachment relation can give guidance to both the assessment and intervention regime.

C. Developmental Cognitive Neuroscience and Neuroconstructivism

Developmental cognitive neuroscience (DCN) is an interdisciplinary scientific field devoted to understanding psychological processes and their neurological bases in the developing organism. It examines how the mind changes as children grow through the interrelations between environmental and biological influences on the developing mind and brain. Thus, DCN may shed light on what has till now been more philosophical nature-versus-nurture and mind-versus-body debates as well as constructivism theories. For the overall topic of this paper, it offers a theoretical framework that build a bridge between prevailing theoretical assumptions in the deafblind field and neuroscience. According to developmental cognitive neuroscience the very concept of "intact and impaired modules" is theoretically flawed because it ignores the dynamic processes of

development. If the typical adult brain is a modular system, as many scientists claims, then those with a developmental perspective must argue that the immature brain undergoes a process of gradual modularization and does not start out with independently functioning modules (Karmiloff-Smith, 1992). This view obviously has implications when development is atypical, raising questions such as whether a process of gradual modularization occurs even when proficient behavioral scores are obtained (Karmiloff-Smith, 2009).

Genetic mutations and environmental factors dynamically influence gene expression and developmental trajectories at neural, cognitive, and behavioral levels. Numerous studies show that the brain of people with developmental disorders seems to develop from the outset along a somewhat different developmental trajectory from the typical case. Thus, the notion that one part of the cognitive system can be impaired while other parts are unaffected is highly questionable (e.g. Karmiloff-Smith, 2007). Another reason to question such assumptions is that we know that, even when development follow typical trajectories, there is much more interconnectivity across brain areas early on in ontogeny and that it is only gradually over the course of development that specialization and localization of function take place (Giedd, et al., 1999; Huttenlocher, 2002). In general, if we want to understand the atypical brain, we need to take into account what happens very early in ontogeny and not merely at the end state (Annaz, Karmiloff-Smith, & Thomas, 2008). In other words, we need to draw a clear distinction between the developing brain and the developed brain (Karmiloff-Smith, 2010).

Neurocontructivist view of the atypically developing brain is a relatively new theoretical field that integrates knowledge from genetics, developmental psychology and neuroscience has taken on studies of developmental disorders, challenging the assumption that brain abnormality causes cognitive abnormality, a one-way arrow, rather than considering a more dynamic bidirectional. So, what happens when gene mutations and atypical experience affect neurogenesis and connectivity, as in neurodevelopmental disabilities? Can we simply adopt the adult neuropsychological approach and consider the atypical brain as a normal brain with parts intact and parts impaired? The answer is *no*.

Neuroconstructivist perspective on development acknowledges the complex relationships between the neurobiological foundations of cognition, the inherent genetic constraints and the environmental

influences. By considering constraints on all ecological levels, from the gene to the environment, neuroconstructivism integrates different views of brain and cognitive development (c.f. fig. 2)

In neuroconstructivism the focus of investigation is the actual process of ontogenetic development (e.g. Mareschal, et al., 2007). It highlights how tiny variation in the initial state could give rise to domain-specific phenotypic differences by proposing that basic level deficits give subtle cascading effects on numerous domains in course of development. In this domain-relevant paradigm, the infant brain starts out with "biases that are relevant to, but not initially specific to, processing different kinds of input" (Karmiloff-Smith, 2015, p. 1). Thus, what is domain-relevant initially becomes specific due to repeated processing of certain types of input.

Figure 2. Different aspects of neurodevelopmental science.

Modified after Westerman et al., 2007

Who? The "assessed" and the "assessor"

In this context "Who" refer to the one being assessed, i.e. the individual with congenital deafblindness, as well as the individual doing the assessment, i.e. the psychologist. Aspects of both are addressed underneath starting with the "assessed".

A. Individuals with Congenital Deafblindness

Individuals with congenital deafblindness and their characteristics has been thoroughly described in the first booklet "Guidelines for Assessment of Cognition in Relation to Congenital Deafblindness" (Larsen et al., 2014). However, there are some issues that were lacking or not elaborated enough in the first booklet that needs to be addressed here, i.e. comorbidity and autism.

A special note on congenital deafblindness and comorbidity

The aim of this section is to give a picture of how often other states and disabilities coexist with deafblindness. A central question when doing assessment is to address is how these coexisting conditions have affected the individual's developmental trajectory and learning potential.

Numerous studies report a higher prevalence of other conditions in individuals that are deaf and/or blind from birth or who are identified with congenital deafblindness. To complicate matters further, the prevalence of sensory impairment is found higher in people with intellectual disabilities than in the general population. These associations have been explained by diverse bi-directional neurobiological processes. Syndromes, perinatal infections and prematurity are factors that increases the risk for congenital sensory-motoric conditions in which the brain cells and neural networks are affected in different degrees. In some instances, these brain abnormalities give congenital sensory-motoric impairments which increase the risk for adverse effects on the child's developmental trajectory resulting in general or specific intellectual disabilities (Kiani & Miller, 2010). In reference to congenital deafness

or hard of hearing, the absence of early auditory stimulation and delay in acquiring language seems to affect neurocognitive processing domains, such as auditory and visual working memory, attention, and inhibition (Pisoni et al., 2008). Therefore, early access to auditory and linguistic experience is essential for development of spoken language, as well as cognitive and emotional control, planning and organization skills.

De Verdier and colleagues (2018) focused on blind children, but the study is also relevant to the DB field. This research group analyzed medical, psychological and pedagogical records of Swedish children with congenital or early infancy blindness (total blindness or light perception at the most) born in 1988–2008. In the total group (150 n), the proportion with several disabilities was high. Only 22% of the children had only blindness, while at least 72% had one or more disabilities in addition to blindness. The most common non-functional impairment group was intellectual disability, autism and motor dysfunction in descending order.

Dammeyer (2011) investigated the prevalence of mental and behavioral disorders among 95 congenitally deafblind adults. Mental retardation was found among 34% and psychosis among 13%, while 74% had a mental and/or behavioral diagnosis.

A national deaf-blind child count in USA gives valuable insights into comorbidity issues (Killoran, 2007). This review, called «Census», summarizes data collected during an eight years longitudinal study of individuals identified as deafblind. According to this count, over 90% of the children and students with either visual or hearing impairment had one or more additional disabilities. The types and combinations of these disabilities were consistent across all age groups and ethnicities. Of those individuals registered as deafblind, 66% also reported having cognitive impairment, followed by physical impairments (57%) and complex health care needs (38%). Despite evident communication difficulties within this group, less than 9% were reported having behavioural challenges, but nearly 30% reported to have additional impairment under the "Other" category.

In sum, these studies show that the higher prevalence of coexisting conditions in congenital deafblindness gives additive challenges increasing the symptom complexity.

A special note on congenital deafblindness and autism spectrum disorder

In autism, social and communicative skills are diminished, but not entirely absent. Individuals with autism show interest in social interaction, but on their own terms. Intersubjectivity and social interaction is displayed in a different and less obvious way. These challenges are displayed by many individuals with deafblindness. In the deafblind field, a dichotomous reaction often prevails when individuals with deafblindness show symptoms, characteristic in autism. We often meet professionals that explain the autistic symptoms as a part of the deafblind syndrome and not as a co-existing condition. Scientific studies show an increased prevalence of autism in individuals with auditory or visual impairment or deafblindness, thus are not supporting this view.

The studies by Brown and Doster (2018) and Roush and Wilson (2013) found has a higher occurrence of autism in the deaf and hard of hearing population than in the total population. Szarkowski and colleagues (2014) reported that children who are deaf or hard of hearing often received the diagnosis autism later than children with normal hearing, with an average age of formal diagnosis not until 6 years 4 months.

In the De Verdier study (2018) mentioned in the section above, were over 72% of the blind children had coexisting conditions, the most common non-functional impairment group was intellectual disability, autism and motor dysfunction in descending order.

Dammeyer (2014) used the Autism Behavior Checklist symptoms of autism among 71 children with congenital deafblindness. In this study, the cohort of children with congenital deafblindness was found to have symptoms of autism on a level similar to children with a childhood disorder other than autism. No association was found between severity of congenital sensory impairment and symptoms of autism.

Hoevenaars-van den Boom and colleagues' study (2009), even though the sample is small gave some interesting findings when investigated characteristics of 10 children with deafblindness and intellectual disability. Half of them also fulfilled the criteria of autism. After assessment with an observation instrument with focus on the categories: Openness for contact; Reciprocity/ joint attention; Communicative signals and functions; Coping with change; Stereotyped behavior; Exploration and play; and Problem-solving

strategies, all children showed impairments in social interaction, communication and language. However, when comparing the two groups, the children with autism showed more impairment in social cognition, such as reciprocity of social interaction, quality of initiatives to contact and use of adequate communicative signals and functions. The groups did not differ in quantity and persistence of stereotyped behavior, quality of play and exploration and adequate problem-solving strategies. Thus, the findings from the Hoevenaars-van den Boom group indicated that differentiating autism from behaviors associated with deafblindness could be possible.

In sum, studies indicate an association between sensory impairments and other conditions, which in turn gives additive challenges. These comorbidity issues need to be acknowledged and addressed to optimize the upbringing and quality of life for each individual.

B. The psychologist´s role in the clinical field of deafblindness

What a psychologist needs to know for clinical practice is learned, in part, through academic pursuits, externship experiences, clinical internship, and postdoctoral training. These are all valuable in building the skills required for psychological practice. However, when it is often the day-to-day experiences gained over time as practicing professionals revealing the nuances and realities of clinical psychology practice that greatly influence the clinicians. You become a specialist in a clinical field by combining practical and theoretical knowledge gathered over time.

As professionals, psychologists have specific responsibilities in the assessment process. We "stand on two legs" by searching for the individual's resources as well as finding and describing challenges. We try to find the children's actual developmental trajectory which guide the type and degree of scaffolding if needed. At the same time, we must acknowledge children's difficulties and describe them often by the use of diagnostics.

Dynamic and qualitative assessment principles are inevitable when assessing a person with disability. Psychologists are trained to administrate tests and interpret testresults and have an understanding of development, cognition and neuropsychological functions. Keeping all this in mind, the psychologists are able to use the standardized tools accommodating the needs of the individual assessed.

As all health professionals, the clinical practice of psychologists is governed by specific health laws. Clinical assessment is therefore always formalized through some kind of referral process and must follow certain rules, such as informed consent from the individual in question, parents or guardians, documentation, procedures for retaining assessment protocols and video films, and so on. Parents are main receivers of the assessment results, analysis, implication and recommendations for their child.

Why? The aims of psychological assessment

According Robert Schum (2004) there is many reasons for investigating children's cognitive functioning.

- To support development
  It is important to get knowledge about the child's cognition and learning strategies. Without investigation, there is greater risk that the child's ability is underestimated or overestimated.

- To make differential diagnostics and understand comorbidity
  Depending on the child's intellectual functional level, simultaneous disabilities may be more difficult or easier to deal with in everyday life. You need a good understanding of the child's medical conditions and cognitive functioning to do differential diagnostics.

- Parents perspective
  The parents are always involved in the assessment process. They always have questions and worries about their child's future development, especially regarding the ongoing development and future independence. Psychological assessment can provide valuable information in reference to care giving and supplement genetic counselling. Hefner and Fassi (2017) emphasizes, that the aim of the genetic counselling must include not only the provision of factual information about syndromes, its cause, and inheritance, but also information about the developmental implications of syndromes features, referral to appropriate resources, and assistance with psychosocial adaptation to this information. Parents want to know about prognosis: mortality, morbidity, sensory deficits, motor development and intellectual outcome.

- Cognitive investigation - an aid in planning efforts
  For a clinical psychologist, particularly in the deafblind field, developmental issues are of central importance. Before starting any type of assessment, there has to be a purpose that directly benefit the child's development. Referrals to psychological assessment often includes or originates from parents or school

personnel worries or questions, some kind of problem they want to understand.

We regard psychological assessment as a tool for promoting learning, health and development. Using the individual's own functional level and profile as a baseline, we can evaluate specific developmental aspects and the effects of interventions. When assessing the individual's baseline, you also "assess" the environment's ability to understand the individual's resources and challenges. This information is valuable in supporting her development. Our joint experience indicates a larger risk for underachievement rather than overstretching in the education system. Many individuals with deafblindness do not get appropriate individualized cognitive challenges within their education despite Special Needs Education. Most often the school staff lack of accommodations is based on ignorance and fear of wrongdoing rather than an unwillingness to assist. In this respect, psychological assessment can provide important information of the individual's ability level, learning strategies and potential, which can guide and optimize education.

In psychological assessment, it is important to establish "the floor level" as well as "the roof level" (level of best performance) of the Individual's abilities. If we only use the "roof" to guide the intervention regime, the individual may be overstretched in reference to achievement level, which can further influence motivation and self-confidence negatively. The individual`s cognitive profile (status) and developmental level, gives information about what kind of interventions can scaffold the individual's development. Our common clinical experience, and in line with literature, children with cognitive and sensory impairment with delay in developmental milestones will increasingly lag behind making the developmental gap between them and age typical children increasingly larger (e.g. Shaw & Jankowska, 2018; Benjamin, et al., 2017). This is one of the main reasons for why early assessment and interventions as well as systematic follow-up assessments are important.

Cognitive assessment can help to establish the agency and right to self-determination of individual's whose cognitive skills are not easily observed or understood. A cognitive assessment procedure can be an act of good communicational partnership and intensive interaction, where the hidden cognitive skills come observable and the individual gets the feeling of being seen and respected as she is.

A special note on psychological assessment and diagnostics

Psychological assessment plays a central role in diagnostics, i.e. whether the individual's challenges are displayed in a type and degree that fulfils one or more diagnosis, for example if the individual has an intellectual disability, and if so the level of severity.

It is a known fact that the use of behavioral diagnoses has constantly expanded and results in increased prevalence of condition like ADHD and autism. This indicates that the concept of normality is becoming narrower and the tolerance for individual differences are lowered. However, in reference to our professional ethical approach all individuals are a part of the human normality.

We state that diagnoses serve several purposes and are neither good nor bad. It is a tool to communicate information about an individual's difficulty more precisely between professionals and significant others. Diagnoses can also give information about prognosis, i.e. possible developmental outcome, recommended treatments, progress or decline, and guidance on special education-needs. For parents living in Scandinavia, diagnoses can also be helpful when there is a need for economic aid and practical-technical support.

For children and adolescents, diagnoses serve as a snapshot of the individual's functional level here and now. Since their development trajectory is still in progress, the diagnosis should be continuously scrutinized and revised. For example, the prefrontal cortex is not fully developed before the mid-twenties. In adults, development is restricted to targeted training of specific motoric or cognitive abilities. While the purpose of adult diagnostics is increased quality of life, for children and adolescents the main goal of diagnoses is promoting physical and psychological development by guiding and optimizing medical treatment.

Diagnoses is important in prioritizing and allocating governmental and municipal economical resources. The identification of strengths enables us to be more specific and practical in our guidance of parents and professionals. It sharpens our ability to make appropriate recommendations.

Lastly, by naming the individual's difficulties through a diagnosis self-acceptance can be promoted. A better understanding of "who I am" can motivate the individual to use compensating strategies and technical aids. A diagnosis can also give a sense of "psychological

belonging" by knowing that one is not alone. Within many diagnoses, interest association groups exist that can give increased feeling of unity and support both for the individual in question and her family.

How (do we get it)? Guidelines for accommodated test procedures

"…We said that in collaboration the child can always do more than he can independently. We must add the stipulation that he cannot do infinitely more. What collaboration contributes to the child`s performance is restricted to limits which are determined by the state of his development and his intellectual potential…" (Vygotsky, 1987, p. 209).

In this section, more general guidelines are given in reference to psychological assessment of individuals with congenital deafblindness. More specific accommodations are given in the next section named "What".

Specific psychometric challenges in the field of congenital deafblindness

Psychometric theory is concerned with the objective measurement of skills and knowledge, abilities, attitudes, personality traits, and educational achievement, and specifically address individual differences. Test methodology is based and driven by theory and empirical studies. As such, psychometricians have used a complexity of knowledge in the development of mental tests and analysis of data collected from these tests. Further, psychometricians have developed methods for working with large matrices of correlations and covariance's. The first psychometric instruments were designed to obtain a measurement of intelligence as shown by the Stanford Binet Intelligence test.

The key traditional concepts in classical test theory are reliability and validity. A reliable measure is measuring something consistently, while a valid measure is measuring what it is supposed to measure. According to classical test theory assessment of actual ability (rather than ability relative to other test-takers) must be assessed by

comparing scores to those of a norm group randomly selected from the population. In fact, all measures derived from classical test theory are dependent on the sample tested.

A known statistical principal in test theory states the relationship between the population's heterogeneity and sample size (typically denoted by n). To ensure an optimum level of precision statistics are applied on a heterogeneous group, which demands a large sample size. This raises one of many psychometric challenges when working in the field of congenital deafblindness. Individuals with this form and degree of sensory deficits are a very heterogeneous group due to the diversity of medical conditions where serious visual and auditory deficits are an integrated part. Large enough sample size to obtain comparative normative data are approximate impossible in our clinical practice.

Further, patients with multisensory challenges such as congenital deafblindness are more prone to show significant variation in their behavior and functioning since this is very context dependent. For example, it will be relatively more challenging to compensate for a sudden change in the surroundings such as light and sound conditions for a person with deafblindness than for a person with cognitive disorder without sensory deficits. Together all these factors lead to severe challenges to ensure test validity and reliability. In order for research data to be of value, other methods must be considered.

One solution to these methodical challenges is to use the subjects own functional level and profile as a base line for later assessment. In this way, cognitive assessment can be used to both evaluate specific developmental aspects as well as effect evaluation such as educational support and cognitive rehabilitation.

Other methodical issues to consider

As mentioned earlier the population with congenital deafblindness is a very heterogeneous group, which implies a need for customizing assessment procedures accordingly. For example, a medical condition that gives serious deficits in both the visual and auditory sensory system can also give rise to motoric challenges, thereby demanding a procedure that takes this into account. Another individual with congenital deafblindness can have excellent motoric skills, have some residual hearing but be totally blind leading to other assessment adjustments. Taking into account each individual's

sensory resources and challenges, the assessment regime must be construed differently.

In addition to the medical condition one must take into account each individual's psychological characteristics, which is a result of omnipresent transactions between heredity and environment, i.e. nature and nurture (Sameroff & Chandler, 1975). Congenital deafblindness is a condition that will influence all these bidirectional transactions in diverse and sometimes unpredictable ways thereby resulting in unique developmental trajectories.
One such consequence that also can influence the cognitive assessment procedure is earlier attachment relations. If this has been insecure, it can influence on how and what kind of relationship that is possible to establish. As such, the individual's psychological history will greatly influence our relationally and communicative approach in reference to building a trusting relationship. This process can be very time consuming but is an essential part and the assessment procedure. Cognitive assessment is always based on behaviors and expressions, either spontaneous as in naturalistic observations or by specific prompts to target distinct cognitive functions as in psychometric assessment. The individual's expressive ability is therefore a concrete measure on mental processing. However, some individuals with congenital deafblindness gives us unique challenges due to readability issues (Nafstad & Rødbroe, 2013). More on this subject in the section on "Language" below (p. 26).

Steps in the psychological assessment procedure

Different elements are included in the assessment process. The presented pointwise order of elements below is parallel to the sequence followed by any psychologist doing cognitive assessment.

- Collection of previous records and investigations
  Before starting the assessment, it is important to get a picture of the individual's medical condition and history; known syndromes and diseases, information of possible pain issues, functional hearing and vision, motor development, everyday functioning, food and sleep routines, psychological and developmental state, and other factors that may be relevant. Collecting previous records of investigations are valuable when preparing the assessment procedure and a support for analysis and evaluation of assessment results.

- Parent report
  Through parent interviews and questionnaires, such as ABAS, BRIEF and Vineland, information of the child's development and current situation are gathered. In addition, you get insights of how the parents perceive and describe their child and their relation, for example is the child easy to understand and please. How is the child's attachment to the significant others? How is the behavioural, emotional and physiological regulation, such as sleep, food intake and preference, activity level and psychomotoric development? What kind of support system are available for the parents? Many children with congenital deafblindness have experienced several hospitals stays of different length from infancy. This will have impact on the child, the parents and their relationship.

- School and preschool report
  Reports from pedagogical personnel are necessary information in psychological assessment since the child`s functioning level are a result of transactional processes between the child and the environment. For instance, a child can show different competences, behaviours or reactions at home than in school, giving rise to important questions about "partner dependence ability". This information is gathered trough inventories and questionnaires as well as free discussions with different school personnel.

- Naturalistic observations
  To get a realistic picture of the child`s everyday functioning it is necessary to observe the child in different naturalistic situations.

  Vignette 1: Gunnar is a ten-year-old boy with Charge syndrome, autism, intellectual disability and uncertain sight and hearing status.

  A lunch situation at school:
  After Gunnar was finished eating, he left for the wardrobe to put on outerwear. He discovers that his boots were still in the school lunchroom. The teacher tells Gunnar to get his boots and Gunnar returns on his own to the lunchroom, which requires a 50 meters walk. He moves quickly through the corridor to a bigger room lying in front of the lunchroom, showing a good sense of direction. Gunnar enters the lunchroom and goes straight to the milk machine (a stop point) despite this is a detour. From there he orientates himself back to his table and locates the boots under the table.

Analysis in reference to different functional domains such as social cognition, language and communication, perceptual-motor function, learning and memory.

Gunnar demonstrates an understanding of the social script "lunch" and the sequence of activities involved. He shows context-dependent procedural memory. He also demonstrates working memory by simultaneously processing different type information such as "shoes are under the table", "they are fifty meters away", "location of the milk machine". Putting all this quickly together, Gunnar successfully plan and solve the problem "finding my boots".

Furthermore, Gunnar shows an ability for spatial orientation, spatial perception and spatial memory. We can also assume that Gunnar has a spatial-bodily-tactile understanding of how objects can be related to each other, for example "boots under the table", "wardrobe and outerwear".

- Semi-controlled observation – "Plan what you want to observe" Often it is necessary to arrange specific learning situations, which in turn can provide information of effective interventions and support (c.f. vignette number 14, p 47 for an illustration).

Standardized methods with different degrees of individual accommodations

Standardized tests must usually be adjusted in different degrees to better fit the child`s specific developmental level and sensory-motoric disabilities (c.f. table 2). However, our clinical experience has shown that some parts of the test batteries are possible to administrate in a standardized manner. Despite the various obstacles that exist, our experience is that it is informative to expose the child to a test situation and test material. It always provides new and complementary information about the child`s abilities and type of scaffolding needed.

Interaction and communication are the core of all psychological assessment. However, many of the individuals that needs assessment often have impressive and expressive communicative challenges. This places special considerations on accommodation, i.e. how can we adjust and synchronize our communication mode to the child's, for example use of sign language and use of augmentative and alternative communication. To secure and

validate the communication personnel that knows the child must have an active role in the assessment process.

- Adjustments of the environment
  It can often be necessary with special considerations in order to adapt the assessment to the individual's developmental prerequisites and needs, i.e. physical environment concerning place, location, lighting and support.

- Support by a significant other
  To get as valid results as possible, assessment should be performed on the child's premises. To ensure that the individual experience the assessment situation safe and positive, the presence of a familiar person often has a calming effect as well as facilitating positive interactions. Further, the person who knows the individual best can help interpret behavior and reactions. Sometimes the familiar person can act as a communication model and guide the psychologist in the interaction with the child. In some cases, it might be a good idea that the familiar person with guidance presents the assignments and materials to the child.

- Energy management and preservation
  Individual's with sensory deficits often have restricted or lowered mental energy. To get reliable and valid assessment results it is important to use different accommodation and help the individual use her mental energy on the problem solving and not at irrelevant stimuli.

Table 2. Examples of modality specific accommodation of psychological assessment

Modality	Accommodations
Hearing	• Use appropriate mode of communication • Use of appropriate and needed hearing technology such as microphone, amplifier. • Make sure that the technology works for the purpose and are effective. • Assure that the assessment situation is free of interfering noise (voices, music, vibrations, air conditioning, and traffic).
Vision	• Use of appropriate vision technology for example computers, magnifying glass, enlarging test materials. • Knowledge of what visual impairment the aids should support, such as near sighted,

	farsighted, stereopsis, field of view, and coloboma. • Use of adjustable desk or similar aids to support vison (bookend). • Vision frame (making choices by targeting the case). • Replacing pictures with three-dimensional stimuli (objects/toys), supporting both vision and bodily-tactile modality. • Enlarging the pictures (e.g. Bayley, Wppsi), giving optional pictures, one picture at a time or putting them on a vision frame. • Enlarging the visual tasks or splitting them up to achieve a higher degree of visual simplicity. • The person might have a need for better contrast between the pictures or more distance between them ("crowding"). Subtest "symbols search" in WISC-V administered by Ipad has less visual information which can facilitate. • In many cases, it might be a support for the child if help is offered in order to maintain the visual focus. For instance if the child is supposed to place a brick next to the chosen picture in the Leiter tests it might be a good idea to support the child by holding the brick and move it from picture to picture, letting the child indicate the chosen solution. Sometimes it possible to read from the mimic expression and look if a choice is made.
Motoric and bodily sensory control	• Helping the child to gain increased bodily-sensory control, freeing capacity so that energy and concentration can be used on performance. • Use of suitable work chair that supports the child's psychomotoric control and performance. • Physical contact can facilitate the child's work and performance. If necessary, let the child sit on the lap in your arms (many children get better attention level and endurance). • Be flexible and shift position when needed. Use the floor if the child gets tired of sitting at the table. • Supporting the bodily-tactile modality in every step of the assessment. • In the interaction, there might be some special considerations – amongst other things regarding the physical contact. How close can you sit, should there be some form of physical

	contact like sitting close together or maybe placing a hand on the back, shoulder or arm of the child. • In the same way, the eye contact must be adapted to the child. Some children may feel uncomfortable with too much eye contact.

The following vignette gives an example of adjusting test materials:

Vignette 2: Ben is a 16-year-old boy with Leigh syndrome, a progressive neurological disorder appearing in early childhood, which can give a variety of neurological symptoms. The boy had profound motor difficulties, was intubated and had no verbal language but a high communicative stance.

Ben was referred to assessment of his intellectual level of functioning before his 18th birthday. The social services suspected the boy to be severely mentally retarded. His parents, family, friends and helpers were convinced that his cognitive functions were intact. His teachers stated that he understood everything they said to him, although they would not speculate about his cognitive level. Ben had several times during his school years tried a computer assisted communication system, but because of nystagmus, it had been difficult to calibrate the screen. In the period of testing, he got a new computer with better technology.

To test Ben's cognition the speech therapist and psychologist had to enlarge the materials used, which was items from Leiter-III (with permission from the publisher) and others. In addition, a dark textile board with Velcro was made as well as on the bag with the enlarged materials. The different choice cards were put on the board with good distance. The personal helper acted as interpreter, pointed and asked yes or no to each card. As the testing personnel got accustomed to the signals from the boy, they were also able to interpret him. Ben needed many breaks for suction of saliva, taking of clothing because of sweating and so forth.

<u>Analysis:</u> During the test procedure, it was discovered that Ben did not choose the cards most to the right on the board. It was detected several problems with his eyesight. The test materials were scanned over to the boys rather large Apple-TV, which made it possible to compensate his sighting problems better by flexible enlargement of the pictures and increasing contrast on the screen. The testing was

supplemented by observations in several settings, anamnesis and clinical interviews with parents and teachers, reading of medical history and research articles about the syndrome. On this basis, an estimate of Ben's cognitive level was possible to evaluate and was found to be subnormal. When the visual impairment was more compensated, the boy had possibility to show his problem solving skills, which earlier was "hidden".

A special note on individualized accommodations

Doing psychological assessment of individuals with multifunctional and sensory disabilities require an open and creative "online" mind. It is often impossible to plan the assessment in detail since you seldom know how you are going to get the performance you seek in advance. This call for some basic principle listed below:

- "Make it playful".
  Regardless of condition, all individuals love fun and games. However, it is not always obvious what will create a playful context. Either way, try to make all assessment playful and have fun. If you have a good time, this positive energy will be conveyed to the individual.

- Be open to individualized adaptions.
  It might also be necessary to adapt test materials – for instance, it is very important to consider which tests to use, as some tests are more suitable for the target group than others.

- Be open to unusual responses in problem solving.
  Sometimes it works better for the person to place a brick or a picture than to point to the right solution. It might also work for some children to point or hit with a hammer or some other object instead of pointing with the finger. Hitting with the hammer might also offer feedback to the proprioceptive sense, which can be motivating and help to keep the arousal level at stable state.

- Be open to find alternative stimuli.
  Some children prefer new and exciting stimuli while others perform better when familiar toys are used. It might also be the case that the design of the materials is disturbing for the person, for instance the spiral back of the book with pictures sometimes can be too exciting and take the focus away from the assignment itself.

- Plan the assessment with a flexible timetable.
  Since you will need more time in the test situation have flexible access to time.

- Consider and implement individual needs when needed.
  It is always important to take individual considerations to the person´s needs, pace and initiatives. Some individuals have a need for a high pace where the assignments are presented in a flow while others have a need for a slow and calm pace. Some individuals profit from much talk and conversation while it is disturbing for others. Moreover, it works well for some individuals to use fun and teasing as a part of the interaction while others need a calmer approach. It is also important to adapt the use of feedback and praise to the needs of the individual.

- The quality of the interaction.
  From the part of the assessor: concentration, emotionality, listening, waiting, adjusting own expressions to the individual's, such as use of voice, prosodies and singing.

- Use of incentives.
  Try to find out what motivates the individual and have prepared for using this when needed.

- If it works well for the individual with rewards in the form of snacks, sweets or a chosen activity it might be an advantage to let this be a part of the assessment.

- Incorporating the "test-script" when needed.
  Some individuals have no or little experience with being tested or exposed to other individuals and materials than they are used to. In these instances, there will be a need to give information of what this means in practical terms wherein the test situation becomes predictable by an obvious structuring conveyed in the preferred communication mode, for example by ritualizing the test procedure by always using the same weekday, starting and ending the session in the same way, presenting same number of tests each visit, and so on.

Vignette 3: Debra is a ten-year-old girl with Usher syndrome in combination with another syndrome.

In cooperation with the pedagogue and parent's the psychologist find a range of activities Debra was fond of. The pedagogue could inform that Debra is most alert after ten o`clock in the morning, and it was therefore decided that this was the best time for doing the assessment. To get enough data the psychologist planned a two-week intervention period. Out of the activities suggested from Debra's parents the psychologist chose a rocking game (rocking back-and-forth in a disc shape swing), a build-and-destroy-game (small blocks build by the adult while the child`s palms on top of the hands, when finished the child pushes so the blocks fall on the floor) and a tactile peekaboo game, in a regular order. Even though Debra knew the games, the presentation and combination was new. The pedagogue incorporated the systematic visits of the psychologist to the child's daily and weekly schedule so the child was prepared. This was presented to Debra each morning. In cooperation the pedagogue and the psychologist found concrete and tactile concrete representation for each game, i.e. a piece of rope, a small building block and piece of fabric. Ten o`clock from Monday to Friday the psychologist came to visit Debra. The psychologist got her own sign and representing concrete. The sessions started by introducing Debra to the first play symbol and was given the opportunity to experience the swing. During the activity, the child was presented the concrete play symbol many times trying to create an association between the game and the symbol. The same procedure was followed under the other two games.

After a short break Debra was presented all the play concretes, one at the time, and the psychologist waited the child`s response. Debra immediately grasped the block and pushed it toward the psychologist, which interpreted this as an expression for choosing the building game. Debra and the psychologist then began in cooperation to build a tower (hand-under-hand).

<u>Analysis:</u> To give the child opportunity to show her competence and her ability to learn from experience, introduction to the "test script" and routinize an assessment session was needed.

What? The type of information psychological assessment can provide

Psychological assessment is a process that uses a combination of methods to evaluate an individual's behavior, personality, capacities and challenges. The results are often depicted in a cognitive profile, which gives information about what kind of interventions can scaffold the individual's development. In this section a description of the most central cognitive domains is given.

In psychological assessment, "what we get" is co-dependent on "how we get it". In this respect, these two sections supplement each other.

Central neurocognitive domains in assessment

We have used Sachdevs model (2014), as a starting point to illustrate some of the domains that are included in psychological assessment, i.e. "Perceptual-motor function", "Language", "Learning and memory", "Social cognition", "Complex attention" and "Executive function". All psychomotoric tests, scales and batteries are more or less based on these domains, which gives domain specific information as well as insights to the general ability. We have adapted the original Sachdevs model to include other domains and subdomains that we find important in psychological assessment of individuals with multiple disabilities. These includes "General ability" with the subdomain "Adaptive function", the subdomains "Sensory integration" and "Cerebral visual impairment" and the subdomain "Language dependent abilities" (fig. 3). For clarification, the different domains and subdomains are numbered.

The Sachdevs model can be useful by directing the assessment focus so one can get insights to individuals functioning level in specific domains, a set of domains transferrable to a functional profile as well as general ability.

Figure 3. Model modified after Sachdevs model 2014.

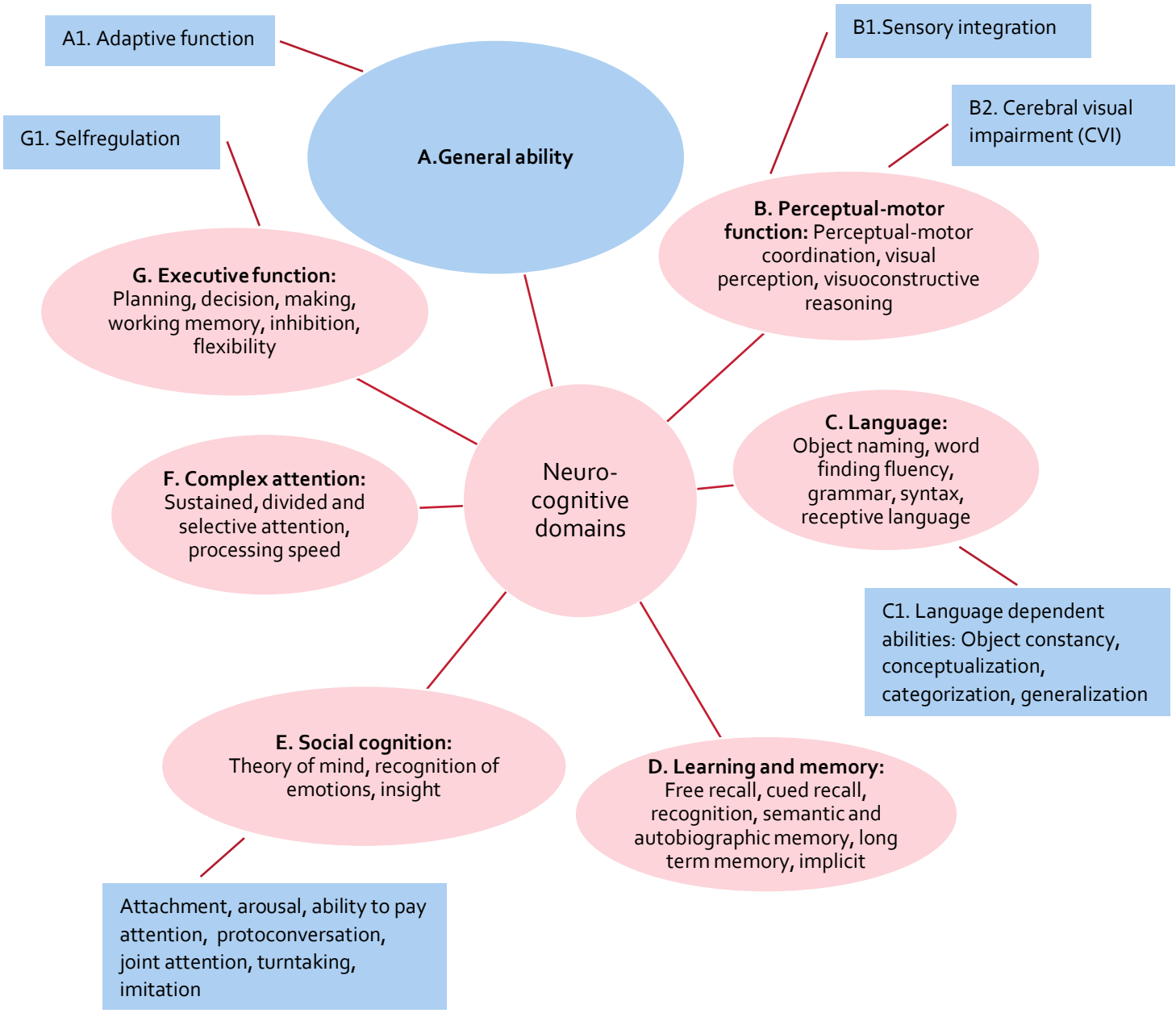


Figure 3. Inspired of Sachdevs model (2014) and further developed in reference to psychological assessment of individuals with multiple disabilities.

A. General ability

In reality, the functional domains are very much intertwined since no part of the brain works alone. When assessing children and adolescents with multi disabilities our focus of interest is mainly directed at the individual's baseline, which serve as a reference in the

evaluation of progress after implementing specific interventions. Another focus of interest is how the individual achieves her results, such as which strategies were used, how did the individual profit from scaffolding and so on. By analyzing elements behind the performance or achievement one gets access to valuable information that can make future interventions more successful. In this respect, a measure of the individual's general ability, often referred to as IQ, is less interesting.

However, psychologist's often get referrals from health care and health law with questions about an individual's general intellectual resources, for example if she fulfills the diagnostic criteria of an intellectual disability (ID, DSM-V; ICD-11), and if so which degree. When teachers have pupil's with subnormal educational progression, i.e. slow or atypical, the most common concerns address the individual's intellectual capacity.

Even though we can experience a reluctance in some parents to an ID diagnosis, often this passes when they observe positive developmental changes due to better adjustment between demands and ability as well as ensuring different aids in the future.

In reference to individuals with congenital deafblindness, special care must be taken to validate the findings. In addition to including parents and professionals, which knows the individual well, this can entail cooperation with another psychologist in the assessment process, both in the preparation, implementation and evaluation. When consented, video recordings of the assessment are used. The results and performance can then be analyzed and discussed with others, such as professionals and parents, to increase assessments validity. Video recordings will also give opportunities to evaluate the individual's degree of engagement and compliance and show the test administrators failures.

A1. Adaptive function

An individual's level and adaptive functioning gives valuable information to the surrounding on accommodations needed in the present, but also serves to guide intervention to specific functional area as well as a reference when measuring progress after targeted interventions. According to diagnostic manuals DSM-V and ICD-11 in addition to psychometric assessment of intellectual level, adaptive function most always be evaluated before a diagnosis of intellectual disability. Vineland interview and ABAS self-report (appendix C) is

widely used and recognized tools for analyzing adaptive behavior. The authors define adaptive behavior as a performance in daily activities necessary for social interaction and self-care. There are four essential principles attached to this definition of adaptive behavior: (1) adaptive behavior is age-related, (2) adaptive behavior is defined by other people's expectations and norms, (3) adaptive behavior is changeable, and (4) adaptive behavior is about a person's typical behavior.

Vignette 4: Beth is 19 old young women with deafblindness.

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

Analysis of the vignette in reference to general intellectual and adaptive ability: The profile was evenly indexed with index score two standard deviations below average. At the subdomain level, a strength was found with adaptability and ADL skills at home, which was on average. Other subdomains were at a low level. Overall, Beth's overall adaptive skills was significantly reduced, but matched her intellectual level. She was tested with Wechsler nonverbal scale of ability. The findings showed that she needed extensive support to gain more independence. A residential placement was more appropriate than independent living conditions.

B. Perceptual motor and sensory function

Fine motoric functions and social competence are generally used as indicators for the child`s developmental level (Fenichel, 2009). The matrix you find in appendix A is adapted from the chart displayed on Kids Sense Child Development (2018). It is designed to serve as a functional screening of fine and gross motoric milestones in reference to typical development. However, is also useful as a reference to evaluate delays and specific ability peaks, as is often the case in individuals with congenital deafblindness.

Assessment of nonverbal abilities are not as straightforward as many might believe. Besides sensory loss, the influence of a number of demands such as speed, eye-hand coordination, motor control, attention and executive function must all be considered. Motor and

sensory-perceptual data are distinctly useful in the assessment procedure. Along with an updated functional assessment of sight and hearing, careful observation by both a physiotherapist and an occupational therapist (Sensory Profile) is recommended prior to psychological assessment.

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

Handedness is an important component of cerebral lateralization in humans and is generally firmly established by age 9. Anomalous early or late hand preference can imply neuromotoric dysfunction. Prolonged ambidexterity, like no sign of hand preference by age 3, is another marker of a possible neurodevelopmental problem. In the examination it is valuable to ask the child to perform a series of actions and to observed directly and quantify hand use and praxis (Baron, 2018).

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

These skills are important to academic success because they may help the child understand how individual parts are related to complex "whole". They may also assist in the acquisition of early reading skills. These skills are also relevant in the social domain, where the ability to form an overview of a situation "the gist" is more helpful than attention to certain details. People with visuospatial

problems often experience anxiety. Not being able to get a quick overview and instead experience the world as a fragmented place can be stressful and anxiogenic.

Visuoperceptual fluid reasoning ability help us detect the underlying conceptual relationship among visual objects and use reasoning to identify and apply rules. Identification and application of conceptual relationships requires inductive and quantitative reasoning, broad visual intelligence, simultaneous processing, and abstract thinking.

Vignette 5: Charles is an 11-year-old boy with a rare genetic condition involving the SOX6 gene.

Charles was a student in an ordinary school, where the teachers found him lazy (was late for class because he could not find his way, did not start working on his sheets etc.).

After assessment Charles showed a distinct developmental profile on WISC-IV with an over average score on verbal ability: Verbal Index of 130, and subnormal perceptual reasoning: Nonverbal Index of 65 (average index score is from 85 to 115). Neuropsychological examination showed that he had Apraxia, Nystagmus and Cerebral Visual Impairment as well as a minor hearing-loss.

Analysis: Due to Charles extraordinary good verbal skills his disabilities were masked. For example, the CVI was not considered as needing special intervention in school. He also had extraordinary able parents giving a lot of support further masking the degree of difficulties.

B1. Sensory integration

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

Individuals with impaired sensory integration may face challenges in perceiving, processing, and responding as expected based on particular combinations of sensory impressions (vision, hearing, smell, taste, tactile, proprioception, vestibular, chronoception). For example, maintaining a conversation at the same time as going down the stairs can be very problematic for an individual with deafblindness. Since the individual must compensate for the visual

and auditory challenges, such as grasp the handrails, and perceive the ground with her feet, look for visual markers and concentrate on hearing. These ongoing cognitive processes will occupy large parts of the individual's mental capacity and she will be less able to perceive or respond to elements in the conversation.

Difficulties with ignoring sensory impressions are another challenge that can occur with impaired sensory integration. Certain types of stimuli can then be overwhelmingly experienced with the person being unable to ignore or phase out the impression. Due to the intensity, even one stimulus can "steal" all mental capacity, which then results in reduced mental availability for other information, although this is initially more important.

Vignette 6: Christian is a 14-year-old boy with deafblindness and gross motoric impairments.

The type and degree of sensory disturbance makes sensory integration difficult, which can be manifested as an attention problem. The surroundings have problems getting in contact with him even though the hearing conditions are adequate. The teacher has complained to Christian parents that their son is disrespectful by ignoring her.

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

B2. A special note on cerebral visual impairment (CVI)

CVI is an umbrella term for many visual impairments that each have many ranges. Vision is complex and is not limited to one segment of the brain, the visual cortex.

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

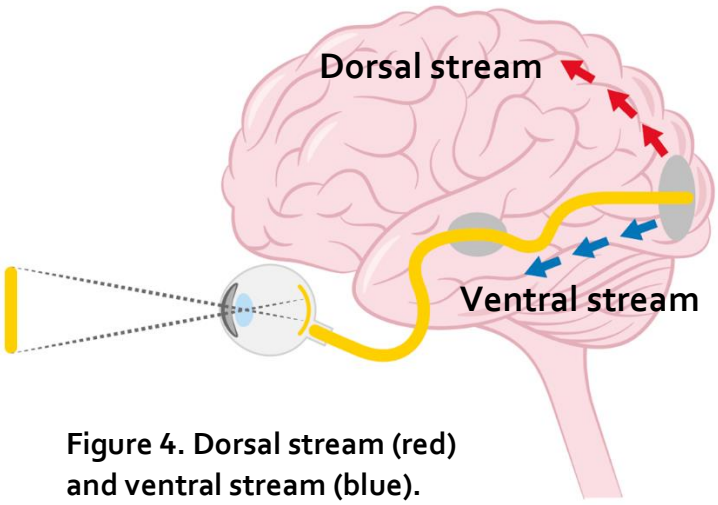


Figure 4. Dorsal stream (red) and ventral stream (blue).

Researchers are now identifying complex neural systems and their effects. Zihl &Dutton (2015) described the effects of CVI in terms of dorsal stream (the "where" system) and ventral stream (the "what" system) functions (fig. 4).

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

Vignette 7: Victoria was a 38-year-old woman with early blindness, a moderate hearing loss and intellectual disability due to extreme prematurity.

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

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

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

There are many unanswered questions about CVI and we find that a multidisciplinary approach is needed along with more focus on the topic both in the deafblind field but also more generally.

C. Language

Language is one of the most sophisticated expressions of cognition in action and psychological assessment of the language domain is one of the most interesting but also challenging endeavors we encounter. To promote language development all kinds of causalities must be detected, understood and addressed. However, working within the deafblind field, there are many new aspects and concepts that must be considered which are not present when evaluating typical language development. Trying to give an idea of this domain's complexity, this section will touch upon some of these issues. Despite unique contributing factors, we firmly believe an understanding of the atypical is derived from knowledge of the typical, thus typical language development is always an important stance. Typical language development is summarized in appendix B adapted from Carr and colleagues (2016).

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

Regarding individuals with congenital deafblindness there is many sensori-motoric barriers to overcome to succeed in all these aspects, from establishing secure attachment to get access to the world, which is prerequisite for language acquisition.

There are many individuals with congenital deafblindness who never acquire conventional language, i.e. speech and sign language despite longitudinal follow-up with targeted interventions. Using Piaget's stages (1976), we can infer that many individual's stays in the sensori-motoric stage for a prolonged period, and some will never reach the next level. However, we want to highlight that all individuals regardless of their disability have a language and are communicative in their authentic way (Rommetveit, 1974). Authentic communication can be difficult to perceive and easily misunderstood because of its uniqueness. The authenticity refers to

a language coming from within the individual, formed from her personal experiences and immediate associations. Thus, authentic communication can be understood as:

"… human communication 'from within', i.e. in terms of the individual experiences and existential conditions of the 'I' actively engaged in the discourse." (Rommetveit, 1974, p. 23).

Authentic expressions are based on events that have had a meaning for the individual, i.e. emotional bodily experiences in specific situations. These meaningful events can be relatively different from what others perceive as significant. Authentic expressions and their basis are inaccessible to others if they do not have in depths knowledge of the individual's personality, personal history, and communicative mode.

An individual's authentic and unique communication mode can lead to issues concerning readability, which refer to how accessible an individual's language and communication is for the communications partner(s) (Nafstad, & Rodbroe, 2013). Individuals with congenital blindness can have additional neurological challenges that compromise their communication in such a degree that it led to low readability. The cognitive assessment procedure must then incorporate a prolonged "getting to know each other"- phase where the persons involved get a better understanding of each other's communication and even in some cases develop a common conceptual framework and viewpoint. The professional must ensure a common conceptual understanding this using a dialogic communicative approach where meaning of oneself, the other and the surrounding world are founded in a relation. Depending on the degree of readability, i.e. high or low, the timeframe of assessment will vary greatly. However, it is important to emphasize that the cognitive assessment starts when the contact with the person in question is established. The professional approach to ensure common conceptual framework, and thereby trust, will pose a very important part of the cognitive evaluation, and should be documented.

An extension of the concepts of "authenticity" and "readability", is "languaging", which originates form Vygotsky's work on the critical role language plays in mediating cognitive processes (Vygotsky 1978; 1987). The foundations of this concept are based on the assumption that language is a way of making personal sense of the world and becoming conscious of oneself. It is a means to understand the world as well as creating one's identity. In the

simplest way, languaging stands for an unbridled, natural way of using language beyond the normative constraints of a language. Languaging it underscores the dynamic relationship between thought and language, in which language ceases to be perceived as a mere conduit, but rather performs a function or "coming-to-know-while speaking" (Swain 2006; 2009). We refer the interested reader to the website of Nordic Welfare Centre, which compiles publications and links to literature which specifically addresses different aspects and levels of interventions in reference to language and communication of individuals with congenital deafblindness.

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

Eva can suddenly hit and be rough with those who are physical near her. This usually happens in connection with her experiencing strong positive and negative emotions. The school personnel regarded this behavior as unpredictable and without any connection to actions in the surroundings. Even though Eva had minimal speech, the school personnel was convinced that she understood verbal information.

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

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

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

For children with congenital deafblindness it is a huge challenge for the environment to provide a stable and individualized linguistic input. Many individuals never develop functional speech or sign language, and if so, requires longitudinal targeted interventions by

dedicated professionals. Vignette number 9 illustrates the benefits of early interventions with extraordinaire communicative skills from the surroundings.

Vignette 9: Case study lent from Tactile Communication (2018, p. 158):[1]

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

<u>Our analysis:</u> The surroundings believed from the very beginning that Santeri had cognitive potential and abilities that it was difficult for him to display. Due to this belief, significant others tried to give Santeri expressive opportunities. His congenital deafblindness was not accepted as an obstacle for linguistic, intellectual or social development.

Matching of "culture language" between the test person and the administrator is a prerequisite for establishing a relationship based on trust and equality. Vignette number 10 gives an illustration of the importance of matched communication.

Vignette 10: Maria is a 10-year-old girl with severely affected vision and hearing.

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

[1] The booklet Tactile Communication (2018) describes tactile language development from multiple perspectives. It contains a description by Emmi Toumi and Riita Lahtinen of Santeri a 16-year-old and deafblind boy.

<u>Analysis of the vignette in reference to verbal ability:</u> Marias authentic language is based on her tactile and olfactory senses. It is a mismatch between Marias understanding of the world and the teacher's. Further, Marias linguistic capacity and the teacher's instructions are not matched resulting in parallel communication. The teacher needs to bridge the communicative gap between them. To do so she must gain access to Marias authentic modes of expressions and use this as a foundation.

C1. Language dependent abilities - Conceptualization, categorization, and generalization

We consider the language domain as a verbal function, which includes impressive and expressive verbal ability, development of verbal concepts, verbal reasoning and acquired verbal knowledge.

Individuals with congenital deafblindness were functional hearing and vision is severely affected often communicate with authentic expressions. This make their communication less accessible, especially for unfamiliar communication partners. As such, they have low readability. To increase their engagement in both immediate and bigger contexts there is a need to evolve the authentic expression into more conventional means of communication. On the other hand, the wish to "normalize" communication can sometimes lead to neglecting "a deafblind approach". Further, cognitive development is co-depended on the development of communication modes and conceptualization. For example, problem solving, and reflective thought is intertwined with linguistic ability.

The capacity to perceive what is familiar, what repeat itself, what is identical and different is the basis of pre symbolic representation and generalization.

Vignette 11: Lisa is a five-year-old girl with intellectual disability and combined visual and hearing impairment.

Lisa's preschool teacher tells her that they are going out for a walk. Lisa responds to her teacher by rolling the wheelchair to the hall stopping at the front door. This is comparable to her response at home when parents communicate "going out".

<u>Analysis of the vignette in reference to conceptual understanding:</u> Lisa has numerous experiences in different contexts with the concept "going out". She shows a generalized understanding of the concept by purposeful actions across different environments.

The ability to generalize entails being able to transfer knowledge from one situation to a different situation. Language helps us to generalize, to see patterns, to over-generalize or under-generalize. It is challenging for individuals with deafblindness to identify the common denominator of objects. For both parents and teachers, it can be difficult to get the child to use their knowledge and abilities across different contexts, for example using their math skills in other situation than in class. When categorizing objects from tactile information alone, such as structure and shape, it can cause overgeneralizing, for example, "all bottles are water bottles", "all round fruits are apples".

Vignette 12: When Gunnar (10 years) was younger, he just wanted to eat in the kitchen at home. The parents teach Gunnar to eat "everywhere". They started eating in many different places together with Gunnar, such as in the car, at restaurants and at family and friends. After a while, Gunnar learned that he could eat in many places in addition to the home kitchen.

Analysis in reference to generalization: Gunnar have difficulties in generalization due to his autism and deafblindness. To overcome some of these challenges the parents help Gunnar actively and concrete to transfer the "eating activity" to many different environments. In this process, he expanded his concept of "eating activity" and got more flexible with time.

Accommodated assessment with Bayles Scales of Infant and Toddler Development

Bayley Scales of Infant and Toddler Development is a comprehensive tool to identify development issues during early childhood. The Bayley scales intend to identify infant and toddler strengths and competencies, as well as their weaknesses. It can provide normative information consistent with developmental domains identified by the current Individuals with Disabilities Education Improvement Act (IDEA) early childhood legislation. Further, the findings can help to determine the need for further in-depth assessment and results compared with growth scores to chart intervention progress.

Even though the scales are directed at children with typical developmental trajectories, it can give valuable information were the trajectory are more atypical.

Vignette 13: John is a 10-year-old boy; has deafblindness, autism, intellectual disability and motoric difficulties.

John's school wanted to understand more of his cognitive abilities; they also wanted to reduce his challenging behavior in terms of biting and scratching. John is tested with Bayley scales with his teacher present, intervening when necessary. The teacher has a good understanding of Johns verbal and non-verbal communication. As well as knowing how to motivate him, their well-established partnership based on trust gives the teacher a position to require and get response were others would not.

Results from assessment showed that John could differentiate different colors, letters (Ipad), which he shows by pointing, using signs or by drawing (numbers). He could count (1 to 5), showed understanding for size (small and large) and weight (heavy and light) and for several geometric shapes. John did two bits puzzles, but when given more complex puzzles he struggled and lost interest. When John worked with concrete material, such as bricks, geometric figures, he showed more engagement working for longer intervals.

Analysis: John presented several cognitive skills in the test situation. In addition to curiosity, motivation, he showed some relational understanding of whole and parts. He had also some basic concepts automatized and symbolic understanding. During assessment, John showed inferential learning and problem solving. The puzzle activity requires functional vison; fine motor skills and good hand-and-eye coordination, all of which is challenging for him. These difficulties have probably been a cause of John's lack of interest and stamina under puzzles.

After completed psychological assessment, recommendations for special school aids were given, the main message were "exposure to cognitive challenges individually adapted in reference to Johns modalities (for example Ipad in schoolwork)". Six month later the school reported that John had become more communicative and engaged in schoolwork and showed less acting out.

Especially in reference to the follow up of individuals with atypical language development, we regard interdisciplinary approach necessary. In addition to the psychologist, perspective on language, other professional perspectives like pediatric, neurologic, speech therapy and pedagogue each can give additional valuable information when trying to understand an atypical language profile and find optimizing interventions.

D. Memory and learning

Like all the other cognitive domains, development of memory is codependent of other functions. Deferred imitation is a way to assess very early memory function, for example the vignette number 17 (p. 55).

Infants learn and build on experience. Even prenatal experiences may later manifest themselves in changes in behavior toward stimuli, as if the baby recognizes songs that the mother has been singing during the pregnancy.

Although theoretical differences exist, both developmental and cognitive science agree that memory is not a unitary trait. It is comprised of different systems or processes serving distinct functions and are categorized by fundamentally different rules of operation. When people refer to "memory" it involves the capacity for explicit recognition of names, places, events and so on, which is termed declarative memory.

The term non-declarative memory represents a variety of non-conscious abilities, including the capacity for learning habits and skills. Putting on clothes, eating with fork and knife, but also emotional memories of pleasant and non-pleasant situations are examples of non-declarative memory.

The distinction between different types of memory is important in a developmental perspective because declarative and non-declarative memory rely on different neural structures that have different courses of development (Bauer, et al., 2011). During development both kinds of memory is differentiated into several subdomains in the visual, tactile and auditive modality that can be tested with several psychological tests.

A declarative memory is autobiographical memory, that is event memory about one's self. For the individual, memories of past events shape current behavior and give us a guide for planning future actions. Events and stories are also important instructional tools; we learn through reading and listening to stories of past events and how they have shaped the world. Especially "good" or prototypical autobiographical memories are specific events that can be located in a particular time and place. Retrieval of them involves "re-living" the experience as an event from the past. These memories change with time. How robust the memory become depends on the encoding needed to consolidate a memory as well as its specificity, how many

details are remembered (Bauer, et al., 2011). An example from the deafblind field is the legendary video "Krabben" where the pedagogue is helping the deafblind girl consolidate by "re-living" an autobiographical memory of crab fishing.

Social influence from the family to the larger cultural group interacts with the characteristics of the child to shape what children ultimately come to view as important to remember and even how they express their memories. Therefore, differences have been found between Eastern and Western children's autobiographical memory. As such, congenital deafblindness can be regarded as a culture where autobiographical memory is more tactile. Assessment of memory in this population is necessary to plan interventions that target memory in order to support personal and social well-being and development. A good example of the encoding of tactile autobiographical memories are outdoor activities, followed by "re-living" the events with a partner and wider social group.

The following vignettes tries to illustrate assessment of social cognition and memory as well as an example on semi-controlled context:

Vignette 14: Elin is a five-year-old girl with combined sensory impairments.

A preschool team wanted help in developing a more functional communication with Elin, a five-year-old girl. There was a great deal of uncertainty regarding Elin's vision and hearing ability. Elin had no ordinary language and communicated through sound and movements. In addition, she had a physical and mental disability. The main goal of the first assessment sessions was to create contact and get a preview of the child`s capacity and abilities through play, for example interests, motivation, activity level, joint attention, social interaction, imitations skills, memory etc. Following games were introduced; draw a ring over a stick, song play with movements, and "interesting apps" on an Ipad . At the next test session, three weeks later we played the same games again with Elin. During the song play with movements, Elin responded positively showing interest by following the teacher's hands and taking initiative in the play. At the game draw a ring over a stick, Elin showed clear interest in the social interaction, but could not be engaged to mimic the activity that the teacher tried to invite her to with both tactile and verbal instructions. When exposed to Ipad and an app (in the form of different color bombs that appear on the Ipad), Elin became quickly interested and psychomotoric active, crawling forward trying to grasp the Ipad . She was investigating the Ipad tactically

using both hands and forehead. The psychologist invited Elin to a play activity, which Elin usually played at home. We called it "the twirling game". She immediately recognized the play, getting active and laughing loudly when twirled by the psychologist. When the psychologist stops, Elin communicates that she wants to continue by mimicking the twirling movement (swinging the body back and forth). The psychologist "answers" the child by continuing the twirling. Giving the conventional twirling sign during a strongly motivating activity, Elin made an attempt to imitate the sign.

<u>Analysis of the vignette in reference to social cognition and memory:</u>
The main purpose of this semi-structured observation was to stimulate Elin's communication, especially her social agency. Elin demonstrates context-dependent concentration, context-dependent joint attention and turn taking, an initial ability to imitate (pre phase) and prosodic memory. Based on these observations we assume that Elin's learning is promoted and favored through the bodily-tactile modality. Elin's shows general developmental delays. The abilities she shows deviates from expected typical development. However, at this stage in assessment one cannot determine the degree of intellectual disability. This will need further investigation with psychometric methods and systematic observations.

Further, the semi-structured situation set the stage for language development. By making definite association between a highly motivating activity and a sign, the child was prone to both perceive this connection as well as imitation. Scaffolding language development is a complex topic and beyond the scope of this paper.

E. Social cognition

Social cognition is affected by all other neurocognitive and functional domains, for example problems with memory makes it difficult to remember social norms and faces, and problems with concentration can give a fragmented impression of the social world. Spontaneous social adaptions require a series of skills, from seeking functions and detecting the salient aspects of a social situation to reacting quickly to fast-changing emotional expressions. In typical development, the facets of social engagement, i.e. social cognitive and emotions, are well integrated in a seamless and synergistic fashion (c.f. appendix D for matrix of typical social and emotional development).

There is a rapid growth in social and emotional areas of the brain during the first 18 months of life. Even before acquiring language, babies learn to communicate through emotions. Already at birth, distinct emotions are present; anger, joy, and fear, which can be expressed without specific cognitive input. The infant's social smile in response to parental high-pitched vocalizations or smile is the first measurable social milestone and usually emerges between one and to two months of age.

Secure attachment relation is regarded as an essential foundation in psychological development, and as such is a prerequisite for an individual's social cognition.

Being born with deafblindness the child access to care, engagement and knowledge of the outer world lies in the caregiver's ability to fill the child's needs and be regarded as a safe base. To gain this trust and secure attachment, which is essential for further psychological development, the caregiver must be able to read and follow the individual's expressions over time. When the individual has low readability, for example by communicating in an atypical fashion or have little or vague verbal and nonverbal expressions, gaining this trust is challenging but essential.

In a psychological assessment, we do not directly make an evaluation of the parent's capacity to care for the deafblind child. However, due to family stress in many cases because of the deafblind child's many challenges, it is important to include the attachment perspective in an evaluation of the need for support to both the child and the whole family.

Arousal

Individuals with congenital deafblindness as other individuals with neurological conditions can often have a problem with the arousal function. Depending on the condition and the severity of it. Can often have to low arousal level with is affecting their accessibility. Therefore, it will have an impact of all aspects of development. One way of increasing the child's arousal level is to find and present some motivating activity and object for the individual.

Ability to pay attention

A healthy infant has a neurological system that is perceptually focused on social contact.

Research shows that the child early pay attention and prefers human voice sounds before other sounds and even if the infant has a weak visual acuity the infant can differentiate mothers face from others. Individuals with congenital deafblindness will not be able to use primary senses in the same way as the typical child. For example, when a parent speaks and look at the child, it will probably give more vague or atypical response.

Proto conversation

In the 1970s researchers in different fields found that as early as 2 months, infants and mothers, while they were looking and listening to each other, were mutually regulating one another's interest and feelings in intricate, rhythmic patterns, exchanging multimodal signals and imitations of vocal, facial and gestural expression. Bateson (1975) termed this interaction 'proto conversation'. Bateson interpreted the infant's behavior as an innate emotive base preparedness for learning language and culture and establishing emotional regulation and social bonds. Meltzoff (2005) suggests that multisensory representations allow one modality to substitute for another in the case of sensory impairment or cerebral palsy.

Joint attention

In joint attention or shared attention, the child following the parents gaze is a prerequisite for development of social interaction and communication (Tomasello,1999). For children with deafblindness "Joint attention" is established and supported by sharing experiences bodily and tactile and with support of the sensory functions that remain. In assessment we are interested in how the child respond to tactile touch and contact, for example: "hand under hand, listening and talking hands", when we mimic his or her activities, movements, sounds and tempo.

Imitation and turn taking

How does the child imitate? Vision and hearing drive the development and helps the child to imitate. Imitation supports the development of different skills, for example linguistic and social skills.

How does the child take turns and interact with adults and peers? Does the child participate in activities and play? What kind of interactions motivates and interests the child? Does the child understand what is expected during turn taking and play? What facilitate turn taking? The ability of taking turns in play and communication is an important building block in mutual communication and social interaction.

Vignette 15: Lisa eats breakfast at preschool. While eating she knocks her fist on the table, and a preschool friend sitting next to her mimics Lisa's knocking. Lisa immediately responds to her friend by returning the knocking. There are a few more "turn-takings of knocking" between Lisa and her friend before the friend leaves.

Lisa sits on the floor spinning one of her wheelchair wheels together with her teacher. They take turns spinning the wheel. The pedagogue suggests that they bring in different "objects" in the wheel giving rise to exciting sounds. The pedagogue communicates with Lisa both verbally and tactically. Lisa follows the teacher's proposal and chooses a new object to the wheel, thus continuing the turn-taking.

Analysis of vignettes in reference to imitation and turn taking:
Lisa demonstrates the ability to imitate in basic turn-taking. She is easy to engage and shows interest in social interaction. The preschool supports and stimulates Lisa's interaction by inviting her to interact. The teacher stimulates Lisa by bringing in new elements in the "script" continuously monitoring and adjusting the game to her ability level. She challenges Lisa socially and intellectually creating opportunities to further development.

Mentalization and Theory of Mind

Mentalization refers to an essential human capacity to interpret behavior in light of underlying mental states, such as desires, beliefs, feelings, hopes and intentions. Mentalization makes other people's behavior meaningful and predictable and is essential to social relationships. For normal development, the child needs to experience a mind that has her mind in mind and are able to reflect on her intentions accurately and does not overwhelm her. Mentalization is not just a cognitive process (theory of mind), it is based on attachment theory and has an emphasis on how the child's early experiences with other people enable them to build up and organize multiple sets of self-other representations (Fonagy, et al. 2004).

Vignette 16: Gunnar can sometimes bite people unexpectedly. The biting can happen when he is happy, angry and in neutral mood and across situations. Its affects classmates, staff and family.

Analysis of vignette in reference to mentalization: Gunnar problems with mentalization (autism) makes it difficult to understand that his biting hurts. His difficulties with self-regulation can explain why the biting also happens in positive and neutral situations.

Complex attention

Sustained, divided and selective attention

Attention is the multifaceted set of skills that enable the individual to be effective in selecting what is pertinent while ignoring distractions (Oates, Karmiloff-Smith & Johnson, 2012). When discussing attention in reference to deafblindness, regarding the neurobiological foundation is expedient since it can give better guidance to functional interventions. On this level, attention is controlled by two segregated but dynamically functional interactive networks: a bilaterally distributed dorsal attention network (DAN) and a right-lateralized ventral attention network (VAN) (e.g. Corbetta et al. 2008). DAN is involved in endogenous and exogenous orienting of attention, while VAN is activated under reorienting of attention in response to salient stimuli. Both genetic and environmental factors influence the organization of the attention networks, for example, visual attention training can improve the attention performance and reshape the attention networks in sighted subjects (e.g. Rueda et al. 2012). On the functional level, attention influences learning from the very beginning of childhood. For example, newborns attention is attracted automatically to salient objects, such as faces. These early orienting behaviors are gradually replaced by more controlled attention that crucial when learning about those stimuli. Attention plays a role in keeping goals in mind, inhibiting inappropriate behaviors as well as the development of working memory (e.g. Adam, & de Bettencourt, 2019).

In reference to individuals with congenital deafblindness, there are to our knowledge no studies that specifically have addressed the complex attention domain. To get some insights, we therefore have to seek and combine knowledge from studies on congenital deafness and congenital blindness. Studies of visual processing in deaf participants have yielded inconsistent results, demonstrating either

an advantage for deaf individuals (e.g. Sladen, et al., 2005), or hearing persons (e.g. Proksch, & Bavelier, 2002), or equivalent performance for both groups of observers (e.g. Bosworth, & Dobkins, 2002). These inconsistencies have been linked to targets prominence and selective visual attention (e.g. Pavani, & Bottari, 2012), whereby processing might be enhanced in deaf observers particularly for tasks requiring peripheral visual attention. It has also been suggested that deaf individuals perform better on tasks that require a global perceptual strategy, in which stimuli are processed as coherent gestalts. Several studies have found supporting evidence for the association between permanent loss of sight and improvement of a wide range of fundamental auditory processes, such as sound localization, pitch discrimination, voice perception and auditory memory (e.g. Gougoux, et al., 2009; Amedi, et al., 2003).

In regard to congenitally and early blind individuals, superior auditory and tactile attention abilities have been observed in blind (e.g. Collignon et al. 2009). It has previously been shown that in absence of vision, both the ability to judge orientation in the haptic modality and bisect intervals in the auditory modality are severely compromised. A study by Cappagli, Cocchi, and Gori (2017) found a strong deficit in proprioceptive reproduction and audio distance evaluation in early blind children and adults. The deficits were not detected in a small group of adults with acquired visual disability. The groups finding supported the hypothesis that in absence of vision the audio and proprioceptive spatial representations may be delayed or drastically weakened due to the lack of visual calibration over the auditory and haptic modalities during the critical period of development

In sum, findings from studies within the fields of congenital or early onset deafness and blindness give supporting evidence for an increased functioning in the remaining modality but also showed cross modality interdependency. Thus, individualized assessment and targeted interventions are always needed.

Vignette number 6 (p. 37) gives an example of complex attention in action.

Processing speed

In this context, processing speed is regarded as a cognitive ability to process different types of information rapidly. It is independent of an individual's gross and fine motoric functions and thus closely related

to performance on higher-order cognitive tasks (Lichtenberger, & Kaufman, 2012). Processing speed is regarded as primal causal agent when explaining deficits on complex cognitive measures in aging populations (Roberts, & Allen, 2016). As put forth by the current theories of processing speed and age, there is a strong age induced interaction between declines in vision and audition and declining cognitive processing speed. In reference to individuals with congenital deafblindness, the Information Degradation hypothesis can contribute to a bio ecological understanding of causalities. According to this hypothesis, higher order cognitive processes are negatively affected (Schneider, & Pichora-Fuller, 2000) due to the weakened or degraded perceptual signals induced either by experimental manipulations or age-related impaired perception. The interpretation of weak perceptual signals requires more cognitive resources than under more optimal conditions, resulting in a greater cognitive load that in turn influences cognitive performance (Zekveld, et al., 2011).

Individuals with deafblindness have by definition degraded auditory and visual senses. To make sense of the surroundings, they have to be continuously alert in regard to input from remaining hearing and vision and try to compensate with other senses to fill in the gaps, i.e. tactile, olfactory and gustatory perception. In addition, this compensatory process requires the online ability to categorize, recall and compare input in a flexible fashion, being very cognitive demanding. The individual is very vulnerable to distractions which can lead to a processing breakdown which makes getting online again mentally exhausting.

When trying to assess the processing speed in individuals with congenital deafblindness several factors can put the test validity at risk. Here we mention three of them. Firstly, increased vulnerability to distractions implicates a strongly controlled environment to ensure that mental capacity mainly is used at the presented task. Secondly, since the main goal of the assessment is finding a measure on processing speed and not perception or deduction, one should avoid presenting tasks that involve novelty. Test material should either already be familiar or become familiar to the participants by setting aside enough time for exploration and conceptualization. Thirdly, assessment of processing speed should involve different modalities since individuals' modalities in general varies in functionality, as in reference individuals who are either left- or right-handed.

Executive function

Being an umbrella term, executive functions encompasses many cognitive sub-domains, such as planning, decision making, working memory, inhibition, flexibility and self-regulation.

Specific attention to the executive modality in individuals with congenital deafblindness is important for daily life functioning, quality of life and for development in general. Getting insights in executive function are essential in choosing workable interventions that also can contribute to cognitive progress.

Executive functions are conceptualized at many levels, all of which are important when understanding, promoting general, and domain specific development in both typical and atypical trajectories. At the neurobiological level, executive function is the human capacity to maintain an overarching control over mental states and behavior are reliant on multiple, distributed and dynamically cooperating brain networks (Stuss & Alexander, 2000).

On the functional level, executive function helps us to act goal-directed by making the individual able to control and distribute attentional resources, enabling planning and anticipate future events, flexible adaptation to changing environmental requirements. In reference to congenital deafblindness there is a need to describe which factors contribute to development of executive capacity, only then can it be possible to scaffold successfully.

Psychological assessment of the executive domain is recommended, both to validate this association as well as getting a deeper understanding of the mechanisms in the search for educational and therapeutic interventions. However, regardless of type and degree of impairment assessment requires the use of many different approaches, methods and analytical evaluation of test performance and results. Often executive functions are difficult to assess with psychometric methods since administration and other test conditions are externally structured and regulated. As such, the context in itself gives valuable support thereby masking a possible executive dysfunction. Cognitive assessment of planning skills, decision making, flexibility and working memory of individuals with congenital deafblindness must often be based on naturalistic observations over time supplemented by prearranged experimental contexts.

When trying to get some insights of an individual's executive abilities pre-setting a facilitating context often is necessary.

Vignette 17: Sara is an eight-year-old girl with deafblindness.

Sara loves listening to music. First finding out from the school personnel which context she listened to music and her favorite song one could prepare a situation making it possible to detect different EF`s. For example, presenting music in an "unusual" context and observe her reactions, both facilitating mental flexibility and emotional regulation. In this vignette, Sara showed some confusion and frustration by beginning crying. Both before and during the song, the pedagogue communicated tactile to Sara that the music session today has switched place with physical therapy. After a couple of minutes, Sara began rhythmic movements with her torso, a movement usually displayed under amusement.

<u>Analysis:</u> By introducing Sara to her favorite song on a different device or in an unusual sound, one could get a picture of her problem-solving ability. Sara usually played her music on a cd player, which she handled primarily alone. In cooperation with the pedagogue, one prepared and presented Sara for a new device somewhat different to the original. Sara explored the new device with interest and after introduction soon figured out it workings, showing both problem solving, mental flexibility and tactile exploration.

The term working memory refers to a brain system that provides temporary storage and manipulation of the information necessary for complex cognitive tasks: language comprehension, learning, and reasoning (Baddeley, 1992). It is a relatively complex system responsible for temporarily holding information available for processing and has limited storage capacity. According to Baddeley, working memory encompasses three subcomponents, each with its own functional role. The central executive, subcomponent one, is assumed an attentional-controlling system and is important when we need to keep track on an ongoing process and try to think ahead for the best solution (like chess playing).

As mentioned in the section about complex attention, working memory and attention act in a co-dependent manner.

Getting an impression of both the working memory and attention domain of individuals with deafblindness can most easily be done by observing reactions and behaviors in everyday life for signs of recollections or confusion of people, plans, activities and locations. If the individual recognizes the psychologist, test assignments and

earlier performance from one week to the next, this gives a good indication of an operative attention system and working memory. In the same manner, it is possible to use test materials, which seem to create interest and engagement to more formally assessment, for example role-playing were the individual must remember what each character said and done. This can be further developed, making the roleplaying increasingly more demanding on the memory processes.

Even though natural and semi-structured observation often is necessary to get a complete evaluation of executive functions, we also experience instances were individuals with congenital deafblindness can be tested with a wide range of psychometric instruments. When this is possible the validity of findings from other methods are strengthened.

Self-regulation

Playing a prominent role for an individual's social accessibility, evaluation of self-regulation deserves a special focus.

The individual's ability to self-regulate is often a concern when individuals with deafblindness are referred to psychological assessment. Since reduced self-regulating abilities often are expressed in obvious and disruptive ways, often this is described as the individual's main challenge. However, self-regulation being a part of the individual's executive functions, many other underlying challenges can both contribute and even exaggerates this regulatory problem. Insights to the neurobiological basis as well as functional aspects can make us more adept to find out which factors and associations contribute in each instance which will be a valuable guide when knowing the level of intervention, for example a need for medication or access to alternative augmentative communication.

The concept self-regulation entails different meanings depending on the theoretical viewpoint and discipline. In a neurobiological perspective self-regulation is a sub serving system to the executive functions and associated to the orbital frontal subcortical circuit of the prefrontal cortex (e.g. Kringelbach, & Rolls, 2004). In this view, self-regulation is regarded as an active, overarching process that involves planning, self-observation, self-reflection and performance adaptations that occur automatically or at a conscious level. On a more functional level, self-regulation explains our ability to regulate our body, behavior, activity and emotions is something that have impact on general development. It is influenced by various factors as

other current conditions as motoric-, sensory- intellectual or neuropsychological abilities. Based on attachment theory and affective neuropsychology, the development of emotional regulation and social regulation begins already in the early interaction experiences we do (Hart, 2008). With increasing age, we can regulate ourselves more and more, language acquisition is an important tool that support self-regulation, it helps us to clarify our needs and boundaries.

Studies about psychological well-being of persons with deafblindness have emerged in recent years showing that particularly anxiety, both as anxiety disorder and obsessive-compulsive disorder is a big problem in the population (e.g. Hartshorne, 2016). Authors stress that problems with emotional self-regulation might be a prominent factor (Ramirez, et al., 2014).

In addition to overall intellectual ability, self-regulation is co-dependent on verbal function. We have many examples of how strengthening an individual's communication possibilities can directly affect her regulatory functions. Our experience is that when the language function is supported this often has a positive impact on inexpedient behavior, such as acting out or social withdrawal.

Vignette 18: Gunnar has had a recurrent acting out behavior for a long time, for example, he has unexpectedly bitten and kicked others. After a period of supervision and an investigation. School and parents describe that Gunnar's outgoing behavior has decreased after adaptation in the learning environment and expanding Gunnar's sign language teaching, his sign language has developed. Gunnar's school day has also become more predictable and the schoolwork more stimulating and challenging.

<u>Analysis:</u> Gunnar has gained an increased ability for self-regulation by being able to communicate what he wants with the support of a growing sign language. Gunnar becomes calmer and more satisfied when he has a clear picture of what should happen during the school day with the support of schedule. The increased challenges regarded schoolwork seems to stimulate and satisfy him.

Discussion

Congenital deafblindness is a multifaceted condition, with both environmental as well as genetic causes. We regard deafblindness as a functional disability with symptoms of severity varying within a spectrum. Children with deafblindness often have challenges across many modalities, which affect function level and can have compound effect on the general development. This poses special challenges in reference to all stages of psychological assessment, including accommodations, evaluation of test results and differential diagnostics.

Our primary focus in this paper has been early development. Due to natural biological maturation separating and understanding contributing factors is somewhat easier in adulthood than earlier in life. This paper mainly discusses psychological assessment of children and adolescents with congenital deafblindness. This choice of focus is derived from the assumption that if the clinician successfully can assess and understand the symptomatology expressed in early childhood and during adolescence, assessment of adults will be less challenging. Broad experience with assessing different congenital conditions support the clinician when assessing adults since the symptoms, functional profile and disabilities often gets clearer with age. Thus, hypothesis of cause-and-effect of a condition can easier be confirmed through anamnestic information.

Psychological assessment is a process of testing that uses a combination of techniques to get hypotheses about a person and their behavior, personality, capacities and challenges. In reference to individuals with deafblindness, a recurrent argument is that "they are untestable". This is contrary to our experience and a worrying attitude, which ultimately can promote discrimination and exclusion. In line with this, Dammeyer (2011) emphasizes the use of psychological, psychiatric and cognitive tests when assessing persons with deafblindness, despite their obvious shortages. The multidisciplinary assessments, combining structured tests and observations, are important in clarifying the possible comorbidities and hierarchies in the diagnostics and in choosing the best treatment and rehabilitation.

Despite the problems with evaluation of "IQ", our clinical practice show that individuals who are met with an "age-matched" approach and within their zone of immediate development are more

confident, feel less stress, and have increased opportunity for participation in their own lives. Finding and using the baseline is a way to support individual's progress and to ensure an individual's rights to legal, economical and practical aids.

One of the main goals for assessment and in line with human rights is increasing independent living and social engagement. Many individuals with deafblindness needs support with communication, access to information, and mobility (e.g. Bodsworth, et al., 2011). In reference to mobility and spatial understanding of the environment, individuals with deafblindness are dependent on others to get access to different aspects of their surroundings. In typical development, coordinated visual and tactile exploration allows the infant to interact with the world. Further, successful spatial orientation relies on accurate perception of the physical self in relation to the environment, which are nearly impossible for an individual with deafblindness without the assistance of others. This dependency in others increase to the risk for other individuals to act as gatekeepers even with best intentions, reducing the control deafblind people have over their own lives. Individuals with severe or profound developmental and communicational challenges can easily be marginalized in the discussion about agency, since they do not express their opinions in traditional formal language or do not even have on independent voice, but need another person to co-create the agency with them (e.g. Komulainen, 2007; Mietola et al., 2017).

In the deafblind field, often a dichotomous reaction prevails when individuals with deafblindness show symptoms characteristic of autism. It seems that professionals regard individuals with deafblindness as "vaccinated" against autism, i.e. cannot coexist with other conditions. These comorbidity issues need to be recognized, discussed and handled. For example, having congenital deafblindness in combination with autism specter disorder gives the individual more adaptive challenges than if the individual had either of the conditions alone. Approaching an individual with a comorbid condition without taking the autism in account can lead increased introversion and passivity. For example, many individuals with autism need to have an environment with clear structure and predictability to ensure psychological safety and be able to socialize on their own terms. Without acknowledging such comorbidity issues the individual will have reduced possibilities to prosper.

Epigenetics is a scientific area that explain how environmental influences actually affect the expression and genes, thus bridging the gap between the nature-nurture dichotomies. Neural development,

especially in the cerebral cortex, is often dependent on neural activity, which can be mediated by experience with the environment. Therefore, cognitive processing itself shapes the neural networks that are responsible for this processing in the first place. These changes to the brains 'hardware' in turn change the nature of representations and their processing, which leads to new experiences and further changes to the neural systems. Therefore, the basis of cognitive development can be characterized by mutually induced changes between the neural and cognitive levels.

According to DCN, the infant brain does not start out like a Swiss army knife with exquisitely pre fashioned tools devoted solely to each different function (Cosmides, & Tooby, 1994). If this were so, there would be little hope of helping children with developmental disabilities to improve their outcomes. Rather, the infant brain is an activity-dependent system that changes from infancy to adulthood, with the cortex undergoing numerous structural, functional, and biochemical changes over time, which leaves us with optimism about how basic research can inform remediation applications.

Due to the neurobiological principles, the human brain is plastic and changeable. Thus, early assessment and interventions are essential.

Through our clinical practices from Sweden, Norway, Finland and Denmark we experience that a relatively large part of the children and youth of deafblind educational and health services have another ethnic background. This leads to additional challenges in reference to psychological assessment but has not been within the scope of this chapter.

In reference to individual with congenital deafblindness the concept ESSENCE: Early Symptomatic Syndrome's Eliciting Neurodevelopmental Clinical Examination (Gillberg, 2018) can be valuable. The core idea behind ESSENCE is that "clusters of problems" rarely exist isolated, but usually overlap or exist in parallel. The concept emphasis the need for early identification of different difficulties in order for the child to receive proper support and intervention as early as possible. Gillberg have therefore addressed the need for a organized health care service to support the development of all children with such "clustered" conditions.

In reference to congenital deafblindness were the prevalence of co-exiting conditions are elevated, ESSENCE gives perfect sense. As Gillberg, we believe that an integrated coordinated health service with a holistic and multidisciplinary medical approach that address all aspects of a child's development is necessary. To improve

developmental conditions for the child it is paramount to support families such that significant others feel secure as caregivers both economical, practical, emotional and psychological.

Epilogue

Writing this publication, we have become very aware of the need to supplement this report with more in-depth knowledge in all the mentioned topics. Further, it has also set forth a necessity to incorporate a more distinct classification of developmental level in reference to type of assessment procedures needed.

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Appendix A

The matrix below is adapted from the chart displayed on Kids Sense Child Development (2018).

Age	Developmental milestones	Possible implications if milestones not achieved
0-6 months	Rolls over front to back and back to front Sits with support and then independently	Poor muscle development for locomotion Delayed ability to play independently
6-12 months	Crawls forwards on belly Assumes a seated position unaided Creeps on hands and knees Transitions into different positions: sitting, all fours, lying on tummy Pulls self to stand Walks while holding onto furniture Takes 2-3 steps without support Rolls a ball in imitation of an adult	Delayed sensory development due to decreased ability to explore the environment Poor muscle development Delayed play skills
18 months	Sits, crawls, walks Still has wide gait but walking/running is less clumsy Pushes against a ball (does not actually kick it)	Delayed play skills Difficulty interacting with the environment due to delayed ability to mobilise effectively Poor muscle development
2 years	Walks smoothly and turns corners Begins running Is able to pull or carry a toy while walking Climbs onto/down from furniture without assistance Walks up and down steps with support Picks up toys from the floor without falling over	Poor muscle development for running and jumping Delayed ability to play independently and interact with the environment Decreased ability to interact socially
3 years	Imitates standing on one foot Imitates simple bilateral movements of limbs (e.g. arms up together) Climbs jungle gym and ladders Pedals a tricycle Walks up/down stairs alternating feet Jumps in place with two feet together Able to walk on tip toes Catches using body	Decreased opportunities for social interaction Poor development of body awareness and movement planning skills Difficulties using playground equipment Difficulties or lack of confidence interacting with other children in active environments (e.g. play cafes, playgrounds)

4 years	Stands on one foot for up to 5 seconds Kicks a ball forwards Throws a ball overarm Catches a ball that has been bounced Runs around obstacles Able to walk on a line Able to hop on one foot Jumps over an object and lands with both feet together	Lack of confidence in movement based activities Difficulties using playground equipment Difficulties or lack of confidence interacting with other children in active environments (e.g. play cafes, playgrounds)
5 years	Able to walk up stairs while holding an object Walks backward toe-heel Jumps forward 10 times without falling Skips forwards after demonstration Hangs from a bar for at least 5 seconds Steps forward with leg on same side as throwing arm when throwing a ball Catches a small ball using hands only	May result in poor self-esteem when comparing self to peers Lack of confidence in movement based activities Difficulties participating in sporting activities Difficulties playing with moving toys such as bikes and scooters
6 years	Runs lightly on toes Able to walk on a balance beam Able to skip using a skipping rope Can cover 2 metres when hopping Demonstrates mature throwing and catching patterns Mature (refined) jumping skills	Difficulty participating in sporting activities May result in poor self-esteem when comparing self to peers Lack of confidence in movement based activities

Appendix B

To set language development in a context, the typical language development for a child is described below (Carr, et al., 2016):

Typical language development	
1 - 5 months	the child is alert to sounds, makes sounds, laughs loudly, produces different sounds for different needs, orients towards sounds.
6 - 12 months	babbles, recognice kind and angry voices, imitatate noice, uses unspecific mama, understands the word no, recognize familiar words, follows gestures (joint attention) commands, saying 2-3 words, understands many words imitates animal sounds
1 - 1½ years	speaks in monologues with multiple sounds that are word-like, uses about 10 words, points to pictures in books, follows two-step commands
2 years	vocabulary of about 300 words, Use I, yes and no, can identify 4 body parts, can form three word sentences
Three years	use phrases, personal pronouns. Vocabulary increases sharply, composes sentences of three to four words, begins to adapt language to counterparty, often asks who, what, when, how, why, questions
Four years	vocabulary över 1500 words, composes sentences of four to five words, can use the the past tence, uses words they do not understand, uses vulgur words.
Five years	vocabulary over 2100 words. Have learned the basics of grammar. It's fun with jokes and puns. Shows an increased interest in the written language, uses sentences of six to eight words
Six to seven years	can say about 10 000 - 15 000 words - expresses an increased linguistic awareness

Appendix C

Social and emotional development for infants and toddlers.
Adapted after Malik and Marwaha (2019):

Typical social and emotional deveopment	
Present at birth	Three distinct emotions are present from birth; anger, joy, and fear, revealed by universal facial expressions. Cognitive input is not required for emotional response at this stage.
Between 1 and 2 months	Infant responds with social smile to parental high pitched vocalizations or smile. She recognizes the caregiver's smell and voice and responds to gentle touch.
Between 2 and 3 months	Infant can use a distinct facial expression to express emotions in an appropriate context. Infant learns to regulate physiologically and need smooth routines. She progressively learns to calm herself, gives a responsive smile and responds to gentle calming.
4 - 5 months	Infant begin turn-taking conversation (vocalizations) begin. Infant learns to manipulate her environment. She lets her caregiver know taking away her toy upsets her or she is happy when held. A sensitive but firm response from caregiver helps infant manage emotional stress. She can recognize the primary caregiver by sight (around 5 months)
Between 6 to 12 months	Effective attachment relationships establish with a responsive caregiver. The infant becomes mutually engaged in her interactions with the caregiver and seeks caregiver for comfort, help, and play. She shows distress upon separation.Stranger anxiety emerges as an infant distinguishes between the familiar and unfamiliar.
8 months of age	Infant develop joint attention skills. She will look in the same direction as the caregiver and follow his gaze. Eventually, she will look back at the caregiver to show that they share the experience.
12 months of age	The child takes part in interactive play like peek-a-boo and pat-a-cake. She uses gestures to wave bye-bye and communicate his interests and needs. Proto-imperative pointing emerges - the child requests by pointing at the object of interest and integrates it with eye contact between the object and the caregiver.
15 months	Empathy and self- conscious emotions emerge. The child will react by looking upset when she sees someone cry or feel pride when applauded for doing a task. The child imitates her environment, help in simple household tasks and explores the environment more independently.
16 months	Proto-declarative pointing emerges - the child points with eye gaze coordination to show interest.
Between 18 and 30 months	Individuation (autonomy) emerges.

	The confidence in the child-parent relationship and continued firm parenting helps the child face environmental challenges on her own. The child's temperament manifests itself more. The child learns to pretend-play (18 to 24 months). She plays next to or in parallel with another child, may imitate others play but cannot play in a cooperative, imaginative way. During preschool years she learns to manipulate her subjective emotions into a more socially accepted gesture. The child refers to himself as "I" or "me" and possessiveness "mine" and negativism "no" emerge.
Between 30 and 54 months	Impulse control, gender roles, and peer relationship issues emerge. Caregiver plays a major role in helping preschoolers define values and learn flexible self-control. The child begin to test limits on what behaviors are acceptable and her autonomy. Pretend play skills and symbolic play emerge (30 months). The play scenarios become more complex with themes and story-lines.
3 years	The child engages more in interactive play, masters her aggression and learns cooperation and sharing skills. She can play with 1 or 2 peers, with turn-taking play and joint goals. Imaginative and fantasy play begin like pretending to be a cat and role play skills develop.
4 years of age	The child master to differentiate between real and imaginary. Imaginary scenarios and play skills are developing and become more complex. She can play with 3 to 4 peers, with more complex themes and pretend skills.
5 – 6 years of age	The child can follow simple rules and directions. She learns adult social skills like giving praise and apologizing for unintentional mistakes. The child likes to spend more time in peer groups and relates to a group of friends. Imaginative play gets more complex, and she likes to play dress and act out fantasies.
7 – 8 years of age	Moral development emerges. The child fully understands rules and regulations. The child shows a deeper understanding of relationships and responsibilities. She can take charge of simple chores, learns more complex coping skills and explores new ideas and activities The child identify more with other children of similar gender and finding a best friend is common.
9 – 10 years of age	The child show increasing independent decision-making and a growing need for independence from family. Peer and friend groups take precedence over family, and parents can use responsibilities and chores to earn time with friends.

Appendix D

Recommendations assessment tools. Some of these assessment tools requires special certification and it is important to ensure this before starting administrating. Further, it is important to always evaluate new tests and updated versions.

Functional domains	**Tests**	**Inventories and rating scales**
General abilities	WPPSI-IV WISC-V Bayley-III Griffiths-III Pep-3 SON-R Wechsler nonverbal scale of ability (WNV) LEITER-III	Vineland-II 5-15/2-5 DPU - Dansk pedagogisk utviklingsbeskrivelse (Dansk psykologisk forlag) ABAS-II CBCL Twenty questions to school and preschool
Execuitve functions	Nepsy-II items D-kefs	BRIEF KSF (Deafblind specific)
Verbal cognition	Bayley-III CELF-IV TRAS REYNELL	CCC2 Children inventory checklist
Social cognition Emotional development	ADOS-II MIM – Marsharck Interaction Method NEPSY-II items Emotional Development Scale (neuroaffective)	ADI-R SCQ – Social Communication Questionnaire Beck-Youth, SRS.... "Jag tycker jag är" CIMBA Child attachment interview
Memory	Rey-Ostereith Complex Figure Test TOMAL-2 NEPSY-II items RIVERMEAD	
Psychomotoric	Bayley-III PDMS-II - Peabody - Developmental Motor Scales 2nd ed. Sensory profile ABC-TEST	
Visuospatial cognition	MVPT-4 and TVPS-4 BENDER HOOPER DTVP-3 The Tactual Performance Test Tactile Form Recognition NEPSY and NEPSY-II items Rey-Ostereith Complex Figure test	5-15 items

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